Saúde e Pesquisa
DOI: 10.17765/2176-9206.2023v16n2.e11320

Participatory educational video for the humanization of health care

Vídeo educativo participativo para humanização da assistência em saúde

Carla Andréa Costa Alves[1]*, Silvia Wanick Sarinho[2], Rosalie Barreto Belian[3]

[1 2 3] Center of Health Sciences, Post-graduation Program in Children and Adolescent Health, Universidade Federal de Pernambuco, Recife (PE), Brazil

***Corresponding author**:: Carla Andréa Costa Alves– *E-mail*: carlaandreacalves@gmail.com

ABSTRACT
Delivering bad news involves not only knowledge, but also affective and ethical difficulties. Objective: To raise the awareness of physicians using a participatory video about delivering bad news in an Intensive Care Therapy, based on SPIKES and on visual anthropology. Methodology: Qualitative, descriptive, and exploratory study in three stages: 1) Diagnosis - participation of physicians and mothers; 2) Development - video production; 3) Evaluation - perception from physicians about the video. Bardin's content analysis was used; Results: Stage 1 showed: inadequate environment, little concern about the mothers, little emotional support, inadequate openness for dialog, inadequate language and communication, little empathy, and need to improve humanization. About the video based on Stage 1, the perception of physicians indicated: increased degree of responsibility, reflections on their professional practices, and encouragement to theoretical knowledge and to empathy in professional relations in the Intensive Care Unit. Conclusion: There are issues in the process of delivering bad news, and the use of educational participatory videos is an important strategy to humanize health care.

Keywords: Health Communication. Education, Medical. Humanization of Assistance. Physician-Patient Relations. Intensive Care Units, Neonatal. Instructional Film and Video.

.

RESUMO
Comunicar más notícias envolve, além de conhecimentos, complexidades afetivas e éticas. Objetivo: Sensibilizar médicos utilizando um vídeo participativo sobre a comunicação de más notícias em Unidade de Terapia Intensiva Neonatal, fundamentado no SPIKES e na antropologia visual. Metodologia: Qualitativa, descritiva exploratória, em três etapas: 1) Diagnóstico-participação de médicos e mães; 2) Desenvolvimento-produção do vídeo; e 3) Avaliação-percepção de médicos sobre o vídeo. Foi utilizada análise de conteúdo de Bardin. Resultados: A Etapa 1 indicou: ambiência inadequada, pouca preocupação com as mães, pouco suporte emocional, inadequado convite para o diálogo, linguagem e comunicação inadequadas, pouca empatia e necessidade de melhorar a humanização. Sobre o vídeo baseado na Etapa 1, a percepção dos médicos indicou: aumento do seu grau de responsabilidade, reflexão sobre suas práticas profissionais e estímulo ao aprendizado teórico e à empatia nas relações profissionais na Unidade de Terapia Intensiva. Conclusão: Há dificuldades no processo de comunicação de más notícias, e a utilização de vídeo educativo participativo representa importante estratégia de incentivo à humanização da assistência em saúde.

Palavras-chave: Comunicação em saúde. Educação médica. Humanização da assistência. Relações médico-paciente. Unidades de Terapia Intensiva Neonatal. Vídeos educativos.

.

Recebido em Novembro 18, 2022
Aceito em Março 03, 2023

INTRODUCTION

Work in the field of health demands humane interpersonal relationships, and communication is a keyword in a process of care that involves the health team and the users[1,2]. In this regard, the National Humanization Policy (PNH)[3] and the HumanizaSUS[4] prescribe the creation of bonds through the relationship between subjects, searching for the promotion of affective and ethical connections between professionals, users, and managers, with mutual support and respect. The principles and directives of the PNH encourage more effective communication processes between these actors, to guarantee that health workers and users are autonomous and co-responsible in care[3].

According to the Medical Ethics Code, in the relationship between physicians, patients, and their relatives, the patient has the right to receive clear and truthful information about their disease. It is a physicians' duty to inform patients and their families about their prognosis and treatment in a way they can comprehend[5].

Communication is a medical competence, determined by the national curricular directives of the medicine graduation courses. It involves verbal and non-verbal expression and should be carried out in a simple and accessible language, which can facilitate the therapeutic and communicative process, ensuring privacy and considering psychological, cultural, and contextual aspects, as well as the patients' life story, environment, and social and family relations[6].

Delivering bad news is a challenge for all health workers, one that is recognized nationally and internationally[7]. It is a complex issue as it includes the need to inform patients and their relatives about diagnoses, prognoses, and difficult and/or unfavorable treatments, considering affective and ethical challenges. Therefore, it is a practice that requires humanization[8]. In Brazil, investigations show that students and health workers have similar difficulties in delivering bad news, especially in regard to life's finiteness[9,10].

Neonate Intensive Care Units (NICU) are an enormous challenge in regard to communicating bad news, since the patients hospitalized are, in general, premature. These cases require a separation of the motherchild dyad, leading mothers to react with feelings of fear, guilt, anger, sadness, and frustration[11]. Particularly in the Brazilian northeast, studies have reported that, both during graduation and during professional training, delivering bad news in an NICU is challenging[7,9,10].

In the history of medical formation, the cure is considered to be the main goal to be achieved. Therefore, the inability to health is still seen as a professional failure. This understanding, present in medical teaching, makes it difficult to deliver bad news to the patients in situations when a cure is unlikely, such as in the case of chronic or terminal diseas[12].

Furthermore, in Brazil, few courses address the delivery of bad news in their syllabi, and there is little practice in the use of communication methods. This has a negative impact on the professional and personal life of the future physician, and in their relationship with their patients[13,14,15].

In order to guide and aid this process, medical literature recommends the use of several protocols which have stages and directives, such as SPIKES, one of the most didactic recognized ones[123,16,17].

The SPIKES[17] proposes six strategic steps to guide the health worker in communication. Each letter in the acronym represents one of the steps to be followed when it is necessary to deliver bad news:

a) Setting - preparing the setting, selecting who should be present, and showing cordial attitudes.

b) Perception - perceiving how much the patient or relative knows about the relative.

c) Invitation - inviting the patient or relative to inform how much they want to know.

d) Knowledge - sharing the knowledge about the situation.

e) Empathy - empathy while responding to the feelings of the patient or relative.

f) Strategy and summary - clarification, for the patient and/or family, about the care strategy.

Nonetheless, one needs more than theoretical learning to change the reality in the practice of services, since directives and protocols do not consider the impact of news on individuals and address emotional aspects superficially[18]. Thus, a participatory educational approach is necessary, one that is based on sensitizing and provoking reflections about practice, so health workers can assess and change their behavior[13,14].

Audiovisual resources have showed positive results in the teaching-learning process of students in the field of health. The goal is to encourage dialog, hearing the other, expressing silenced voices, working with and not for the participants, producing shared knowledge that can mediate and transform reality, giving space to the neglected areas of health[18].

Participatory audiovisual resources are produced with the participation of the target audience, aiming to develop critical sense and the ability to reflect. These resources use cinematographic techniques based on the emotions experienced, thus encouraging self-assessments and a critical reflection about the issues in the daily life and their potential solutions[19].

In the audiovisual field, the principles of visual anthropology are the base for social and behavioral research. These principles consider the advance of knowledge about the social groups involved and their social and cultural contexts, which can be understood and analyzed in the light of visual media, whose representation can affect the perception and understanding of the study objects[20]. Also important are the principles of interdisciplinarity, collaboration, and ethics, responsibly articulated to collect and manipulate visual media, the collaboration between participants, and the combination of different fields and areas of knowledge[21,22,23,24,25].

The faithful reproduction resulting from attentiveness to words, gestures, and contents of the verbal and non-verbal expression of the persons on film is essential to understand the message transmitted[19]. The videos, from the theoretical perspective of visual anthropology, encourage self-criticism, helping the participants to understand reality[21].

This article presents and discusses the results of an educational intervention, using a participatory video about the delivering of bad news, created in focal groups formed by mothers and resident physicians from an NICU.

The entire health team of the NICU takes part in delivering bad news and is impacted by it, but we chose resident physicians in pediatrics as our target audience as they are still undergoing their formation and are more likely to accept learning and disseminate their results in the health team.

To organize the statements of mothers and resident physicians in the NICU, we used the SPIKES protocol and its six steps, due to its popularity and didactic nature, when it comes to guiding workers about the delivering of bad news[26,27,28].

In the context of this research, we understand that the methodology from visual anthropology aids in the process of health communication, in the dialog between professionals and relatives, in the improvement of the knowledge about health processes, in the understanding of the needs of the subjects, in helping the formation of health worker, in research on communicational practices in health, in the improvement of the quality of the services and care provided, and in the humanization of health[29].

METHODOLOGY

This study was carried out with resident physicians and mothers of newborns hospitalized in the Neonate Intensive Care Unit of the university hospital of a federal university in the northeast of Brazil, from August to December 2019, considering the theoretical perspective of the framework SPIKES[30] and visual anthropology. This is a qualitative, descriptive, and exploratory research, which considers the interpretive understanding of the statements of the participants and the meanings produced in their analyses[31].

The health team responsible for NICU care includes different health workers, who participate in the delivering of bad news and suffer its impact, and are, therefore, the object of this study. Nonetheless, the participation of resident physicians was prioritized due to the fact that they are still in the midst of their formation process, being more likely to accept the results learned and to disseminate their results in the health team.

This study was organized in the following stages:

Stage 1: **Diagnosis -** Two focal groups (FG) were created, GF1 with 12 physicians and FG2 with 6 mothers, to produce information about the delivering of bad news in the NICU, in order to understand the communication process.

Stage 2: **Development -** A video was produced to respond to the needs found in the first stage, using the recorded statements from physicians and mothers from Stage 1.

Stage 3: **Evaluation -** A third focus group (FG3) was created presenting and discussing the video with seven pediatric residents. Data collected was analyzed, forming perceptions about the video.

The procedures carried out in the three stages of the research can be found in the diagram of Figure 1.

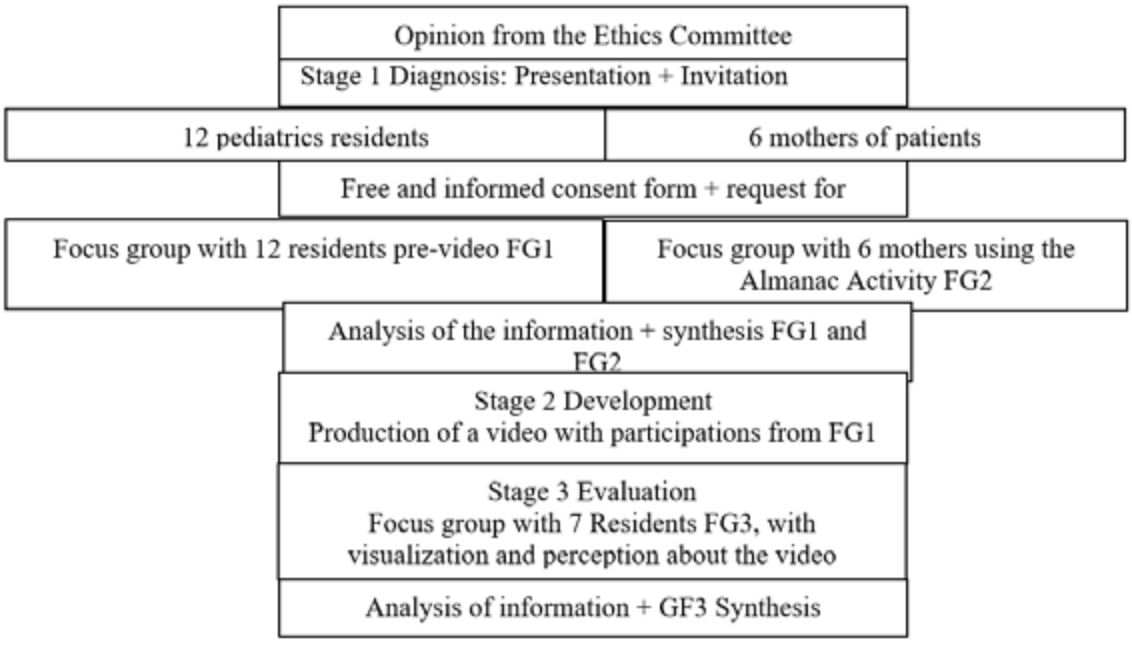

Figure 1. Diagram of methodological procedures
Source: Alves (2023).

FG1 was carried out in August 2019 and lasted for 2 hours and 22 minutes. FG2 was carried out on August 19, 2019, and lasted for 52 minutes. Finally, FG3 took place on December 19, 2019, and lasted for 23 minutes.

We invited the resident physicians and mothers to participate due to the fact that they were at the service being studied during the period of the intervention. Before the start of this study, we contacted the pediatricians responsible for the pediatrics residency, all resident physicians, and all mothers of newborns then hospitalized in the NICU. We explained the importance of the research, its goals, and scheduled the best day and hour with the participants invited. No participant refused participation or abandoned the study. The residents and mothers available participated from the beginning of the research to its end.

The focus groups included the following moments:

1) Scheduling.
2) Setting organization and preparation.
3) The group was welcomed, and we presented to the participants the organizers and the goals of the activities that would be developed.
4) In the FG that included the mothers (FG2), we carried out the Almanac activity, to encourage conversation based on the active methodologies of the MCS (Sensitive Creative Method) and the DCS (Sensitive and Creative Activity) [32]. This activity includes the clipping out and pasting of pictures, drawings, phrases, and words from several origins, associated with the central topic or questions: "Delivering bad news in the NICU".
5) Script with questions based on the QCCM (Physician Communicative Behavior Survey)[33], with a patient version and a physician version. Each participant had space to present their own perceptions to the group, and the collective discussion was based on these perceptions.
6) Collective analysis and validation of the data produced.

The FGs had three facilitators, which carried out the conversation, observed and interacted with participants: the researcher and two professors - all of which had experience in focus groups for qualitative experiences. In addition to the participants and facilitators, the person responsible for recording the images and audios was also present, but remained silenced and did not interact with the participants and facilitators from the first focus groups of mothers and residents.

Most participants in the focus groups was willing to talk, to comment on the statements of their colleagues, and to manifest themselves about the topic and its developments, expressing their opinions. All participants from the focus groups started and finished the focus groups together.

The mothers and residents who would have their participation in the focus groups recorded had previously agreed to have their images and statements used to produce a video.

When the statements started to repeat, with no new information and topic saturation[34], the groups were concluded. The participants were thanked, and the facilitators made themselves available to clarify doubts or talk further on the topic.

After the focus groups were carried out, we listened to the recordings and transcribed all statements in full. They were categorized using domains defined a priori, according with the six steps of the SPIKES protocol. The qualitative analysis of the information collected in the three focus groups was carried out using Bardin's approach to content analysis[35].

All participants read, understood, and signed the Free and Informed Consent Form (FICF), and filled in the participant

characterization form with their personal data. This study was approved by the Research Ethics Committee and was approved under opinion 3.060.832.

The secrecy and anonymity of participants were maintained by replacing the names of residents with the letters RES, and that of the mothers with the letters MAE (for the Portuguese word for mother). Also, the faces of the participants in the videos were blurred.

RESULTS

Almost all residents considered themselves to be female (11/12; 91.7%); all of them had a religion; and one reported being pregnant (1/12; 0.3%). Table 1 shows other characteristics of the physicians who participated. It is worth noting that little more than half of them (8/12; 66%) described having previous experiences with the delivery of bad news.

Table 1. Characterization of the resident physicians from FG1

Year of graduation			Current year of residency			Place of formation			Experience delivering bad news		
	n	%		n	%		n	%		n	%
2015	1	8.3	1st year	6	50	Alagoas	7	58.3	Yes	9	66.6
2016	2	16.6	2nd year	6	50	Paraíba	1	8.3	No	3	33.3
2017	6	41.6				Pernambuco	2	16.7			
2018	3	33.3				RioGrandeNorte	2	16.7			
						Santa Catarina	1	8.3			

Source: Alves (2023).

The characterization of the mothers of premature newborns. members of FG2. can be found in Table 2. It stands out that most had complete high school.

Table 2. Characterization of the mothers of the participants of FG2.

Origin			Educational level			Number of pregnancies			How long she had been with the newborn in the ICU (days)		
	n	%		n	%		n	%		n	%
Capital	2	66.6	Elementary	2	66.6	Primiparous	5	83.3	< 5	1	16.7
Countryside	4	33.3	High school	4	33.3	Multiparous	1	16.6	6-10	1	16.7
									11-20	2	33.3
									21-30	2	33.3

Source: Alves (2023).

ALMANAC ACTIVITY: STRATEGY TO ENCOURAGE THE PARTICIPATION OF THE MOTHERS IN THE FOCUS GROUP.

This activity aims to encourage the participation in the group by clipping out pictures, drawings, sentences, and words related to the main topic of this study. The art generated by the Almanac dynamic showed how difficult the day-to-day life in an ICU was for the mothers of newborns.

MAE 1 chose the image of a sad and lonely child. This image showed her feelings about her experience in the NICU.

MAE 4: "I chose the image of a pregnancy and of a birth that, here, was normal. It was something that happened to me here. Because of that, my boy was born with a respiratory problem, and he still can't... [crying] ...he was born too tired, and he's still, now that he's 1 month and 17 days, kind of, only now he's getting better. He's still very tired."

MAE 6 "I chose this image because it means a lot to me A guy going up a mountain and behind him there's a fall."

MAE 3 "My image was fatigue or mental and physical tiredness. The mental side messes up our psychological side here. We suffer a lot too, and the physical tiredness."

MAE 5 "I chose silence. And education too. And attention."

MAE 2 "Mine, I chose a person on fire... [crying]. To represent our pain... [crying]."

EXPRESSIONS OF MOTHERS AND RESIDENTS REGARDING THE DELIVERY OF BAD NEWS IN THE NICU (FG1 AND FG2)

The statements of mothers and residents are summarized below and were used to produce the video. To facilitate the analysis and organization of the diagnosis for the elaboration of the video, the statements were categorized according with the SPIKES protocol (Table 3).

Table 3. Abstract of results from Stage 1 according to SPIKES protocol guidelines

(Continua)

SPIKES CATEGORIES	RESIDENTS	MOTHERS
SETTING	Inadequate setting Deficient structure Bedside communication Difficulties in the work process No predetermined time to talk with the mothers	Inadequate setting Deficient structure Feelings of being in a prison and noise Little embracement Dissatisfaction with NICU rules Little privacy
PERCEPTION	Little perception from the mothers Little emotional support to the residents Work overload and stress	Little concern about what the mothers know about their children's disease Dissatisfaction with the multiprofessional team Little emotional support Isolation Little embracement
INVITATION	Rare invitations to dialog Physicians wait for the mother to require Work overload Little access and little availability	Rare invitations to talk Inadequate invitations Fear of searching for information
KNOWLEDGE SHARING	Inadequate language Learns watching Work overload and little time Little sensitivity and listening Few conversation strategies Inadequate articulation in the team	Inadequate language and communication Trouble understanding Little sensitivity

(Conclusão)

SPIKES CATEGORIES	RESIDENTS	MOTHERS
EMPATHY	Empathy x Technical ability Difficulties dealing with the death of children Emotion as a problem, not as a tool Distinct personalities Frustration and escapes The need to receive updates and emotional support from the team Trouble saying the truth without causing hopelessness	Variety of feelings Little emotional support Little empathy from the team Reduced feeling of being a mother
SUMMARY/STRATEGY	Improve sensitivity Use religiosity Think together with the mothers Clarify doubts More listening Caring about the opinion of the mothers Improve the environment and the work process Value humanization more	More secrecy More respect to the opinion of the mothers More attention More sensitivity and emotional support

Source: Alves (2023).

THE PARTICIPATORY VIDEO PRODUCED

The video showed the practical, often inadequate, reality of the delivery of bad news in the NICU. It presented the theoretical knowledge prescribed by SPIKES in order to cause health workers to reflect on their practices about this type of communication. The target audience of the video are pediatrics residents.

The video was constructed according to the needs and difficulties found by mothers and residents. The diagnoses found by FG1 and FG2 participants, which were used to produce the video, were: Inadequate settings; Lack of perception about the other; Inadequate invitations to talk; Inadequate sharing of information; Not putting oneself in the shoes of the other; Lack of summary and strategies with the families of the patients. The stages of the script for the video can be seen in Figure 2.

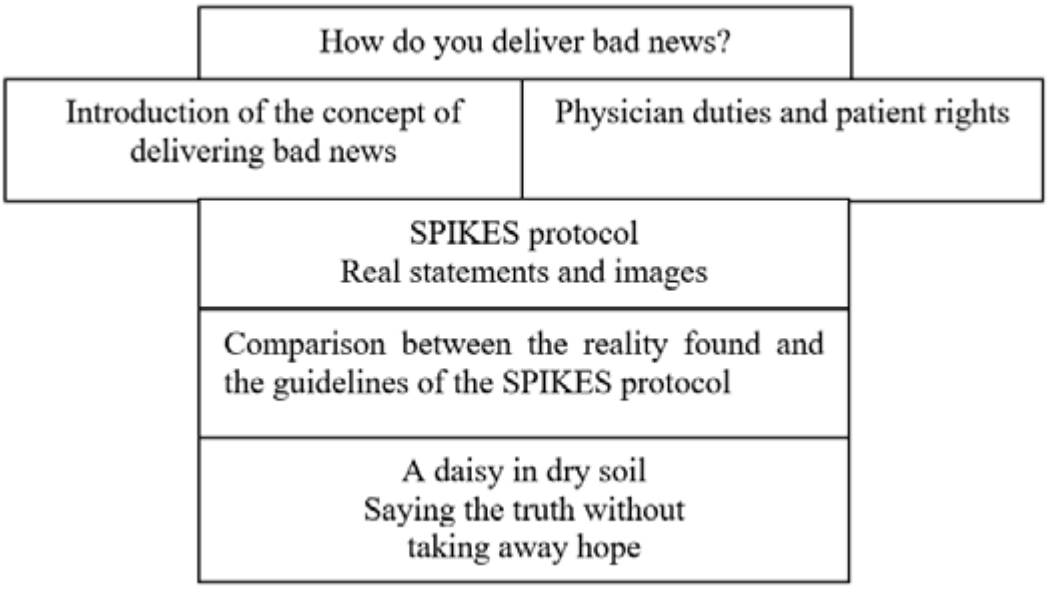

Figure 2. Diagram of video production
Source: Alves (2023).

The video lasts for 12 minutes, so the spectator would not abandon it, and it can be watched in the daily routine of the residents, mentioned in the diagnosis as an excessive overload. The title was written over a black background: "How do you deliver bad news?" The dark color was chosen to create an association with the severity of the topic addressed.

Before the SPIKES guidelines were shown, some concepts were mentioned to introduce the topic, including images of babies in their mothers' hands and royalty-free soft soundtracks found on-line. The physicians received information about their duties and the rights of the mothers regarding information about the health of their children in the NICU. The definition of a "bad new" is presented, with images of physicians accompanied by soft soundtracks.

After the SPIKES was introduced, images and audios produced by the participants are shown at each stage. Each SPIKES stage had a unique visual identity, so the spectators knows where they are in regard to the context of the stage being addressed. In all stages of the video, we emphasized the reality observed, and later showed what would be adequate communication, as guided by the protocol.

The ending of the video leads the spectator to a summary of the stages of the protocol, to allow retaining the topic. Also, in the ending of the video, there was a touching statement from a crying mother talking about the pain of being the mother of a premature baby, in addition to a royalty-free image found on-line of a daisy blooming in dry land, with the captions: "Telling the truth without taking away hope". This ending aimed, once again, to trigger empathy and show its importance in the communication of bad news.

PERCEPTION OF THE RESIDENTS REGARDING THE CONTRIBUTIONS OF THE VIDEO FOR THE DELIVERY OF BAD NEWS (FG3)

The residents understood the relevance of the video, due to the fact it showed the reality of medical practice, thus encouraging the self-evaluation of their attitudes in regard to the "Delivery of bad news in the NICU". They noticed the importance of valuing listening and the need to listen to the mothers in the following statement:

> **RES 13** "Suddenly this is it: showing something that, in actuality, is done really poorly, as in the statements of the mothers, and suddenly, people, at least, start doing it differently, more empathetically.

Thus, the video was found to be an instrument to promote a reflection about the professional practice related with the delivery of bad news in the NICU. The video also contributed for the residents to have a perception about the degree of responsibility physicians need to have in regard to the lives of newborns and their relatives, as the statements below show:

> **RES 11** "The video contributed to increase the degree of responsibility we must have."
> **RES 13** "Maybe people need an awakening, right?"

According with the pediatrics residents, the video helped them learning how to deliver bad news using the real statements and images of relationships in the NICU, as the reports below indicate:

> **RES 3** "Sometimes you have a lot of technical knowledge, but you can't really understand how it is inside that situation, that context, right?"
> **RES 2** "After our first meeting, we went through a very complicated case: a child with lymphoma, but the resident already had an experience using SPIKES, so it wasn't that difficult."
> **RES 11** "So, well, we practiced everything adequately using SPIKES."
> **RES 11** "We did most of the SPIKES. We called the family, asked them to sit, talked first with the parents, then with the child. We practiced empathy, tried to put ourselves on their shoes."
> **RES 11** "The video contributed to improve the knowledge we must have."

Regarding the perception of the pediatrics residents, the participatory video encouraged empathy in the residents who participated, as the following statement shows:

> **RES 1** "The video contributed to improve empathy. Actually, the most important word is empathy."

From the perspective of pediatrics residents, the video reiterated the importance of learning the theoretical knowledge adequately, with sensitivity, as the following statement reiterates:

> **RES 2**"We have to think that the child, that being, is loved by somebody, right? Then we find this sensitivity."

The importance of the role of the video in encouraging changes in the practices at the NICU was recognized, albeit with reservation, considering the complexity of the process of changes in this topic, as the following statement shows:

> **RES 2** "Of course, the video is not enough, but it is extremely important."

Some factors can make it more difficult to deliver difficult news in the NICU routine, such as: the work process, the personality of each individual physician, and the obligation of dealing with life and death daily, which can impair the possibility of delivering bad news in the NICU in a humane way. Still, the pediatrics residents believe that the most difficult part is not learning the theory, but to put it in practice without making the patient or relative lose hope.

The video reiterated this, as the statement below shows:

> **RES 13** "The hardest part has to do with the last phrase in the video, saying the truth without taking hope away, right? I think this is the hardest part, saying the prognosis, saying what they will face from now on, without bringing the patient down."

Therefore, from the perspective of the pediatrics residents, the video encouraged improvements in the following aspects: Theoretical knowledge; Degree of responsibility; Empathy; Encouragement to self-criticism and reflection; and Valuing the hope of the family.

DISCUSSION

Below, we discuss the results found in during the stages of this research. We separated our discussion in topics, to make understanding easier. They were organized chronologically.

EMBRACING MOTHERS IN THE FOCUS GROUP

The need for maternal health care is emphasized by the Brazilian National Humanization Policy[3] as something essential to put in effect the embracing and humanization of Single Health System users. Workers who attend in the NICU are also expected to understand the extreme physical and mental exhaustion of mothers and be sensitive and empathetic in order to help them[17,36].

The "Almanac" activity encouraged mothers to participate in the focus groups by asking them to clip out and paste figures related with the topic or the main research question. Some of the art encouraged by the activity and produced by the mothers showed the difficulties they confronted in the day-to-day life at the NICU.

Mothers expressed feelings of fear and sadness in their collages in the almanac. These feelings were discussed in previous studies[37,38], as they were expressed by the mothers of newborns hospitalized in NICUs during their first visit to their child. Such feelings indicate the need for the entire health team to undergo specific training, in order to ensure they have the correct understanding and allow them to help forming a bond between mother and child, a situation oftentimes precarious and difficult. Larger meetings, including the health team and the family of patients are indicated to clarify questions the family may have, and also to enable the hospital team to reflect on the assistance they are providing[38].

THE REALITY IN THE NICU, FROM THE PERSPECTIVE OF MOTHERS, REGARDING THE DELIVERY OF BAD NEWS

Both mothers and pediatrics residents noticed the structural limitations of the NICU in this investigation. The delivery of bad news has usually been taking place at the bedside of the patient, with no privacy or embracing of family or newborn. Also, there is no specific time for communicating with the family and information is given at the leisure of the professionals.

The structural issues in the physical space of the NICU being studied, and the attitudes of the health team that did not consider humanization, are not in accordance with the findings of a previous study, where the NICU care analyzed showed that the health workers were sincere and calm, there was a good relationship between physician and family, and a proper location to deliver bad news. This perception is different in public and private hospital services. The opinions of patients indicated that, in the first, the way

in which this type of information is delivered is worse[39]. Therefore, we believe that the structural difficulties found in the NICU studied here are associated with the need to organize the service in the public sphere.

A NICU health team that seeks to improve the medical-family relationship must focus on the family, assessing what they are really understanding about the disease of their children in order to clarify doubts about diagnoses, prognoses, treatments, and progression.

Work overload and little time in the daily life at the NICU were mentioned as justification for the fact that physicians did not perceive the families, and did not follow, or followed inadequately, the SPIKEs guidelines, such as the invitation to talk. Embracing the users is a guideline of both the PNH[3] and the HumanizaSUS[4]. Both recommend qualified listening, which can guarantee the perspective necessary to understand the needs and priorities of the user, increasing the effectiveness of the practice. If the structure of the service needs to be improved, a reflective, motivated, and empathetic team will be able to move in the right direction in association with the management.

Attention and empathetic understanding are essential in assertive communication[40]. The knowledge about SPIKES[30] allows questioning the attitudes of physicians as they invite patients/families to for talks in the NICU. In our study, findings related with invitations that took the form of "screams", according to the statements of mothers, can indicate an extrapolation of power relationships, understood as normal in medical-family relationships, further reducing the autonomy of the mothers in the NICU. These attitudes are not acceptable in interprofessional communication and especially in communication with the families of the newborns, who are in a very vulnerable position.

Power relationships are generally associated with knowledge. The intervention using the participative video showed an unbalance in power relationships, generating reflections about them, and the possibility of a consequent rebalancing. Inadequate attitudes are a signal of the suffering felt by those who, often, feel powerless when struggling with the difficulties of health care services[41].

It is essential to share information adequately, but sharing knowledge about the disease and the diseased is not enough: it is essential to consider how this information is shared. Our research showed that most residents have adequate theoretical knowledge, but learn how to deliver bad news through observation in service, and may be influenced by inadequate examples and by complicating factors as they give this type of information[7,12].

In our research, the technical language used in the NICUs to inform about the health situation of a patient pushed families away from the multiprofessional team, which is not in accordance with the dialogic SPIKES principle[30], according to which sharing knowledge is something based in respect to the differences and inclusivity, not simply representing the passage of information. Especially in public hospitals, adapting the language to communicate with a patient's family is essential The perception about how much the family knows about the disease of their child and their educational level must be considered by the physicians so they can clarify information as needed, contributing for the autonomy of the family in regard to care.

Another important guideline of the SPIKES[30] protocol is the summary of information to be shared with the patients and their families, aiming to generate therapeutic plans that respect the possibilities and desires of the family who is receiving bad news in the NICU[17].

In the opinion of the mothers who participated, the medical team is also responsible for psychological support. this corroborates a

study where patients considered their physician as one of their most important sources of psychological support, and empathetic attitudes as the most powerful way to provide this support, as they reduce the isolation of the patient, express solidarity, and value the feelings and thoughts of patient and family[42]. These findings show that mothers understand the complexity of the communication of bad news, which goes beyond the transmission of technical knowledge and is supported by the professional NICU team.

Regarding the perception of residents about the delivery of bad news, suggestions included improving the physical structure available for he multiprofessional in the delivery of bad news and in the work process of the NICU (training), valuing humanization in health and benefiting all those involved in the process. An important finding is the perception of residents about how necessary the emotional dimension is in the learning process - a need made clear by the difficulties of forming relationships in the NICU.

It is not easy to put oneself in the shoes of another, and to tell the truth without killing their hope. Empathy is one of the directives of the SPIKES[30] protocol, related with learning aspects that involve feelings[17]. It is not easy to adapt the theoretical knowledge to a practice that involves feelings, affection, and emotion.

This suggestion from the physicians is in accordance with the concerns of the National Humanization Policy, regarding the physical and emotional care of the patients, their families, and health workers, considering the continued education of these workers and administrative support to the professional team, to the structure of the work environment, and to the work process.

It must not be forgotten that pediatrics residents are professionals already graduated, but still in an educational process. This means they require an education based on reflective, dialogic, and participatory instruments, in order to enhance their capacity for empathy and communication with the mothers of their patients[43]. This is a challenge for professional practice, but it is also a pillar for the formation of these health workers[44].

THE PARTICIPATORY VIDEO AS A STRATEGY TO SENSITIZE AND CAUSE REFLECTIONS IN RESIDENTS

All residents who participated in this study informed that they became more aware of the importance of learning how to deliver bad news and found that it was valid to use the video with the SPIKES as a theoretical guide.

The video was evaluated by the pediatrics residents as an important tool to encourage reflection about the delivery of bad news in the NICU by using problematization and empathy. In this context, the participatory process of video creation promoted the aspects of sensitization and reflection, allowing experimenting and getting in touch with the associated emotional aspects. These aspects were also addressed in the focus group carried out later with the residents, using the video with the recordings of the mothers.

The use of methodologies that include films has been described in literature with good results, as they allow broad analyses and comparisons of the social environment and its representations[45]. The film is an important mirror, not only to reflect about how each group represents itself, but also to represent the other, promoting respect for the differences between individuals. Therefore, its effects on participants go beyond traditional training[46].

As a resource to mediate permanence education, the video can reach more health workers, and be used in interventions with other teams, institutions, and contexts. Consequently, it allows sharing important information, raising the awareness of the residents for the issue

of delivering bad news at a low cost. Also, it is easily accessible and can be conveniently fitted in the work hours of the workers, who are merely using a preexisting resource. This potential is in accordance with the updates in the PNEPS (National Policy for Permanent Education in Health), which prescribes the use of new strategies and formative modalities to make viable permanent education actions in the health services, attending closely to the needs of the users[47]

CONCLUSION

The educational intervention using a participatory video, produced based on the real statements of mothers of newborns and pediatrics residents in the context of the NICU, enabled more advanced discussions about the topic, and can lead to changes in practice through reflection and the valuing of empathetic attitudes. This is important, as residents are still in the midst of their formation process, and their increased likelihood to accept learning can contribute to reduce the suffering of all those involved in the process of communicating bad news.

We do not believe that the small number of participants was a limitation of this study, since, in this strategy, the most important factor is the level of the discussions and the profundity of the immersion in the relevant emotional and affective aspects. It would be possible to apply the video in a larger-scale strategy, albeit with more limited effects, by exhibiting it to other groups of health workers and managers, leading to discussions in the particular context of these new groups.

Since this study evaluated the perception of the residents, future studies should assess the actual changes in their practice, to further improve their ability to deliver bad news and, therefore, that of the health team in the NICU. We believe and recommend that strategies based on practical observations, such as the one presented in this work, would contribute to develop this ability more adequately, and should be inserted in the syllabus of medical courses and continued education programs.

REFERENCES

1. Pinho LB, Santos SMA. O relacionamento interpessoal como instrumento de cuidado no hospital geral. Cogitare Enferm, 2007,12 (3):377-85. O relacionamento interpessoal como instrumento de cuidado no hospital geral | Cogitare enferm;12(3): 377-385, jul.-ago. 2007. | LILACS | BDENF (bvsalud.org) DOI 10.5380/ce.v12i3.10038

2. Peduzzi M. Equipe multiprofissional de saúde: conceito e tipologia. Rev. Saúde Pública, 2001; 35(1):103-9. (PDF) Equipe multiprofissional de saúde: conceito e tipologia SciELO - Brasil - Equipe multiprofissional de saúde: conceito e tipologia Equipe multiprofissional de saúde: conceito e tipologia https://doi.org/10.1590/S0034-89102001000100016

3. Brazil. Ministério da Saúde. Secretaria de Atenção à Saúde. Política Nacional de Humanização. PNH. Brasília (DF): Ministério da Saúde, 2010. Política Nacional de Humanização PNH: Humaniza SUS | Brasília; Ministério da Saúde; 2015. [14] p. Folhetoilus. | MS (bvsalud.org)

4. Brazil. Ministério da Saúde. Secretaria de Atenção à Saúde. Política Nacional de Humanização. Cadernos HUMANIZASUS. Brasília (DF): Ministério da Saúde, 2010. https://bvsms.saude.gov.br/bvs/publicacoes/cadernos_humanizaSUS.pdf

5. Conselho Federal de Medicina (CFM). Código de Ética Médica. Brasília: CFM; 2010. codigo de etica medica.pdf (cfm.org.br)

6. Brazil. Ministério da Educação. Diretrizes curriculares-cursos de graduação- Medicina. Brasília (DF): Ministério da Saúde, 2022. rces003_22 (mec.gov.br)

7. Campos CACA, Silva LB, Bernardes JS, Soares ALC, Ferreira SMS. Desafios da comunicação em Unidade de Terapia Intensiva Neonatal para profissionais e usuários. Saúde debate, v41, n especial, 165-174, jun 2017. https://doi.org/10.1590/0103-11042017S214

8. Monteiro DT, Quintana AM. The communication of bad news in icu: perspective of doctors. Psic.: teor. e pesq., v. 4, 2016. https://doi.org/10.1590/0102.3772e324221

9. Bushatsky M. Pacientes fora de possibilidade terapêutica: percepções de cuidadores, estudantes e profissionais de saúde diante da finitude e de cuidados paliativos. Tese. 2010. Recife-PE. RI UFPE: Pacientes fora de possibilidade terapêutica: percepções de cuidadores, estudantes e profissionais de saúde diante da finitude e de cuidados paliativos

10. Cavalcante M, Vasconcelos M, Grosseman S. A Comunicação De Más Notícias Por Estudantes De Medicina: Um Estudo De Caso. CIAIQ 2017, v. 2, 2017. https://proceedings.ciaiq.org/index.php/ciaiq2017/article/view/1517.

11. Camargo CL, et al. Sentimentos maternos na visita ao recém-nascido internado em Unidade de Terapia Intensiva. Ciência, Cuidado e Saúde, Maringá, v. 3, n. 3, p. 267-275, set/dez. 2004. https://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/5394

12. Pereira CR. Comunicando más notícias: protocolo paciente. Tese apresentada a Universidade Estadual Paulista. Faculdade de Medicina de Botucatu para obtenção do grau de Doutor. Botucatu; sn.; 100 p. 2010. Comunicando más notícias: protocolo paciente | Botucatu; s.n; 2010. [99] p. graf, tab. | LILACS (bvsalud.org)

13. Almeida MTC, Batista NA. Ser docente em métodos ativos de ensino-aprendizagem na formação do médico. Revista Brasileira de Educação Médica, 2011 v. 35, n. 4, p. 468-476. https://www.scielo.br/j/rbem/a/cdKBP3HnpMHyMpqgK9wD9rR/?format=pdf&lang=pt

14. Ronconi AC, Bernini DSD. O uso de metodologias ativas no ensino médico: um estudo bibliométrico do ano de 2017. Revista Esfera Acadêmica Humanas, 2017; 2(1), 6-18. https://doi.org/10.1590/S0100-55022011000400005

15. Vogel KP, et al. Comunicação de Más Notícias: Ferramenta Essencial na Graduação Médica. Rev. bras. educ. med., 2019; Brasília, v. 43, n. 1, supl. 1, p. 314-321. https://www.scielo.br/j/rbem/a/pCSW5SbwjD4MSCSpnG4WB9K/?format=pdf&lang=pt

16. Narayanan V, Bista B, Koshy C. BREAKS Protocol for Breaking Bad News. Indian Journal of Palliative Care, 2010; 16(2):61-65. DOI: 10.4103/0973-1075.68401. Protocolo 'BREAKS' para Breaking Bad News - PubMed (nih.gov)

17. Buckman R. Breaking bad news: the S-P-I-K-E-S strategy. Community Oncology, 2005; v. 2, n. 2, p. 138-142. DOI:10.1016/S1548-5315(11)70867-1

18. Fieschi l, Burlon B, de Marinis MG. Teaching midwife students how to break bad news using the cinema: an Italian qualitative study. Nurse Educ Pract. 2015; 15(2):141-7. DOI: 10.1016/j.nepr.2015.01.008

19. Silva IMC, Salvador LM. Vídeo participativo e educomunicação: o vídeo participativo como um processo educomunicativo. RELICI-Revista Livre de Cinema, v. 7, n. 2, p. 63-74, maio-ago, 2020. http://www.relici.org.br/index.php/relici/article/download/253/284

20. Lisboa MES. Antropologia visual e documentário: uma análise do documentário Promises. Revista Científica do Departamento de Comunicação Social da Universidade Federal do Maranhão - UFMA -São Luís - MA, jan./jun. 2014 - Ano XIX – n. 14. https://periodicoseletronicos.ufma.br/index.php/cambiassu/article/view/3513

21. Sardelich ME. Leitura de Imagens, Cultura Visual e Prática Educativa. Cadernos de Pesquisa, 2006. v. 36, n. 128, maio/ago. https://doi.org/10.1590/S0100-15742006000200009

22. Landa MB. Olhar in(com)formado: teorias e práticas na antropologia visual/Mariano Báez Landa; Gabriel o. Alvarez (Org.). Goiânia; Editora da Imprensa Universitária, 2017. ebook_olhar_inconformado.pdf (ufg.br)

23. Eusébio AJ, Magalhães SB. Filme etnográfico e o estudo do cotidiano: o uso de recursos audiovisuais na pesquisa sociológica. Revista Café com Sociologia., v. 6, n. 2, p. 57-71, 2017. https://revistacafecomsociologia.com/revista/index.php/revista/article/view/716

24. Barbosa A, Cunha ET da. Antropologia e imagem. Rio de Janeiro: Jorge Zahar Ed., 2006. https://www.academia.edu/38613816/Antropologia_e_Imagem_Andrea_Barbosa

25. Ribeiro JS. Antropologia visual, práticas antigas e novas perspectivas de investigação. Rev. Antropol., v. 48, n. 2, p. 613-648, 2005. https://www.revistas.usp.br/ra/article/view/27220

26. Lino CA, et al. Uso do protocolo SPIKES no ensino de habilidades em transmissão de más notícias. Rev. bras. educ. med., Rio de Janeiro, v. 35, n 1, p. 52-57, jan./mar. 2011. https://doi.org/10.1590/S0100-55022011000100008

27. Emadi-Koochak H, et al. Breaking HIV News to Clients: SPIKES Strategy in Post-Test Counseling Session. Acta Med Iran., v. 54, n. 5, p. 313-7, mayo 2016.
https://pubmed.ncbi.nlm.nih.gov/27309479/

28. Silva, RBL. Comunicando notícias difíceis na Unidade de Terapia Intensiva. Arquivos Catarinenses de Medicina, v. 44, n. 1, p. 82-92, 2016. https://revista.acm.org.br/index.php/arquivos/article/view/13

29. Ramos N, Serafim J. Comunicação em saúde e antropologia fílmica. In: XII Congresso Latinoameicano-ALAIC. 2014. https://congreso.pucp.edu.pe/alaic2014/wp-content/uploads/2013/09/Natalia-Ramos.pdf

30. Kaplan M. SPIKES: a framework for breaking bad news to patients with câncer. Clin J Oncol Nurs., v. 14, n. 4, p. 514-516, ago. 2010. https://pubmed.ncbi.nlm.nih.gov/20682509/

31. Minayo MCS. O desafio da pesquisa social. In: Minayo M.C.S. (Org.), Deslandes S.F & Gomes R. Pesquisa Social: Teoria, Método, e Criatividade. 2010; (29a ed). Petrópolis, RJ: Vozes, 9-29. idoc.pub_minayo-maria-cecilia-de-souza-ciencia-tecnica-e-arte-o-desafio-da-pesquisa-socialpdf (1).pdf

32. Cabral IV, Silveira A, Bubadué RM. Pesquisa baseada em arte: aplicação do Método Criativo Sensível em estudos qualitativos. Workshop Congresso Ibero Americano em Investigação Qualitativa 2020. Proposta18_CIAIQ2020_Workshop_PesquisaBaseadaemArte_PT_Varios.pdf

33. Croitor LMN. Percepção de Pacientes do Comportamento Comunicativo do Médico: elaboração e validação de um novo instrumento de medida. Belo Horizonte, 2010. dissertação Luciana M N Croitor abr2010.pdf (ufmg.br)

34. Trad LAB. Grupos focais: conceitos, procedimentos e reflexões baseadas em experiências com o uso da técnica em pesquisas de saúde. Physis: Revista de Saúde Coletiva, v.19, n. Physis, 2009 19(3), 2009. https://doi.org/10.1590/S0103-73312009000300013

35. Bardin L. Análise de conteúdo. São Paulo: Edições 70. Análise de conteúdo | São Paulo; Edições 70; 2016. Análise de Conteúdo | São Paulo; Edições 70/LDA; 2009. 281 p. | LILACS | colecionaSUS (bvsalud.org)

36. Paro HBM da S. Empatia em estudantes de medicina no Brasil: um estudo multicêntrico. São Paulo: 2013. https://www.fm.usp.br/cedem/conteudo/publicacoes/cedem_124_tese_helenaparo.pdf

37. Camargo CL, et al. Sentimentos maternos na visita ao recém-nascido internado em Unidade de Terapia Intensiva. Ciência, Cuidado e Saúde, Maringá, v. 3, n. 3, p. 267-275, set/dez. 2004. https://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/5394

38. Carvalho LS, Pereira CMC. As reações psicológicas dos pais frente à hospitalização do

bebê prematuro na UTI neonatal. Rev. SBPH [Internet]. 2017 Dez [citado 2023 Mar 02] ; 20(2): 101-122. Disponível em: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1516-08582017000200007&lng=pt.

39. Chehuen Neto JA et al. Health professionals and the delivery bad news: patient perspectives. Rev Med Minas Gerais., v. 23, n. 4, p. 518-525, 2013. https://rmmg.org/artigo/detalhes/415

40. Leiria M, et al. A aplicabilidade da comunicação na psicologia. International Journal of Developmental and Educational Psychology, v. 1, n. 1, p. 435-442, 2020. https://www.redalyc.org/journal/3498/349863388043/html/

41. Martins A. Biopolítica: o poder médico e a autonomia do paciente em uma nova concepção de saúde. Interface - Comunic., Saúde, Educ., v.8, n.14, p.21-32, 2004. https://doi.org/10.1590/S1414-32832004000100003

42. Baile WF, et al. SPIKES – A six-step protocol for delivering bad news: application to the patient with cancer. The Oncologist, v. 5, p. 302-311, 2000. doi: 10.1634/theoncologist.5-4-302.

43. Soares AK.F, et al. Comunicação na atenção à saúde a partir das experiências de estudantes e professores de Enfermagem: contribuições para a alfabetização em saúde. Cien Saude Colet., v. 27, n. 5, p. 1753-1762, maio 2022. https://doi.org/10.1590/1413-81232022275.21462021

44. Machin R, et al. Diversidade e diferença: desafios para a formação dos profissionais de saúde. Ciência & Saúde Coletiva, v. 27, n. Ciênc. Saúde coletiva, 2022, 27(10), out. 2022. https://doi.org/10.1590/1413-812320222710.07332022

45. Ramos N. Cinema e pesquisa em ciências sociais e humanas: contribuição do filme etnopsicológico para o estudo da infância e culturas. Contemporanea - Revista de Comunicação e Cultura, v. 8, n. 2, 2011. https://periodicos.ufba.br/index.php/contemporaneaposcom/article/view/4817/3575

46. Gomes AH, Andrade L. Mediação audiovisual e educação permanente: Cenas de um percurso de formação com trabalhadores do SUAS. Psicologia: ciência e profissão, v.42, e234194, 1-14, 2022. https://doi.org/10.1590/1982-3703003234194

47. Brazil. Ministério da Saúde. Política Nacional de Educação Permanente em Saúde: o que se tem produzido para o seu fortalecimento? 1ª edição revisada, Brasília, 2018 https://bvsms.saude.gov.br/bvs/publicacoes/politica_nacional_educacao_permanente_saude_fortalecimento.pdf