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Breaking bad news in neonatal intensive care units

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Abstract

The SPIKES protocol is one of the most didactic tools to teach the communication of bad news, a skill that requires sensitivity and preparation. This article analyzed the perceptions of pediatrics residents and the mothers of neonates about the communication of bad news in a neonatal intensive care unit. This is a qualitative, descriptive and exploratory study, based on visual anthropology, in which the SPIKES protocol was used in two focus groups, with Bardin's content analytics approach by categories. Problems were reported as inadequate environment to break bad news, limitations in the perception of mothers, lack of medical availability to talk, inadequate language and difficulty to deal with emotions, clarify doubts and discuss strategies with family members. Reflection on these issues aims to improve theoretical learning and stimulate self-criticism, seeking empathy and the humanization of care.

Keywords: Health communication. Intensive care units, neonatal. Humanization of assistance.

Resumo

Comunicação de más notícias em unidade de terapia intensiva neonatal

O protocolo Spikes é um dos instrumentos mais didáticos para o ensino da habilidade de comunicar más notícias, que exige sensibilidade e preparo. Neste artigo foram analisadas as percepções de residentes de pediatria, bem como de mães de neonatos, sobre a comunicação de más notícias em uma unidade de terapia intensiva neonatal. Trata-se de estudo qualitativo, descritivo e exploratório, baseado na antropologia visual, no qual o protocolo Spikes foi empregado em dois grupos focais, com abordagem analítica de conteúdo de Bardin por categorias. Foram relatados problemas como ambiente inadequado para comunicar más notícias, limitações na percepção das mães, falta de disponibilidade médica para conversar, linguagem inadequada e dificuldade para lidar com emoções, esclarecer dúvidas e discutir estratégias com os familiares. A reflexões sobre essas questões visa melhorar o aprendizado teórico e estimular a autocrítica, buscando a empatia e a humanização da assistência.

Palavras-chave: Comunicação em saúde. Unidades de terapia intensiva neonatal. Humanização da assistência.

Resumen

Comunicación de malas noticias en la unidad de cuidados intensivos neonatales

El protocolo SPIKES es uno de los instrumentos más didácticos para enseñar la capacidad de comunicar malas noticias, lo que requiere sensibilidad y preparación. Este estudio analizó las percepciones de los residentes de pediatría y de las madres de recién nacidos sobre la comunicación de malas noticias en una unidad de cuidados intensivos neonatales. Se trata de un estudio cualitativo, descriptivo y exploratorio, basado en la antropología visual, en que se utilizó el protocolo SPIKES en dos grupos focales para categorizar el enfoque analítico del contenido. Se reportaron problemas como ambiente inadecuado para comunicar malas noticias, limitaciones en la percepción de las madres, falta de disponibilidad médica para hablar, lenguaje inadecuado y dificultad para lidiar con las emociones, aclarar dudas y discutir estrategias con los miembros de la familia. Las reflexiones sobre estos temas pretenden mejorar el aprendizaje teórico y estimular la autocrítica, buscando una atención más empática y humanizada.

Palabras clave: Comunicación en salud. Unidades de cuidado intensivo neonatal. Humanización de la atención.

Research

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Communication is a relationship; therefore, it is not reduced simply to the act of speaking, being rather a set of actions that include verbal and non-verbal behaviors used in dynamic interactions between people [1,2]. Through the connection between subjects, bonds are formed, which are essential for humanization in health care. Thus, good communication leads to a process of affective and ethical bonding between professionals, users and managers, fostering a coexistence of mutual support and respect, as recommended by the National Humanization Policy [3] and HumanizaSUS [4].

Bad news is any information that produces a negative change in the prospects about a person's present and future, requiring transparency in the physician-patient or physician-family relationships [5]. Therefore, communicating bad news is an important aspect of medical training, but it represents a challenge for all health care professionals, due to its complexity and several sensitive aspects involved [6-8]. Several studies have detected problems in the preparation to communicate bad news in several countries, including Pakistan, Iran, Australia, India, Malaysia, and Brazil [9-12].

In addition to these difficulties, reports of daily challenges experienced by health care teams working in neonatal intensive care units (NICUs) exist, thus requiring reflection on and discussion of technical, scientific and ethical aspects of care, both for critical patients and their families. This is an imperative process, particularly in the case of physicians under training, as it focuses on improving the quality of care and the relationship between physicians and families [13]. All this involves sensitizing the health care team, in addition to stimulating reflection on listening to the target population, which, in the case of NICUs, are caregivers and/or family members.

There are no single rules or models for adequate communication in the health care area, so the effectiveness of this process depends on flexibility to adapt the professional technique to each circumstance, according to the various contexts: cultural, social, educational and family contexts [2]. Accordingly, some protocols have been used to assist health professionals in understanding how to communicate difficult news. Among such protocols, one of the most didactic and known is the SPIKES protocol, in which each letter represents a stage of learning how to communicate bad news [14-16]:

- Setting (S): adequate beginning, with preparation of the setting, considering the manner of communicating and who should be present, that is, it is the beginning per se;
- Perception (P): perception of the family member's knowledge about the disease;
- Invitation (I): invitation to determine how much family members would like to learn about the patient's disease;
- Knowledge (K): the sharing of information with family members;
- Empathy (E): empathy to deal with the feelings of family members;
- Strategy and summary (S): summary of information and conduct of strategies together with the family, focusing on planning patient treatment.

Visual anthropology consists in using audiovisual resources to assist in the health communication process, encouraging dialogue between professionals and family members. This includes learning about health processes, understanding the needs of subjects, assisting in training health professionals and researching communication, service and health care practices, in addition to humanizing care [17].

The precepts of visual anthropology are dialogue, subjectivity, empathy and perception of subjects' opinion and culture by partaking their daily life. Thus, there is encouragement to reflection, complexity, analysis of the social context and participation of the subject in the critical assessment, maintaining ethics, honesty and commitment to the person [18].

This qualitative, descriptive and exploratory study analyzed the perceptions of pediatric residents and patient mothers about the communication of bad news in NICU, based on visual anthropology and using the SPIKES protocol in the focus groups' conversations and content analysis by categories according to Bardin [19].

Method

This project was conducted by means of a qualitative, descriptive and exploratory study,

seeking to interpretively understand the discourses and meanings they produce [20], being organized into two stages. In the first stage, two focus groups were established to understand the difficulties in a NICU regarding the processes of communicating bad news between professionals and mothers of newborns. In turn, in the second stage, the information and recordings produced during the conversations in the focus groups were analyzed with the purpose of understanding the participants' perceptions of the communication of bad news in NICU.

One of the focus groups (FG) [21] consisted of pediatric residents (FG1) and the other FG consisted of mothers of neonates admitted to the NICU (FG2). We used the following instruments: sensitive creative method [22], using the creativity and sensitivity dynamic, or almanac dynamic [22], to stimulate conversations in FG2; and the Physician Communicative Behavior Questionnaire (QCCM) [23], in addition to the SPIKES protocol [14-16], which guided the preparation of questions for the FGs.

First stage

FG1 had 12 pediatric residents, while FG2 consisted of six mothers of newborns who were or had already been admitted to the NICU. Three facilitators with experience in qualitative research FGs (among them, the researcher of this study) participated in both FGs.

Participant sampling and recruitment were by convenience, and most participants in both FGs were willing to speak, comment on their colleagues' interventions and express their views on the topic and its developments. The questions were similar in the two FGs, although the language was adapted to facilitate participants' understanding, who started and ended the conversations in the FGs together, in which all took part, with no opt-outs or refusals to participate.

Due to the quality and quantity of information produced in the two FGs, it was not necessary to repeat them, and with the closure of the groups, when the discourses began to be repeated, the participants were thanked and time was made available to have doubts clarified. They agreed that FGs should be recorded and signed the informed consent form (ICF) before the start of the study.

The FGs had the following times: 1) scheduling the time; 2) preparation of the setting; 3) reception of the group and presentation of the organizers and the objectives of the activities; 4) stimulation of conversations, in FG2, based on the almanac dynamic [22]—in which figures, phrases and words related to the theme or the central question are cut and pasted; 5) prepared questions based on the QCCM, for patients and physicians, giving each participant the possibility to present their perception to the group, based on which the collective discussion began; and 6) collective analysis and validation of data.

Second stage

At this stage, the information produced during the conversations in the FGs was analyzed in order to understand the participants' perception of the communication of bad news in a NICU. After the FGs, the recordings were listened to and fully transcribed, and the discourses and their meanings were classified according to the six guidelines of the SPIKES protocol, and later analyzed in relation to the constructs of visual anthropology [16,17]. After transcription, the discourses were analyzed based on Bardin [19]. To maintain confidentiality and anonymity, pediatric residents were identified by the initials "Res," participating mothers as "Mot" and facilitators as "Fac."

Results

Among the 12 pediatric residents of the first FG, which lasted 2 hours and 22 minutes, half attended the first year of residence, and the other half attended the second year. Most of them had attended a public university and completed undergraduate programs between 2015 and 2018. All had already had contact with hospitalized neonates and their mothers; eight had theoretical experience in communicating bad news only as undergraduates; and four had no theoretical experience in this area.

Among the six mothers, whose FG lasted 52 minutes, four were from the countryside and two from the state capital; four had attended high school; and two had completed only elementary school. All were inexperienced

regarding hospitalization in NICU—five of them were in their first pregnancy; the babies were all premature and were hospitalized for 9–37 days.

Almanac dynamic

At the initial conversations, mothers were asked to think of images that represented their experiences in the NICU when accompanying their children. Magazines were randomly distributed, and mothers were to make clippings and collages of these images on cardboards. Some artworks, stimulated by the almanac dynamic [21], revealed the daily difficulties of the mothers of babies admitted to the NICU: an exhausted young man with a bomb hovering over his head, one person climbing a mountain, another asking for silence and yet another catching fire. The participants expressed in their accounts the personal representations for the chosen images:

"*My image was fatigue or mental and physical tiredness. The mental* [tiredness] *affects our psychological health in this place. We also suffer a lot from the physical tiredness*" (Mot 1).

"*For mine, I chose a person on fire...* [crying]. *To represent our pain...* [crying]" (Mot 2).

"*I chose silence, also education and attention*" (Mot 3).

"*I chose the image of a pregnancy and childbirth here that was normal. It was something that happened to me here. Twenty-four hours after my water broke, I told the doctor that I really wanted my boy to have* [a] *cesarean birth. I didn't care about myself, about my recovery, but I did care about him. Because of that, my boy was born with respiratory problem and to this day he does not...* [cry]... *He was born very tired and today, after about a month and 17 days, he is recovering. He is still very tired*" (Mot 4).

"*I chose silence. And also education. And attention*" (Mot 5).

"*I chose this image because it means so much to me. A guy climbing a mountain and behind him there is a precipice*" (Mot 6).

Categories: SPIKES protocol guidelines

Both in the residents FG and mothers FG, it was found that there was no adequate setting to communicate bad news in the NICU. Considering the first step of the SPIKES protocol, which relates to preparing the setting to support patient families, it was observed that there was no humanized service:

"*She'd come, sometimes I was with my son and she'd say very loud: come here, I wanna talk to you*" (Mot 4).

"*Here, was on the bedside!*" (Res 1).

It was found that residents had no concern as to the mothers' understanding about the clinical condition of their children. As for the second step of the SPIKES protocol, related to the family members' perception about the patient's disease, we observed deficient interpersonal relationships:

"*I think I'm the one who ended up isolating myself*" (Mot 2).

"*But didn't anyone notice your isolation?*" (Fac 1).

"*I don't know*" (Mot 2).

"*So she spent many days in the ICU and she didn't know what the problem with the child was. She only knew that the child* [condition] *was serious*" (Res 2).

Both groups realized that there was no medical initiative, space or time for conversations between family members and the multidisciplinary team. As for the third step of the SPIKES protocol, related to the invitation to learn about patient diagnosis, treatment and prognosis, family members were often not invited to talk properly:

"*They don't know how to talk to us, they don't know how to call us, they don't have the education to call us, they just ignore us*" (Mot 3).

"*We're always on a hurry, so sometimes we don't have time to call the mother to talk*" (Res 3).

The two groups understood that in the communication in the NICU the language is inadequate. As for the fourth step of the SPIKES protocol, which concerns sharing information,

mothers do not understand the medical language used in conversations:

"*When I didn't understand, I asked them to repeat. I'd say: 'Can you repeat it?'*" (Mot 5).

"*Some parents have no understanding at all, even if you try to speak in very basic language. Even so, I think that every day you have to reinforce the same thing because most of them there do not understand it*" (Res 3).

With regard to empathizing with others, the two groups realized the difficulty in dealing with emotions. The fifth step of the SPIKES protocol, involving empathy, was one of the most difficult in health care relationships:

"*I felt very guilty. I cried too much*" (Mot 6).

"*At the time of breaking the news I started crying, I was in no condition, I started crying and remembering my niece*" (Res 4).

The two groups noted that there is no space to talk to family members, clarify their doubts, or even discuss strategies with the family. The sixth step of the SPIKES protocol, which involves summarizing and outlining strategies together with family members for the patient's future, was not conducted at NICU:

"*They, as if they were going to impose it. They don't ask if we want it*" (Mot 4).

"*Even with all the work overload, we've already been through it and we know we can do it*" (Res 7).

The work process and overload, the personality of physicians and the obligation to deal with life and death on a daily basis were some factors that hindered the communication of bad news in the daily routine of the NICU:

"*There were few good moments, but there were more painful ones, because most nurses are very bad*" (Mot 2).

"*It was very traumatizing for me and maybe if I had received this training before it would help me*" (Res 5).

"*Professionals don't want to break the news or don't want to file a death certificate because they don't want to be related to the fact of death*" (Res 2).

Discussion

The participants of this research reported many difficult moments that could have been minimized if there had been adequate preparation of the professional team, physical structure and good working conditions to receive the family members of the newborns in the NICU. The structural flaws of the analyzed NICU (considering the Setting category of the SPIKES protocol), for example the lack of a reserved and adequate room to communicate bad news to patient families, favor the distancing between physicians and mothers, impairing the communication of difficult outcomes [8].

To avoid isolation and support physician-patient and physician-family relationships, the principle of health professionals' commitment to families should be reinforced, establishing an affective and ethical bond between professionals and users, as recommended by visual anthropology [17,18].

The Perception guideline of the SPIKES protocol [16] was hampered by accumulated work, which prevents the team from aligning to communicate with the family. Residents indicated that there is no time to perceive family members in the context of the NICU, which is consistent with the work of Leite and Vila [13] and Campos and collaborators [8], who report difficulties in the daily routine of ICU health care teams.

Such difficulties include the stress of dealing with death and families and the scarcity of material and human resources, in addition to the lack of unity and commitment of team members, which leads to fatigue, discouragement and a sense of failure. The foundation of visual anthropology [17,18], of valuing the knowledge and experiences of subjects in their socioeconomic and family context, strengthens the second step of the SPIKES protocol [16], that is, the perception of others and what these subjects can or want to know about their reality.

Residents reported that, in the routine of the NICU, physicians give little value to the invitation of patients' families for conversations.

To justify this failure in the third stage of the SPIKES protocol [16] (Invitation), once again they indicated difficulties in the work process, such as work overload and scarcity of human resources, in addition to the responsibility to save lives, to the detriment of adequate communication and good relationship between physician and family.

However, residents acknowledged that the daily difficulties of work in the NICU did not prevent them from valuing empathy and trying to communicate better with the babies' mothers. This corroborates the ideas of Peduzzi [24], who denies harm to technical projects when multiprofessional, cooperation and communication actions are adequately coordinated. Dialogue is one of the most important foundations of visual anthropology [17,18], and it is through dialogue that knowledge is disseminated, reflection is stimulated, and reality is changed.

The fourth stage of the SPIKES protocol [16] (Knowledge) indicates the need for preparation to adapt the technical language to the understanding of families, mainly due to the varying levels of education of users in public NICUs. The language used with the patients' families was considered inadequate in the studied NICU, leading to misunderstandings and hindering communication between health care teams and family members.

The communication process is ineffective when the professional technique does not adapt to the cultural, social, educational and family context [2]. Visual anthropology [17,18] emphasizes the importance of understanding the reality of families, enabling the empowerment of subjects and raising their awareness critically so they can modify their practices.

The fifth stage of the SPIKES protocol (Empathy) [16] showed difficulty in dealing with their own emotions and with the family members' reactions to the bad news communicated. This is consistent with the study of Coutinho and Ramessur [25], in which empathy was the aspect perceived by medical students as more difficult to learn to apply to the daily medical routine, justifying the need for continuous professional training in the area. Visual anthropology [17,18] addresses the ability to put oneself in someone else's place, understand them and offering opportunities for their evolution.

The last competence of the SPIKES protocol [16] is to summarize and discuss strategies about the future of patients with their families (Summary and Strategy). Pediatric residents, once again, reported lack of space and time to clarify doubts of family members and discuss strategies. These failures were justified by means of the deficient physical space, work overload, inadequate preparation for communication, and difficulty in dealing with emotions and death.

Accordingly, Kovács [26] refers to the balance between technical capacity and emotion as a constant challenge for health care professionals. When the family is encouraged to discuss about the patient, space is provided for respect for ethics and truth, but without depriving people of hope [16].

Final considerations

In the work in NICU, adequate communication of bad news is hindered by factors such as: overload of activities; deficiency of material and human resources; lack of time and space for conversations between users, multidisciplinary team and service managers; lack of adequate preparation for communication; and difficulty in dealing with emotions and death.

This situation requires discussion between subjects involved in the process: multiprofessional team, users and managers. Therefore, dialogue between health care users, professionals and managers is encouraged, suggesting continued educational interventions for professionals as a means to improve the relationship between physicians and families and, consequently, the humanization of health care.

The exploratory character of this study fosters the continuation of research and in-depth analysis of aspects of the work process and organization in NICUs in order to improve the communication of bad news. However, at the same time it represents a limitation, considering its type of design, which does not assess changes in professional practices.

Finally, this approach also helps to sensitize physicians under training to reflect on the reality of their work and encourages the pursuit of continuous education in this field and spaces for dialogue to improve the communication of bad news in NICUs.

It is not easy to learn this type of communication; however, as this is a medical competence required in the daily routine of NICUs, it is necessary to foster humanized medical training, the pursuit of continuous education, and better working conditions. Accordingly, the reality of the studied NICU is not adequate to the guidelines recommended by the National Humanization Policy; therefore, this research contributed so mothers could report failures in the communication between users and professionals, enabling the expression of views of those who had little space toxspeak.

In short, reflecting on the difficulties inherent in the process of communicating bad news helps to sensitize physicians as to seeking theoretical training, in addition to stimulating self-criticism, focusing on empathy and humanization of care in NICUs.

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Research

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