

Breaking bad news in pediatrics

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Abstract

This integrative literature review investigates the delivery of bad news in pediatrics. Scientific database search included studies published between 2015 and 2022, which indicate that bad news should be disclosed in an empathetic, objective and frank manner, involving both the child and their caregiver, but partial and adapted to the child's understanding or maturity. Finally, this study brings suggestions and scientific evidence about delivering bad news in pediatrics, contributing to further enrich knowledge on the subject, especially for the healthcare professionals who deal directly with this context.

Keywords: Health communication. Child health. Pediatrics.

Resumo

Processo de comunicação de más notícias em contexto infantil

Este estudo investiga a transmissão de más notícias em contexto infantil por meio de revisão integrativa da literatura. As buscas nas bases de dados científicas compreenderam trabalhos publicados de 2015 a 2022 e os resultados indicaram que a transmissão de más notícias deve ocorrer de forma empática, objetiva e franca, envolvendo tanto a criança como os acompanhantes, mas, no caso de crianças, a comunicação deve ser parcial, com adequação do conteúdo ao entendimento ou maturidade. Por fim, este estudo visou trazer sugestões e evidências científicas sobre a transmissão das más notícias na infância, contribuindo ainda para enriquecer o conhecimento sobre o assunto, principalmente para os profissionais de saúde que lidam diretamente com esse tipo de situação.

Palavras-chave: Comunicação em saúde. Saúde da criança. Pediatria.

Resumen

Proceso de comunicación de malas noticias en el contexto infantil

Este estudio evalúa la transmisión de malas noticias en el contexto infantil mediante una revisión integradora de la literatura. La búsqueda en bases de datos científicas incluyó artículos publicados entre 2015 y 2022, y los resultados revelan que la transmisión de malas noticias debe realizarse de forma empática, objetiva y franca, implicando tanto al niño como a los cuidadores, pero en el caso de los niños, la comunicación debe ser parcial, adaptando el contenido a su comprensión o madurez. Por último, este estudio pretende aportar sugerencias y evidencias científicas sobre la transmisión de malas noticias en la infancia, a la vez busca contribuir con más conocimiento sobre el tema, especialmente para los profesionales de la salud que tratan directamente con este tipo de situaciones.

Palabras clave: Comunicación en salud. Salud infantil. Pediatría.

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When talking about bad news, the human body naturally reacts with a rush of adrenaline and noradrenaline, neurotransmitters that prepare it for emotions such as fear, anxiety, and stress. This is a defense mechanism since the organism presents the same type of response to dangers found in the environment¹.

An example of a stressful situation is receiving bad news in healthcare institutions, identified since the diagnosis, as there are situations that can drastically and negatively change the patient's expectations for the future². As part of the subjective scope, reactions to bad news are perceived by different people with different levels and intensities, being influenced by a series of factors such as personality, family and social support, religion, culture, and experiences of each person³.

Furthermore, communication is a process of assimilation and interpretation of information, concurrently to a sharing of emotions between transmitter and receiver. In this sense, communicating is a fundamental skill, but the process of communicating bad news is a difficult task. It is necessary to identify one's own emotions and those of the other person for an efficient interaction, not affecting either party critically⁴.

Many professionals have difficulty informing the actual health conditions of the patient or their family members. These situations are complex, and some physicians find it difficult to express their feelings, as they confuse empathy and involvement in the demands of professional limits, making assertive communication with patients and family members complex⁵.

The complexity of transmitting bad news extends to the children's context, where there are debates about the specificities of communication, as transmitting this type of information to a child or adolescent can involve ethical, social, and legal aspects. In this sense, communicating bad news to pediatric patients causes dilemmas for healthcare professionals. Physicians often find themselves with their hands tied due to the impossibility of transmitting information when considering factors such as the child's age, maturity, and understanding, or even the parents' annoyance⁶.

It should also be noted that, in addition to the aforementioned obstacles, capable of interfering

in the communication process, it is necessary to assess the understanding of the news transmitted to the guardian/family member, thus analyzing their decision-making capacity. Furthermore, it is required to consider that communicating bad news becomes an arduous responsibility for healthcare professionals. This process demands sensitivity and ethics to decide the best way and time to inform the child or adolescent of bad news, primarily if it is related to a diagnosis or prognosis⁶.

The way the disease is seen culturally and the justification of protecting the patient from their diagnosis or prognosis as attempting to prevent suffering are also essential factors. These factors can interfere with the transmission of information and the patient's participation in decision-making. However, a study shows that telling the truth has proven to be an essential therapeutic resource, reducing the feeling of isolation and contributing to cooperation between patient and professional⁷.

The transmission of bad news is a subject widely identified in healthcare facilities. However, it is little addressed in scientific studies or even during academic training, highlighting the importance of further investigations. Therefore, this work aims to identify and analyze scientific evidence on how bad news is communicated in children's context. Furthermore, when relating to the theme and the universe of children, the study brings ethical debates and suggestions based on scientific evidence on how bad news should be transmitted in the pediatric setting.

Method

This research is composed of an integrative review of the literature, that is, it aims to synthesize results obtained in research on the topic systematically, orderly, and comprehensively⁸. For the operationalization of this study, six steps were considered: 1) identification of the topic and selection of the guiding question; 2) establishment of inclusion and exclusion criteria; 3) selection of articles; 4) categorization of articles; 5) analysis of studies; and 6) synthesis of knowledge⁹.

The literature search was carried out in the SciELO, LILACS, PubMed, and MEDLINE databases in the first quarter of 2023 and comprised articles published from 2015 to 2022. The following

descriptors and their combinations in Portuguese and English were used to search for articles: “health communication *and* child health *or* pediatrics”; and “transmission of bad news *and* child health *or* pediatrics,” controlled and arranged in the Health Sciences Descriptors of the Virtual Health Library (DeCS/BVS) and the Medical Subject Headings, of the National Library of Medicine (MeSH/NLM).

National and international articles whose content was available in full and free of charge were included within the established timeframe. Duplicates, case studies, those that did not directly relate to the topic, and those with insufficient information were discarded.

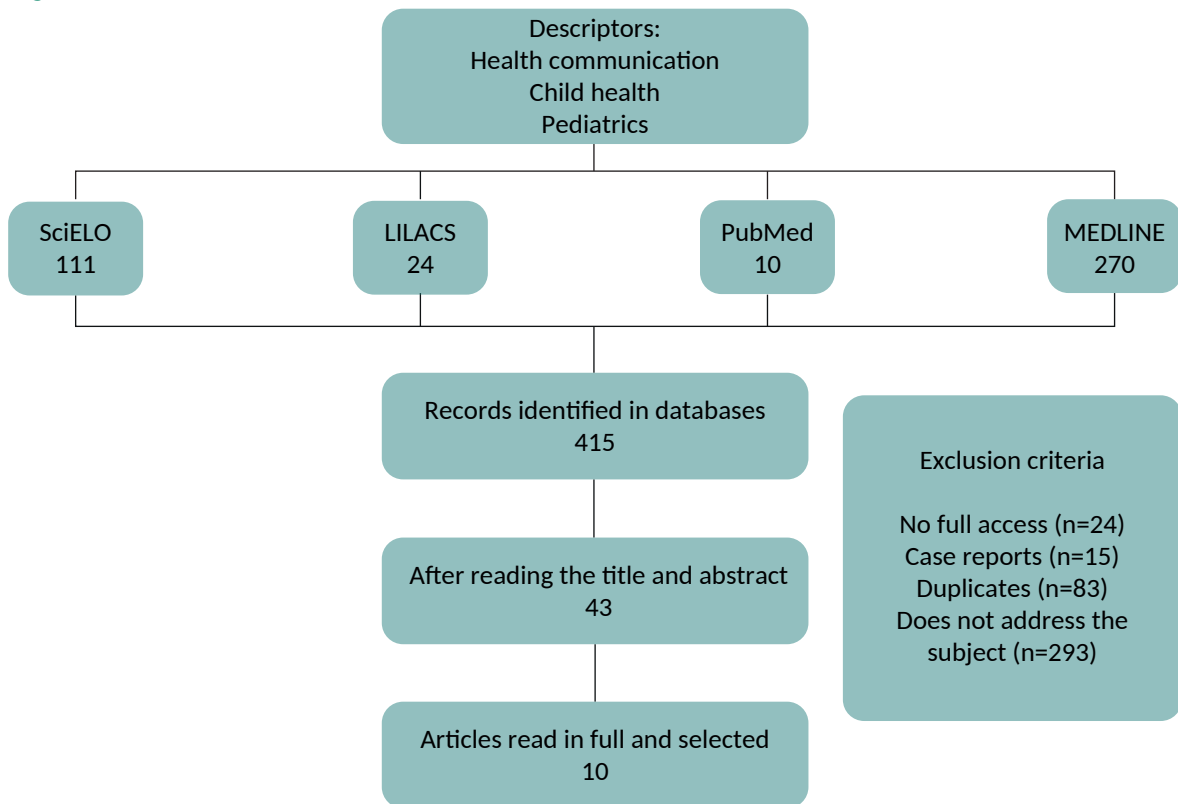
Initially, a survey of all the materials found was carried out, and then the abstracts were read to

determine which met the established criteria. The articles chosen were critically and cautiously read to understand how literature presents itself concerning the topic studied. Once these steps were completed, the material was analyzed to address the main contributions of this research.

Results

Ten articles were selected that met the review criteria. A few national and international articles cover the communication of bad news in a pediatric context, given the scope and difficulty of dealing with the topic in the hospital context. PRISMA¹⁰ flowchart was used to present the processes of study selection and identification (Figure 1).

Figure 1. Flowchart with review details



Most of the excluded publications were related to health communication in general, focused on the diagnosis itself, and without specific thematic involvement with bad news or children’s

health. Research, especially articles that involve questions about bad news, is constantly related to pedagogical perspectives during undergraduate studies and/or residency, generally for physicians.

Therefore, it is essential to highlight that the specific topic of news transmission in pediatrics requires further studies.

Most of the studies selected are qualitative (50%) and integrative reviews (20%), while cross-sectional (10%), bibliographic (10%), and methodological

(10%) studies reached the same proportion. Studies in medicine prevail, although one of them is in nursing. To facilitate understanding, Chart 1 briefly presents the selected articles with the following information: authorship, year, objective, method, and main results.

Chart 1. Presentation of results

Authors; year	Purpose of the study	Method	Main results
Afonso, Minayo; 2017 ¹¹	To understand the importance of communication, which includes expressions and control of emotions, and how physicians balance proximity to children and family members and objectivity in their work.	Qualitative research	The team must inform the child/adolescent about their diagnosis, as far as they want to know, and explain all procedures during treatment. When children are very young, information is transmitted to the family.
Gonçalves and collaborators; 2015 ¹²	To identify strategies used by pediatricians to communicate bad news to patients.	Cross-sectional study	The professionals chose to partially provide the information to the child, considering their age and level of understanding. The importance of talking to parents about decision-making is highlighted. Emotional support is essential.
Zanon and collaborators; 2020 ¹³	To identify scientific evidence of communication elements in communicating bad news in pediatrics.	Integrative review	The form of transmission must be empathetic, honest, and objective. Failures and/or noise must be avoided.
Soeiro and collaborators; 2020 ¹⁴	To analyze the perceptions and experiences of pediatricians concerning communicating bad news when caring for children with cancer.	Qualitative research	Partial exclusion of the child during the communication process, according to understanding and maturity. The news must also be given to the person with the most significant emotional bond with the child.
Santos and collaborators; 2015 ¹⁵	To identify the harmful effects of communication between healthcare professionals and families of hospitalized children.	Qualitative research	The act of communicating should be part of professionals' daily practice.
Fontes and collaborators; 2017 ¹⁶	To describe how the process of communicating bad news is established and identify how nurses practice communicating bad news.	Integrative review	The professional must be honest and balance revealing the truth with the family member/patient's hope of continuing treatment. Academic training must be improved.
Setubal and collaborators; 2017 ¹⁷	To describe residents' evaluations and perceptions of a training program on disclosing bad news in perinatology based on video analysis and Spikes' strategy.	Qualitative study	Resident pointed to the Spikes protocol as a guide to systematizing bad news. A proposal is to include training in residency programs.

continues...

Chart 1. Continuation

Authors; year	Purpose of the study	Method	Main results
Zampoli; 2018 ¹⁸	To analyze communication with family members of perinatal patients with the possibility of palliative treatment.	Bibliographic study	Faced with the suffering caused to companions/parents, communication in a humane and empathetic way can offer significant support for understanding and acceptance of the disease. The protocol is seen as a helpful tool for communicating bad news.
Soeiro, Vasconcelos, Silva; 2022 ¹⁹	To understand the challenges intensive care physicians face in communicating bad news, using some problematized issues in bioethical discussions as the axis of analysis.	Qualitative study	The findings reveal the importance of developing communication skills in the pediatric ICU, both in the relationship with the child and with their family members/caregivers. A lack of academic training for death results in a dialogue aimed primarily at parents and/or guardians. Communication with pediatric patients tends to be poor, opening up space for silencing or limiting information, especially in more serious conditions.
Zanon and collaborators; 2022 ²⁰	To create and validate the content of a guide to monitor the communication of HIV diagnosis in childhood.	Methodological study with a participatory approach	The professional must support the family in communicating the diagnosis to the child honestly, hopeful, empathetically, objectively, and available to answer questions. Professionals and family members/companions must listen to the child, considering their particularities in their clinical and life context and evaluating their demands according to their stage of child development. Professionals and families must reach a consensus about communication, and healthcare services must recognize the child's right to know their diagnosis.

The results showed that the transmission of bad news must occur in a scenario that involves empathy, objectivity, and frankness and that both the child and companions must be involved. For children, communication must be partial, with the content of the diagnosis or prognosis being adapted to the understanding or maturity of the child. Thus, the child is treated as a subject of rights, with autonomy in their health-disease process¹¹⁻²⁰.

Discussion

Communicating bad news is one of the most challenging tasks in clinical practice among healthcare professionals²¹. In this regard, some studies are conducted to discover the best way to carry it out. Based on the findings of this review, it is highlighted that many of the works

focus on recommendations on aspects seen as fundamental in communication.

Among such recommendations are offering emotional support¹², transmitting the news in an empathetic, honest, and objective way¹³, and maintaining the hope of the patient and family in the treatment¹⁶. From this perspective, the authors emphasize that the healthcare team must transmit the information to children and adolescents, except that, in cases of very young children who cannot fully understand the situation, the transmission must be directed to their family¹¹.

Children usually are partially informed about bad news, considering their age and level of understanding, which supports this result¹²⁻¹⁴. It is also necessary to highlight the importance of talking to parents or guardians to make a joint decision about the amount of information and how to provide it¹².

In contrast, there are cases in which the healthcare professional faces an ethical impasse, such as when family members request not informing the patient's health status to the children themselves²², often to "protect them"⁶. There are also circumstances in which the family pretends that nothing bad is happening and feigns ignorance, a simulation often reciprocated by the patient attempting to avoid worrying the family. Such situations increase isolation and prevent patients from talking openly about their condition, a process that, for them, can be fundamental²³.

In such situations, healthcare professionals must develop new attitudes to produce the beneficial effects of keeping children informed about their health status. Transmission must respect the uniqueness of each child, according to their stage of development, their demands, their possibilities of understanding, and their "time"²⁴. Accordingly, scholars^{25,26} concluded that parents and professionals must give due importance to the patient's desire to be involved, although the needs of the parents and the patient may differ.

Minimizing factors such as noise and/or communication failures is essential in this scenario¹³. Noise is associated to the professional's inability to deal with emotions, whether their own or the patient's, and to the use of a language inaccessible to the family. The failures are related to techniques that are not significant during transmission, such as silencing and the transmission of misleading information.

Such deficiencies can affect the patient's understanding of their health status, increasing anxiety, hindering their psychological adjustment, and causing distrust. In other words, failure to provide information interferes with adequate understanding and leads to several obstacles in adherence to treatment. On the other hand, the correct way of reporting reduces patient uncertainty and contributes to acceptance of the disease²⁷.

The habit of communicating must be regularly present in the relationship between professionals, family members, and children, providing humanized care in which those involved feel welcomed and guided. Consequently, their anxiety levels regarding the situation are reduced, which also contributes, in turn,

to the effectiveness of communication in this triad and, therefore, to the treatment¹⁵.

Therefore, it is reiterated that family support promotes understanding and fosters the ability to deal with suffering, pain, and problems. In other words, when the professional team realizes the consequences of the hospitalization and values dialogue, it is possible to include the family and the child in transmitting information²⁸.

Another essential factor that must be considered during transmission is the emotional bond. The news should preferably be given to parents or legal guardians. However, there are cases in which it can also be intended for the person with the most significant emotional bond with the child—possibly their caregiver and/or the companion present during hospitalization¹⁴.

From the bond of affection established, the child builds their emotional structure and capacity for internalization, which is influenced by their experiences and their relationship with the environment in which they are inserted²⁹. Through this bond and emotional intimacy, the transmission may become less conflicting for the child¹⁴.

It is also important to emphasize that the transmission of bad news causes suffering to parents/companions. Empathetic and humanized communication can reduce suffering, helping to understand and accept the disease. Furthermore, the Spikes protocol is considered a helpful tool in this process¹⁸, and its association with empathy can strengthen the bond between physicians, family members, and patients and contribute to the academic training of healthcare professionals³⁰.

The Spikes protocol was created based on reflections and consideration about this complex and fundamental process of communicating bad news. This instrument aims to facilitate communication through six steps to guide professionals from planning to the moment after the bad news is transmitted, seeking to minimize impacts³¹.

The steps are: 1) setting: preparation for the meeting; 2) perception: uncover of what the patient knows about their health status; 3) invitation: an invitation to dialogue; 4) knowledge: transmission of information in plain language; 5) emotions: an approach to patient's emotions; and 6) summarize: summary of everything that was

said, in addition to establishing goals and strategies for facing subsequent challenges^{22,32,33}.

Resident professionals highlighted this protocol as a guiding instrument to organize the delivery of bad news, being capable of helping to understand the emotional needs of patients¹⁷. At the same time, it is necessary to include it in similar training in residency programs. Bad news, when poorly or insensitively delivered, can cause emotional disturbances in the family, and communication can be improved through already structured and organized protocols, such as Spikes³⁴.

Furthermore, healthcare professionals found a curricular deficit concerning professional training for delivering bad news when approaching academic training. They perceive this lack because they sometimes do not feel prepared to communicate the case adequately, using the personal or professional knowledge acquired through experience. Thus, the importance of implementing professional techniques aimed at this type of communication is evident³⁵.

Final considerations

Although there are dilemmas regarding delivering bad news, it is concluded that it must

occur empathetically and objectively, and that the child and their family members must be involved in this process. However, these findings do not end the debate on the topic, mainly because, as with any research, some limitations must be recognized, among which breadth stands out. This study only covered full articles, searched in the abovementioned databases, and within the time frame, which limited its outcomes.

Despite these limitations, one cannot fail to recognize some of the contributions made by the study to advances in knowledge on the subject. The results regarding the two variables studied (delivering bad news and child health) contribute to the literature, in which there is a lack of recent studies. Another contribution is the importance of studying the topics discussed here: transmitting bad news is seen as an arduous task for most healthcare professionals, who have difficulty informing the patient or family member about the patient's actual health conditions.

Finally, the possibility of new studies involving a broader and more diverse scope must be considered, guaranteeing greater representativeness and generalization of results. At the same time, other research methods are suggested, such as qualitative analyses that use case studies.


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