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Communication of bad news from the perspective of oncologists and palliative care physicians

Comunicação de más notícias na perspectiva de médicos oncologistas e paliativistas

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ABSTRACT

Introduction: Communication is essential to medical practice; however, it is constantly performed inadequately, mainly in the context of communicating bad news. The bad news is that it causes a negative change in the patient's life, resulting in an unpleasant change and modifying his future perspective. In Western medicine, due to the predominance of the curative model, bad news is understood as failure or incapacity of professional competences, causing physicians to distance themselves and causing patient dissatisfaction. Given these circumstances, the SPIKES, P-A-C-I-E-N-T-E, and Class communication protocols emerged.

Objective: To evaluate the dynamics of bad news, with respect to the use of specific protocols and the main difficulties experienced, as well as to identify the influence of communication on the doctor-patient relationship.

Method: This is a descriptive study with a qualitative methodology, using a semi-structured interview script prepared by the authors. Twelve interviews were carried out with physicians from the Oncology and Palliative Care sectors of the Instituto de Medicina Integral Prof. Fernando Figueira (IMIP), which were recorded and transcribed for further analysis. The data was categorized according to Minayo's proposal.

Results: The approach to bad news was very similar among professionals, regardless of the use of communication protocols, with SPIKES being the best known among them. The study revealed that the main difficulties faced by physicians when communicating bad news are related to the environment and time of consultation, high patient demand, doctor-patient-family bond and the medical feeling of not meeting expectations or being frustrated by the experienced situation. A clear influence of communication on the doctor-patient relationship was also identified. The need to update the curriculum of medical schools, including theoretical-practical training in communicating bad news, was also verified.

Conclusion: The use of bad news communication protocols is not presented as an essential condition for effective communication; however, it allows greater assertiveness and clarity during the conversation. Therefore, the implementation of communication strategies in the health context is suggested, allowing improvements for both professionals and patients.

Keywords: Communication in Health, Communication Barriers, Doctor-Patient Relationship.

Introdução: A comunicação é indispensável à prática médica, entretanto, constantemente, é realizada de forma inadequada, principalmente no âmbito da comunicação de más notícias. A má notícia é aquela que causa alteração negativa na vida do paciente, provocando uma mudança desagradável e modificando sua perspectiva de futuro. Na medicina ocidental, pelo predomínio da visão curativista, más notícias são compreendidas como insucesso ou incapacidade das competências profissionais, causando afastamento dos médicos e insatisfação dos pacientes. Diante dessas circunstâncias, surgiram os protocolos de comunicação SPIKES, P-A-C-I-E-N-T-E e CLASS.

Objetivo: Este estudo teve como objetivos avaliar a dinâmica da comunicação de más notícias, quanto ao uso de protocolos específicos e às principais dificuldades vivenciadas, e identificar a influência da comunicação na relação médico-paciente.

Método: Trata-se de um estudo exploratório, descritivo, com metodologia qualitativa, em que se utilizou um roteiro de entrevista semiestruturado elaborado pelos autores. Realizaram-se 12 entrevistas com médicos dos setores de oncologia e de cuidados paliativos do Instituto de Medicina Integral Prof. Fernando Figueira (IMIP), que foram gravadas e transcritas para posterior análise. Os dados foram categorizados segundo a proposta de Minayo.

Resultado: A abordagem de más notícias foi muito semelhante entre os profissionais, independentemente do uso de protocolos de comunicação, sendo o SPIKES o mais conhecido dentre eles. O estudo revelou que as principais dificuldades enfrentadas na comunicação de más notícias dizem respeito ao ambiente e tempo da consulta, à alta demanda de pacientes, ao vínculo médico-paciente-família e à sensação médica de não corresponder às expectativas ou se frustrar pela situação vivenciada. Identificou-se também uma clara influência da comunicação na relação médico-paciente. Constatou-se ainda a necessidade de atualização da grade curricular das escolas médicas, incluindo a formação teórico-prática em comunicação de más notícias.

Conclusão: O emprego de protocolos de comunicação de más notícias não se apresenta como condição indispensável para comunicação efetiva, contudo, possibilita maior assertividade e clareza na condução da conversa. Assim, sugere-se a implementação de estratégias de comunicação no contexto da saúde, de modo a possibilitar melhorias tanto para os profissionais quanto para os pacientes.

Palavras-chave: Comunicação em Saúde; Barreiras de Comunicação; Relações Médico-Paciente.

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INTRODUCTION

Communication is essential to all human interaction, including medical practice, as it is capable of providing better quality care in health services¹. However, this dialogue constantly occurs in an inadequate manner, mainly in the context of communicating bad news².

Bad news can be understood as the one that causes a negative change in the patient's life, resulting in an unpleasant change, either directly or through its repercussions³, since it is information that significantly changes the patient's future perspective⁴, affecting their physical or mental state, as well as their already consolidated lifestyle⁵.

As the professionals' training remains very much focused on the promotion, rehabilitation and protection of life, bad news is understood as the failure of therapeutic measures or incapacity of professional competences. It is also verified that the bad news not only affects the person who receives it, but also the person who transmits it, with a frequent reaction of defense and distancing by the doctors, and the patient may then react with dissatisfaction and despondency, due to the lack of embracement in a moment of fragility⁶.

Assuming that communication skills can be taught, strategies have emerged for a more assertive communication of bad news, with the SPIKES, P-A-C-I-E-N-T-E, and CLASS protocols being the ones that are mainly recognized.

The SPIKES protocol is organized into six steps.

- Setting up: describes the moment prior to consultation, in which the doctor prepares to communicate, studying the case, and organizing a physical space.
- Perception: related to observation of how much the patient is aware of the situation. 'Invitation' seeks to understand how much information the patient is willing and able to receive.
- Knowledge: the act itself, of communicating the bad news. It is recommended to start with introductory phrases that induce the patient to perceive the coming of bad news; avoid technical terms and build the information with sensitivity, so that it is not received abruptly; and confirm what has been understood.
- *Emotions:* Reflects the empathetic moment, saved to welcome the patient's emotions.
- Strategy and summary: The next steps of the therapeutic follow-up and situations that may arise are explained⁷.

The P-A-C-I-E-N-T-E protocol, based on SPIKES and adjusted to Brazilian reality, consists of seven steps: P – Prepare, expresses the verification of the news and finding a physical

environment with privacy and comfort; A – Assess how much the patient knows and wants to know; C – Invite the patient to the truth; I – Inform the news in adequate amounts, using adequate velocity and quality for understanding; E – Emotions, allow the patient to express themselves freely; N – Do not abandon the patient, make sure they will get medical help; T-E – Outline a strategy, planning the next necessary care and therapeutic options⁸.

The CLASS protocol has five steps. The first concerns the conversation environment; the second aims at the aptitude and willingness of medical listening; the third refers to the patient's emotions and empathy; the fourth is an outline of strategies, presenting the therapeutic recommendation and its stages in a way that can be understood; and, finally, a synthesis of the topics discussed during the conversation is carried out, checking if there are any doubts⁹.

It is observed that the protocols have similarities related to assistance through a systematization of the communication of bad news, aiming at a more satisfactory doctor-patient relationship for both⁷⁻⁹. However, this objective is not consistent with the scarce analysis of the effects of protocol use. Therefore, further scientific exploration is necessary, as it is of interest to both health professionals and patients.

This study aims to assess the dynamics of communication of bad news, with respect to the use of specific protocols and the main difficulties experienced, as well as identifying the influence of communication on the doctor-patient relationship.

METHOD

This is an exploratory and descriptive study with a qualitative methodology, using a sociodemographic and professional questionnaire, and a semi-structured interview script prepared by the authors with the following guiding questions:

- Can you comment on the process of communicating bad news in your professional practice?
- Do you use any communication technique when reporting bad news?
- What are your biggest difficulties when communicating bad news to the patient?
- Have you heard about protocols for the communication of bad news?
- If so, what is your view on their usefulness and expediency?
- If you use them, what are your difficulties when using these protocols?
- How do you see the impact of using protocols for more assertive communication with the patient?
- In your opinion, what are the impacts of this communication on the doctor-patient relationship?

Twelve interviews were conducted with physicians from the oncology and palliative care sectors of Instituto de Medicina Integral Prof. Fernando Figueira (IMIP), and all were recorded and transcribed for further analysis. The data were categorized and evaluated according to Minayo's proposal¹⁰. The number of interviews was defined according to the saturation criteria. This study was carried out according to the provisions established by Resolution n. 510/16 of the National Health Council for Research on Human Beings and the Declaration of Helsinki.

RESULTS AND DISCUSSION

Twelve professionals were interviewed. Regarding the sociodemographic profile, seven (58.3%) doctors are female, nine (75%) self-declared to be white, seven (58.3%) are married, ten (83.3%) are catholic, seven (58.3%) have a family income greater than 12 minimum wages, and twelve (100%) live in the municipality of Recife, state of Pernambuco, Brazil. The youngest physician is 26 years old, and the oldest is 53, with a mean age of approximately 38.4 years. As for the professional training, eight (66.7%) completed only the medical residency, two (16.7%) have a master's degree and two (16.7%) have a Ph.D. The mean time of academic training was 13 years, while the mean time working in the oncology or palliative care sector was 7 and a half years. Of the total, seven (58.3%) had already received some training in communicating bad news.

The content of the interviews was divided into three thematic categories: "Bad news approach", "Difficulties in communicating bad news" and "Influence of communication on the doctor-patient relationship".

Bad news approach

In oncology and palliative care, bad news related to diagnosis, treatment, complications, recurrence, and end-of-life issues are routine and require a suitable approach. This topic was divided into 3 subcategories: "Medical knowledge about protocols and other strategies used to communicate bad news", "Academic training on the communication of bad news" and "Effects of using communication protocols for conveying bad news".

Medical knowledge of protocols and other strategies used to communicate bad news

Among the existing communication protocols for conveying bad news, SPIKES is one of the most popular worldwide¹¹. In the literature, the greater prominence of SPIKES is justified by its flexibility¹². In the present study, this popularity was also demonstrated, as most professionals reported knowing only the SPIKES protocol, and the remainder did not know any, with emphasis on the following answers:

I know and have incorporated SPIKES (P6).

I use some techniques. But as for a protocol, honestly, I don't remember (P3).

I must have heard about it [about other protocols], but the only one that I have already tried to practice was the SPIKES protocol, because it is more of an everyday use (P1).

Other protocols were not mentioned by any of the interviewees. However, it is noteworthy that the P-A-C-I-E-N-T-E protocol is based on SPIKES and that the CLASS protocol essentially has the same six steps as SPIKES, arranged into five steps^{8,9}. All protocols are based on the same axis, supported by the identification of what information patients have and what their expectations are; offering information clearly and according to the patient's wishes; providing support; and highlighting the importance of cooperative participation¹³. Although it does not specify names, the similarities between the protocols were recognized in the following statement:

I think these protocols are all kind of similar. The feeling I have is that most of them are based on SPIKES. When a different one appears, I immediately say that it is a modified SPIKES (P12).

The similarity of the approaches was observed, even among the professionals who did not have knowledge about the protocols, demonstrating that they rely on points considered essential for adequate communication with the patient¹³. According to the literature, a consistent preference for cancer patients is direct and clear communication, as long as their feelings are taken into account¹⁴. This practice can be achieved through the use or non-use of protocols, as shown in the following reports:

I don't know any protocol, but I try to extract a little information from the patient about their condition and, as they tell me what they understood, I explain (P2).

Ido not use any protocol. I try to use a simpler language, giving the person time to understand. I always ask if they understand, if they know what is happening, the treatment, the evolution, the outcome itself... (P4).

Academic training on the communication of bad news

Regarding the academic training focused on communicating bad news, the respondents reported having had little or no discussion on the topic, as well as access to protocols. It is known that communication skills training programs can provide greater awareness of emotions and represent an opportunity to practice communicating bad news¹². However, the professionals' reports showed a gap in the theoretical-practical training during undergraduate school and even during the residency period:

When I was in medical school, I didn't have that kind of training. We didn't even talk about palliative care, I never had anything about it. I learned about it only in the Oncology residency, I did not even have it in Internal Medicine. But it is very important [to know some protocol], especially when you have no experience (P3).

Communication with patients should be developed further during undergraduate school. In Internal Medicine, I only had contact because I had a geriatric and palliative staff. During undergraduate school, it was in the internship, during a rotation with the same staff, but nothing specific or directed (P8).

In fact, studies carried out in different countries disclose a lack of training during academic formation, which explains many of the problems reported by health professionals^{9,11,15}. In Brazil, a recent study with 162 medical schools found the teaching of communicating bad news in only 41 of them¹⁶. Therefore, it is necessary to improve the curriculum on this topic¹⁷. Regarding this need, the following statement stands out:

I find it very strange and different not having had contact with this in undergraduate school. It is essential, it should be included in undergraduate training, practiced since the beginning (P1).

Effects of using communication protocols for conveying bad news

The literature supports a communication strategy for conveying bad news in which the aspects of the protocols are incorporated and adapted to the physician's experience and the required specific needs. It will not be always necessary to follow all the steps of SPIKES, for instance; it is important to be guided by the patient's demand and not just stick to the checklist¹⁸. The effectiveness of the communicative process demands flexibility, and it is important that the protocols help to face eventual obstacles, but without hindering the uniqueness of the moment⁷. The interview reports and the literature are in agreement:

We are based on SPIKES, but we adapt it to our reality and the patient's needs. Often, I don't need to use the full protocol or only the protocol is not enough (P7).

Communication protocols are a little different from clinical protocols. [...] With a communication protocol, there is no such strictness. It should not harden the relationship; after all, we are talking about communication. There is no formula (P5).

I really like the SPIKES checklist, but I have added things I learned over time, while working with colleagues and with the patients themselves (P11).

The physicians' opinion on the usefulness of protocols, such as SPIKES, was based on their didactic organization of the main pillars on which the transmission of bad news is

based, aiming to cause the least possible negative effect on the patient⁵. Another positive effect would be the emotional reassurance of physicians and patients. For the professional, the bad news is often linked to frustration and guilt and, particularly in the oncology consultation, great anxiety is experienced by the patient and their family¹⁹. Therefore, a tool that provides emotional support translates into the establishment of a better doctor-patient relationship, since one of the key aspects of communication is emotional stability and support²⁰. This can be observed in the following reports:

I use SPIKES, its assumptions and principles for a more compassionate communication [...] I keep remembering it, no matter how nervous or emotional I am, no matter how much I think the conversation is taking too long, that I need to give some orientation, the SPIKES protocol guides me (P12).

I really like SPIKES, because it gives a sense of ambiance and "settings". I think the protocol helps you to review cases on a daily basis in an organized and appropriate way, considering the number of patients and the fact that it is not a simple conversation that can occur anywhere (P11).

Difficulties in communicating bad news

Oncologists and palliative care professionals find themselves in situations that demand the communication of bad news. At that moment, several difficulties may arise, from which three subcategories were selected: "Impasses related to the environment, time and demand", "Impasses related to the doctor-patient-family bond" and "Medical feelings".

Impasses related to the environment, time and demand

Regarding the work circumstances, an overload of patients in the service, little availability of time during consultations and an inappropriate environment in terms of embracement and receptiveness were found in the interviews. In the international literature, not having enough time to manage the situation and provide greater support to the patient was the main source of complaint among health professionals²¹. However, there were also complaints by the physicians regarding the lack of an adequate place for the conversation, as well as patient demands and relationship problems between the health team members²². This last point was not evidenced in the present study; however, there was an agreement related to the other points in the following reports:

The main problem is regarding space. Something that really bothers me is that there is always someone who comes in to get something. Sometimes it distracts me a lot and even irritates me. If I had an adequate room just for conversations it would be much better (P12).

The hardest part is the volume. I hardly have a day with few patients or few things to do. This makes it impossible to spend 30 minutes or 1 hour on a bad news communication. Thus, sometimes there is no adequate place or enough time. Excessive noise and demand end up not allowing us to give each patient the right amount of time to talk (P11).

Impasses related to the doctor-patient-family bond

Some situations are considered to be more complex. In the literature, physicians describe it as extremely difficult to communicate bad news to patients with whom they have a closer relationship²³ and consider it a deeply apprehensive situation to deal with younger patients¹⁴. In agreement with these studies, the following statements are evident:

What affects me the most is telling the patients you have known for longer, when you have been following the treatment and the disease progresses. This is the most difficult moment because you already have a bond with the patient, right? (P3).

The most difficult situations are always those when the patient is very young, when they have a small child, when patients demonstrate great spiritual suffering and feel they have not lived according to the principles they thought were important... and at the time of death, they feel despair (P12).

Another difficulty pointed out by the professionals is caused by the family itself. In their eagerness to protect the patient from greater suffering and from the emotional conflicts that may arise, it is common for the family to try to intervene in the communication process, requesting that the truth be "fractionated" and the individual spared from the news. This desire to spare the patient an adverse prognosis has been an impediment to a more direct communication¹⁴. Moreover, a study has shown that the increase in the anxiety of patients after receiving bad news is associated with the increase in anxiety of relatives who accompany them²⁴. These questions were also raised by the interviewees:

Sometimes, it is the family itself that complicates things, with that conspiracy of silence. The body belongs to the patient, they have every right, they are lucid and the family does not want to tell them. For me, the biggest difficulty is when that happens (P3).

The family, in most cases, is not prepared and gets more distressed than the patient, further destabilizing them. It is not easy dealing with this situation (P10).

Medical feelings

Regarding personal vicissitudes, a problem that was pointed out, in agreement with the literature, was to communicate bad news without hindering the patient's hope

and expectations regarding their future^{14,21}. In this regard, the following statements stand out:

There is a bad feeling, I suffer because the situation exists. Not because I'm the one talking, but because the person is going through it. As a physician, I see myself in the role of helping them to go through that and I'm worried about how the patient will deal with that news after leaving the office (P8).

I feel bad for not living up to the expectations. This affects me a lot and makes me sad (P1).

In view of the curative perspective, still very present in western medicine, the end of therapeutic resources is often seen as a failure of medical skills and the capacity of Medicine itself²⁵. These aspects can affect the transmission of bad news, which can be overly direct or end up being euphemistic and generate a lack of understanding of the real situation, as reported in the following statements:

My biggest difficulty is recognizing that I may not be able to help as much as I would like to. It gives you a certain feeling of helplessness, of failure. It is inevitable, at least for me (P9).

In everyday life, some cases generate an emotional lack of control. I feel bad about having to give bad news, sometimes I even try to mask it (P1).

Moreover, one's personal fear of death can also affect the professionals. The literature shows that a considerable part of the medical community does not consider itself qualified to talk about this in depth, either because it is a general taboo in society or because of the physician's own denial, who feels uncomfortable because death is something uncontrollable or because of the remembrance of their own finitude^{23,26}. However, there was no perceptible consensus in the interviews about this difficulty:

I think the biggest problems we face as the medical class are the miscommunications. Often due to a difficulty by the doctor himself, instead of the patient, to talk about death and the lack of a cure. To admit, as a physician, that I am not comfortable with the subject (P11).

I see death as something that is part of life and that everyone will get there someday. You can be sad, but you have to get over it (P5).

Influence of communication on the doctor-patient relationship

Quality communication has an impact on the improvement of the patient's general condition, comprising several personal needs, particularly psychological ones. It has been described that the way bad news are delivered influences as much as the bad news themselves, and can

have a negative impact, if given incorrectly, causing anxiety, suffering, misunderstandings and resentment; but, when offered adequately, it generates understanding, acceptance and harmony²⁷. The literature reveals that most complaints regarding professionals are related to their communication skills and not to their academic competences, which directly impacts the way they face their diagnosis and adherence to therapy²⁸. In this regard, the following statements stand out:

Communication will change the entire characteristic of the relationship, whether the patient will believe in the treatment, whether they will trust you or not. It can have a terrible impact if you communicate in a bad way or make a mistake in thinking that the patient understood what you said and they did not understand (P3).

When communication is effective, you can better guide the patient regarding symptom control. There is no oncology without good communication. It prevents suffering, physical and emotional exhaustion and make the patient experience more autonomy (P11).

The literature also recalls that, in addition to verbal communication, other aspects influence the doctor-patient relationship, such as empathy, honesty and coherence, in addition to body language and eye contact. Additionally, the professional must always try to understand the patient's reality, with an empathetic and compassionate attitude, however delimiting that that experience does not belong to them²⁹. In this regard, the following reports stand out:

Good communication is essential for the doctor-patient relationship to thrive. And I am not just talking about the verbal communication, there is also the non-verbal one, the willingness to help, availability, the look. But you need to establish a certain barrier. Knowing that the problem is serious, but not exactly yours. We have to learn how to separate this to survive in the profession, otherwise it becomes too difficult (P9).

I think a person can just be compassionate. Thus, compassion should be the mandatory protocol for everyone who wants to communicate adequately in this context of suffering (P12).

CONCLUSION

Communication strategies can promote, in an organized way, a space of embracement, safety and clarity for patients in a moment of fragility. However, the use of protocols for communicating bad news is not an essential condition for effective communication, since even physicians who did not use protocols, but based their communications on a script structured according to their personal experience, achieved a good doctor-patient relationship. However, the protocols allow

greater assertiveness and clarity, which might not be so well achieved in an empirically instituted communication.

We also verified the need to update the curriculum of medical schools, including communication techniques, skills and protocols as part of the fundamental spheres of learning for clinical practice, improving both the training of professionals and the satisfaction of patients and their families with the service.

Despite being limited to the perspective of physicians in a hospital and selected specialties, the present study revealed that the main communication difficulties concern the environment and the duration of the consultation, high patient demand, the doctor-patient-family bond and the physician's feeling of not meeting expectations or being frustrated by the experienced situation.

A clear influence of communication on the doctorpatient relationship was also identified. Therefore, it is suggested the development of more studies exploring this skill, as well as ways to implement communication strategies with quality in the context of health, allowing improvements for professionals and patients.

AUTHORS' CONTRIBUTION

All authors contributed substantially to the study design, planning, analysis, data interpretation, drafting of the manuscript, critical review of the content and approval of the final version of the manuscript.

CONFLICTS OF INTEREST

We declare that there is no conflict of interest.

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