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Bad news: meanings attributed in neonatal/pediatric care practices

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Abstract

An exploratory, descriptive and qualitative study was conducted with nine health professionals working in the areas of medicine and nursing in the neonatal and pediatric intensive care unit of a teaching hospital located in the countryside of the state of Rio Grande do Sul, Brasil. The objective was to identify the meanings attributed to the communication of bad news, articulating them with professional practice and the manifested feelings andemotions that this task awakens in health professionals. The data were collected in a semi structured interview and studied with content analysis. Death was found to be the main meaning attributed to bad news. Standardized protocols or routines in the practice of reporting bad news were not observed. The significant degree of suffering of health professionals performing this occupational practice was evident. The data of the present study emphasize the importance of problematizing and reflecting on this theme in the hospital environment.
Keywords: Truth disclosure. Health communication. Physician-patient relations. Psychology, medical.

Resumo

Más notícias: significados atribuídos na prática assistencial neonatal/pediátrica

Trata-se de estudo exploratório, descritivo e qualitativo, realizado com nove profissionais da saúde que atuam na área da medicina e enfermagem em unidade de terapia intensiva neonatal e pediátrica de hospital de ensino localizado no interior do estado do Rio Grande do Sul. O objetivo foi reconhecer significados atribuídos à comunicação de más notícias, evidenciados na prática profissional e nos sentimentos e emoções que essa tarefa desperta nos profissionais. Os dados foram levantados por entrevista semiestruturada e trabalhados por análise de conteúdo. A morte foi evidenciada como o principal significado atribuído às más notícias. Não foram observados protocolos ou rotinas padronizados na prática de comunicação de más notícias. Foi notório o significativo grau de sofrimento do profissional da saúde que realiza essa prática ocupacional. Os dados deste estudo enaltecem a importância de problematizar e refletir sobre a temática no ambiente hospitalar.
Palavras-chave: Revelação da verdade. Comunicação em saúde. Relações médico-paciente. Psicologia médica.

Resumen

Malas noticias: significados atribuidos en la práctica asistencial neonatal / pediátrica

Se trata de un estudio exploratorio, descriptivo y cualitativo, realizado con nueve profesionales de salud que trabajan en el área de medicina y enfermería en una unidad intensiva neonatal y pediátrica, en hospital universitario situado en el interior de Rio Grande do Sul, Brasil. El objetivo fue reconocer significados atribuidos a la comunicación de malas noticias, evidenciados en la práctica profesional y en los sentimientos y emociones que esta tarea despierta en los profesionales. Los datos fueron recolectados en entrevistas semiestructuradas y trabajados por medio de análisis de contenido. La muerte se destacó como el principal significado atribuido a las malas noticias. No se observaron rutinas o protocolos estandarizados en la práctica de la comunicación de malas noticias. Fue notorio el grado significativo de sufrimiento del profesional de la salud que realiza esta práctica en el trabajo. Los datos de este estudio enfatizan la importancia de problematizar y reflexionar sobre este tema en el ambiente hospitalario.
Palabras clave: Revelación de la verdad. Comunicación en salud. Relaciones médico-paciente. Psicología médica.

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Declaram não haver conflito de interesse.

Research

Healthcare is currently going through a paradigm shift as a result of modernization, technological advances, and increased life expectancy. Health professionals must, therefore, become increasingly open to meetings, dialogues, and clarifications about illness. Communication becomes a fundamental step for good relationships between healthcare professionals, patients, and their families. It is a vital tool in healthcare as it strengthens relationships, develops patient autonomy, and fosters trust [1-3].

However, communication is not a simple act; it involves unique beliefs and values that may affect the transfer of information. It also includes ethical dilemmas, precepts, and principles. Other factors that may influence the quality of communication are the immediacy of society, the speed and urgency demanded of professionals, the excessive use of technical jargon, infantilizing speech, fatigue, cultural contexts, personal beliefs, and lack of training [3-5]. Sometimes the message communicated is painful for the patient and family to hear; in other words, it is "bad news". The most famous definition of bad news was proposed by Robert Buckman and adopted by several scholars: news that seriously affects the outlook of the individual regarding his or her future and that may, directly or indirectly, result in negative changes in his or her perspective on life [1,6,7].

Communicating bad news, whether related to treatment failure, disease progression, or imminent death, ends up being a difficult task for the professional, who shares in the anguish and feelings of the patient. The person assigned to perform this task may feel uncomfortable and experience intense emotions, even feelings of sadness, anger, guilt, and incompetence for not being able to prevent the negative outcome. Communication may become formal and indifferent as a defense mechanism. Moreover, the reluctance to communicate bad news is associated with the stress that this task causes [1,4,5,7].

Literature on the subject reveals frequent problems in communication between health professionals, patients, and family members, going as far as to call this communication "precarious". Communication is considered a critical element for high-quality care. Some studies recognize poor communication as one of the main sources of patient complaints, highlighting the negative repercussions suffered by the patient and/or their family over a long period of time. Thus, we can see that the communication of bad news is complex and necessary, meriting action and research on the subject [3,7-8]. This study, based on literature [1-8], sought to recognize the meanings associated with "bad news", identifying them both in professional practice and in the feelings and emotions of the healthcare professionals (doctors and nurses) who perform this task.

Methods

This was a qualitative, exploratory, and descriptive study carried out with healthcare professionals working as doctors and nurses in the neonatal and pediatric intensive care unit (ICU) of a teaching hospital in the countryside of the state of Rio Grande do Sul, Brazil. The neonatal and pediatric intensive care unit was chosen for its unique characteristics, which demand constant improvements in communication. One particularly important characteristic is the complexity of dealing with childhood illness or death. People who deal the most directly with this subject were chosen as participants.

Professionals were approached individually in the intensive care unit. The purpose of the study was explained, as was the voluntary and anonymous nature of participation. Informed consent was obtained from all participants. Of the nine health professionals, two were medical school graduates, one was a medical (resident), three were medical students, and three were trained nurses. Of the graduates, the most experienced participant was a physician with 33 years of experience, and the other had practiced medicine for a year and a half.

Among the graduate participants, the average time spent practicing medicine was 15 years. All the students interviewed were engaged in internships and expected to complete medical school within a year. A heterogeneous sample was collected to evaluate possible differences in methods of communicating bad news. In terms of gender, the sample had seven female professionals and two males.

Procedures

First, the researcher was given access to the unit in which the research was carried out. After the environment was assessed and observed, several professionals were randomly chosen to participate in the study. Direct or indirect experience in communicating bad news was the criterion for inclusion. All participants were individually approached and informed about the study, its objectives, and its methods. After the individuals agreed to participate, a semi-structured, 30-minute interview was scheduled. Once complete, the

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interviews were transcribed fully and reliably by the researcher for analysis.

The research instrument, based on research already carried out on the subject [4,7], included data related to sample characteristics, such as age, education, and time practicing medicine, and open questions on the subject of "bad news". The questions included personal insights, professional experiences, and communication methods. All of the interviews were conducted at the intensive care unit between January and October 2016.

Data Analysis

To analyze the interviews, the content analysis technique was used to create thematic sections in three stages: pre-analysis, material exploration, and data processing [9]. After exploring the material, three categories were created: "*I'm sorry*", "*It's not good news!*", and "*It's awful*!", seen in Table 1. The first refers to the meanings associated with bad news; the second, to how to communicate bad news; and the third, to the emotions and feelings of those who relay bad news. To ensure anonymity, participants will be indicated by the letter "P" followed by numerals (P1, P2, P3 ...).

Table 1. Quotations from participants exemplifying each section

"I'm sorry" – meanings associated with bad news	*"It's not good news!" – how to communicate?*	*"It's awful!" – emotions and feelings of those who relay bad news*
"It's saying to a parent that their child has died, the worst news imaginable." (P2)	*"There is no strategy! A strategy to communicate that their child died? There isn't one; it doesn't exist!"* (P2)	"It's painful; it's awful; it's very painful, but you have to do it. You have to say to them that their baby died." (P2)
"Bad news is always related to moments when you destroy someone's hopes. Whether it's news that someone died or news of a worsening clinical outlook." (P5)	*"I try to explain to the family, simply, that the situation is critical. There's no one way; you have to sort of improvise what you're going to say. I try to be very human in these situations* (...) *you have to be sincere and explain what's really happening."* (P3)	*"It's a bit frustrating for us, because it has to do with our profession, that we're not going to reach our goal. You're not going to be able to help this family get its child back."* (P3)
"[Bad news] *is always related to death or a clinical decline."* (P6)	*"You sit down to talk, explain all the points, express yourself, and don't omit any information during the course of treatment. I think that is important, definitely."* (P7)	*"My own protection, a shell I created, but we cry, we suffer."* (P5)
"Bad news is always telling the family about a death." (P7)	*"No, we don't learn anything about this in training. I think we should have something, or a course about coping, whether with bad news or unpleasant situations."* (P5)	*"There are times when the whole team leaves in tears; it's not easy for us at all; there's a mix of feelings."* (P9)

Bad news in everyday practice

The neonatal and pediatric context presents nuances in relation to other hospital units. Here, healthcare professionals deal with the life and death of children. In other words, they constantly need to deal with the suffering of family members and their unmet expectations while also facing the task of constantly relating "unnatural" events, along with the stress caused by this task [10]. Thus, communication in the neonatal and pediatric context is indispensable. When communication is good in healthcare, it becomes possible to take on and ameliorate the feelings of pain, helplessness, frustration, stress, and anxiety experienced by the child's family in cases of unfavorable news.

When approached, study participants were given an opportunity to discuss the research topic and highlight aspects that they considered pertinent to their practice. The work was carried out with a heterogeneous sample to identify possible differences in the perception and communication of bad news. However, no significant differences were observed in this regard, since all participants considered giving bad news to be a difficult task, demonstrating a gap in professional training. In the following sections, this paper will discuss the results found, highlighting the meanings associated with the idea of bad news, the methods used to communicate it, and the emotions and feelings perceived by professionals in their practice.

"I'm sorry": meanings associated with bad news

In this section, we will explore the meanings that the interviewees associated with bad news. These meanings are tied to the subjective opinion of each professional and are either related to their perception or acquired from work experience and assimilated though identification with colleagues:

"I always tried to pay close attention to the way she dealt with these situations, and since I identified with her, I started to adopt an approach more or less similar to hers," (P3);

"Well, it was a time of my life that was very… [difficult] *I think that's what gave me the confidence that I now have to relay bad news.* (...) *My training was on the job, without any help*"(P5).

Empiricism and informality characterize the interviewees' knowledge about their ability to communicate bad news, which was gained by experience. The meaning associated with bad news is also conveyed subjectively in the acquisition and process of learning this skill [3]. The practical training of performing this activity demonstrates that the construction of meanings goes beyond the intimate and unique characteristics of each subject.

Clinical deterioration and death stand out in this study as meanings associated with bad news. A similar finding was described by Baile et al. [7], who also related these meanings to a single perspective on bad news. Clinical deterioration presupposes a higher possibility of death, which is therefore the main meaning associated with the concept of bad news: *"It's saying to a parent that their child has died, the worst news imaginable."* (P2). Therefore, the fear of death is the primary and most obvious meaning related to the communication of bad news.

Nowadays, talking about death is considered taboo, as it is seen as the most horrible thing, an absurdity imbued with intense suffering. The way that death is understood is intimately related to culture and the times. In today's technological society, death is seen as a failure, which instills insecurity and fear. In this way, society clearly demonstrates its difficulty in viewing death as the last, natural stage of life [1,5]. As members of society, healthcare professionals share society's beliefs about death. They too tend to view it as a failure, which, in their case, goes beyond the social dimension and extends to the professional sphere, as suggested by the literature [11,12] and corroborated in one participant's response: *"We couldn't get their blessed heart to beat again, could we?"* (P2).

Relating a death demands emotional willingness and readiness from the healthcare professional. Being the bearer of bad, irreversible news can often be seen as professional failure, and it shakes up the messenger emotionally. To experience the death of another is considered an indirect experience of one's own death. This reality, which happens to everyone involved in the dying process, is especially poignant for healthcare professionals, since it involves constant reflection on their personal and professional attitudes on the finite nature of life [13,14].

When considering these themes related to the communication of bad news, we can identify that, in this study, death is perceived as the worst news that can be reported to the family in a neonatal and pediatric intensive care unit. This result may be influenced by the intense and highly complex situations experienced in the realm of intensive care. However, it is a result confirmed by other studies [4,15]. The more that healthcare knowledge progresses, the more the end of life is feared and denied. Thus, learning to relay bad news is an important step in facing the death taboo that is currently one of the greatest difficulties in the scientific training of healthcare professionals [13].

"It's not good news!": How to communicate?

This section describes the way participants communicate bad news, discussing themes related to this practice. Initially, it was identified that, for them, communication is understood as a daily activity in healthcare, and, therefore, it is imperative to carry it out in the best way possible. The quality of communication can be a determinant of therapeutic efficacy, making communication a complex activity that can be extremely difficult to perform [2,8].

The data showed that the interviewees do not use or recognize the validity of standard protocols or routines. The participants deny the presence of these protocols, justifying the impossibility of creating strict norms to standardize the way that bad news is communicated, which they understand as unique: "*There is no strategy! A strategy to communicate that their child died? There isn't one; it doesn't exist!*" (P2).

Literature presents a different opinion on the subject, emphasizing the importance of acquiring knowledge and skills to communicate bad news. The use of protocols is conceived as a guideline for practice and is recognized as being of great use to

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healthcare professionals, as it helps them to address obstacles that may arise during the process. Studies also emphasize that the planning of the conversation with the patient or family must take into account the unique features of each subject [3,14,16].

In terms of training for communicating bad news, university programs were found lacking. They ranged from an absolute absence of academic preparation to deal with these situations to crude training that was poorly positioned in the flow of the course. This training does not enable the professional to communicate bad news satisfactorily for either himself or the patient:

"*No, we don't learn anything about this in training. I think we should have something, or a course about coping, whether with bad news or unpleasant situations."* (P5)

"In the third semester, when we still haven't had experience with patients, we have a course and something in the psychiatric classes" (P8).

This lapse in vocational training is also identified in literature. Certain studies show that a large number of the professionals surveyed never received any type of training, having acquired knowledge only on the job [4,14,16]. Unfortunately, this gap influences the quality of the communication provided. The lack of training drives the reluctance of professionals to communicate, just as informal, brief, and non-empathetic communication encourages even more negative repercussions for those who receive unfavorable news [2-6].

In this way, the inclusion of "bad news" in the curriculum is relevant, as it is necessary to break the pattern of teaching skills unrelated to clinical practice. Research suggests dramatization, role playing, and workshops as methodological strategies, with positive results [16]. The primary goal in modifying teaching techniques is to create opportunities to discuss the quality of communication, thus benefiting patients, families, and healthcare professionals.

In describing how they communicate, participants highlight the importance of the presence of the physician presence and the need to retrieve the patient's medical history and explain the situation. They also consider it important to explain things clearly, with expressions and words that are easy to understand but that indicate that the news is not good. Note that these precautions, exemplified in the following statements, are consistent with guidelines from literature [7,17]:

"We are a team, and I accompany the doctor who is on my shift. I leave it up to him to speak, and I provide support" (P9);

"You sit down to talk, explain all the points, express yourself, and don't omit any information during the course of treatment. I think that is important, definitely." (P7)

"[You say] '*I wish I had better news'; you try to recap everything that happened in the patient's evolution"* (P3).

The Spikes protocol, developed by Robert Buckman, a medical oncologist and pioneer in studies on bad news communication, presents important steps to be considered during when communicating with patients and families. Among these are several items not identified in this study: 1) concern regarding the environment in which communication will take place; 2) verification of the patient's and/or family's understanding of the illness; 3) reception of the emotions that arise; and 4) sharing the strategies used to continue care [7,17].

This study noted the following strategies and resources for communication: the importance of sincerity, striving to relay accurate information, the importance of the bond between the healthcare professional, patient, and family, and empathic contact as a means of solidarity with the suffering of others. In addition, religiosity also appeared as a possible way to support and comfort others:

"I show solidarity when it comes to religious matters – it's quite valid; when a person believes in something, it is a way to find comfort"(P6).

You have to make things clear; you have to be sincere and explain what's really happening." (P3);

"It is important, when you give this news, to have a bond, for the family to trust you. And no matter how bad this moment may be, you could make it better, even if only a little bit. In these moments, they need human warmth and kindness"(P4);

"You have to have empathy. It is quite important. Always think, 'How would I like [to receive the bad news] if it were me?' "(P8);

Both sincerity and a therapeutic bond are fundamental in healthcare, where the rights of care recipients are of primary importance. One topic that participants mentioned that was not identified in previous studies was - religiosity. We believe that the mention of this subject can be attributed to the individual characteristics of the unit where this study was carried out.

Another attribute highlighted by the study participants was empathy. Empathic behavior in interpersonal relationships embodies the contemporary demand for greater awareness with one another, and is undeniably essential when communicating bad news. By demonstrating empathy, the professional gives the patient and/or family support to face the critical situation; this support is indispensable to establish an environment of emotional comfort. Empathy establishes a relationship in which not only the content of what has been said influences the message, as tone of voice, rhythm, gestures, touch, and silence also help to convey the idea of warmth and welcome [17-19].

The difficulties encountered are associated with ignorance of the emotions presented by the patient and/or family in reaction to the news. This shows that the more irreversible the facts, the greater the degree of difficulty. These data corroborate the previous studies [1,6,20]. These difficulties reinforce the importance of protocols that may assist the professional with the emotional nuances involved in the communication of bad news [4,15,21].

Based on the themes discussed here, we can see that this issue goes beyond the simple act of communication, beyond the transfer of information. There are complex elements involved here that demand further study, learning, training, remodeling, and improvement in the future. The professional, in carrying out this task, not only communicates the bad news to the patient and family, but also shares in it. This topic deserves more attention because it is directly related to the preservation of the health and the well-being of the professional.

"It's awful!": Emotions and feelings of those who relay bad news

The subject of "bad news", as already indicated, is closely related to emotional themes. Although they share the communication process, this situation is obviously experienced differently by those who convey the news and those receive it. This section presents and discusses themes related to the emotions and feelings of health professionals who undertake the practice of communicating unfavorable news. Literature has little to say about this subject. However, professionals are known to commonly experience emotions, although often repressed or not revealed [20].

We can observe that the feelings of health professionals are frequently ignored in favor of technique and rational discourse. However, the emotions of the professionals in carrying out their activities directly influence the care provided to others. The therapeutic relationship is known to be mutually affected, due to the phenomena of transference and countertransference in interpersonal relationships [18]. The literature highlights insecurity and anxiety [5,21] among the emotions and feelings professionals experience in their practice. Study participants revealed various emotional responses, mainly feelings of impotence, frustration, and avoidance:

"I feel like a bad person, a person unable to keep that poor thing alive. Jeez, it's awful! I could not keep this poor thing alive, right? You ask yourself what was missing, what you failed to do, where you went wrong. You always think you've made a mistake. You always keep searching and searching. You are not God, but you want to act as if you are and keep everyone alive" (P2);

"You run away; you sort of watch from afar since you can't manage to be present" (P1).

When reflecting on these feelings, we can see high self-expectations as well as cultural themes related to what is expected of the doctor figure. These feelings suggest the presence of defense mechanisms, since healthcare professionals inadvertently identify with the negative nature of the news. We could say that the refusal or fear of being affected by the suffering of others is manifested in the rigid attachment to technique and intellectualism, subsuming the psychosocial aspect [5,11,19].

When analyzing these data, we can affirm that the emotions present when reporting bad news prove the suffering faced by professionals: "*There are times when the whole team leaves in tears; it's not easy for us at all; there's a mix of feelings*" (P9). In addition, we see that the interviewees face difficulties in recognizing the suffering they experience due to their occupation. Many choose to repress it, probably because of the distorted way that this theme is understood in their field.

The care given to critically ill patients can be viewed as an aggravating factor for emotional exhaustion, considering the implications of imminent death. The symptoms of anxiety, depression, and burnout, which develops progressively, exposes the occupational stress and physical and emotional exhaustion faced by healthcare professionals working in intensive care units [22]. These issues show the importance of frequently providing moments of integration and reflection on the practice to validate the feelings and emotions that professionals experience due to their occupation, all in an effort to promote the healthcare worker's own health.

Final considerations

The study found that the main meaning associated with the concept of "bad news in health care" is death. The fear of death and its imminence in the neonatal and pediatric intensive care unit is what makes this news difficult and complicated to report. The study also showed that it is necessary to consider the personal experiences and subjectivity of professionals, as these subjects may influence the communication of bad news. However, it is best to address these issues in other contexts, in an effort to understand possible alternative meanings associated with the concept of bad news.

As for the methods used for this process, participants mentioned important care guidelines, such as the right to clear, precise information and empathic contact. However, we see that this subject is scarcely brought up in professional training, demonstrating the need to include courses and training in undergraduate and graduate curricula. In this way, practical skills are acquired and complemented by the unique characteristics of each worker. As a result, we note the lack of standardization and the absence of some important features highlighted in literature.

The act of relating bad news causes healthcare professionals significant emotional distress. The feelings discussed in this paper are related to widespread social beliefs about death and cause a significant degree of suffering among workers. This theme contributes to the professional's fear or refusal to report this type of news. In addressing feelings and emotions, it was possible to demonstrate their relationship with the health of the worker; however, we suggest further studies on this matter, considering the scarce literature on the subject.

This study highlights the relevance of this complex theme in the context of healthcare, demonstrating the various intersections across the practice. There are still few surveys that consider the professional's perception of reporting bad news. However, this study included a group of professionals from a single unit of a hospital, which limits the results. Thus, we suggest that the themes investigated here are explored in other units and institutions, as well as with larger groups, in order to support our findings and stimulate the search for ways to better perform this difficult task.

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Participation of the Authors

Caroline Lau Koch was responsible for developing and carrying out the survey. Aline Badch Rosa supervised the project and, along with Simone Caldas Bedin, co-oriented and reviewed the study

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Research