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REVIEW

End-of-life: let's talk about communication

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ABSTRACT

INTRODUCTION: The aim of the present work was to analyse the role played by communication in the medical-health intervention and how to transform it in a practical support for the health professions and the patient's outcome.
EVIDENCE ACQUISITION: Through a review of the literature the meaning of bad news is analyzed and the main models aimed at helping doctors and health care teams communicate the bad news (the NURSE protocol, the PERCS protocol and the SPIKES protocol) are described.
EVIDENCE SYNTHESIS: Starting from the meaning of bad news and the communication models available, authors discuss the impact of bad news on the patient, on the doctor and underline the need for the teaching of communication for doctors and degree students, as well as the need for training in communication with the patient.
CONCLUSIONS: The complexity of the doctor-patient relationship implies communicative exchanges, in which the effectiveness of the information provided by the doctor depends on the emotions felt in communicating it, and the understanding of what is communicated depends on the patient's emotional state. It appears urgent, therefore, to create a training path that stems from the standardization of the results obtained from sector studies and that aims to replicate the socio-health practices considered to be of excellence. The communication effectiveness is indispensable for an adaptation process that expresses the citizen's ability to adapt to changes in the environment, to grow and age, to heal after a sickness, and to suffer and wait, more possible serenely, the death.

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KEY WORDS: Terminal care; Truth disclosure; Health communication.

Introduction

Communication plays an essential role in every person's life. This acquires significance when the context in which it takes place is the medical one. Medicine today differs from past centuries as it has evolved enormously, changing the face of many pathologies once defined as incurable. Furthermore, not only have the technologies available for medicine changed, but the patient, while continuing to be the fragile person in need of help, is more informed than in the past, through the mass media and social networks, more aware of the disease and therapies. Despite this, they need to communicate, tell and receive answers and attention.[1]

Patient "take care" focuses on the patient, taking into account the impact of the various aspects of the disease on them. In communication, there has been a shift from a paternalistic model up to the 1970s, centred on the doctor as the only and exclusive connoisseur of the truth, to a model centered on the patient.[2] It is, therefore, necessary and proper that the doctor does not focus exclusively on the pathology but also on the effects it has on the patient from an ethical, psy-

chological and relational point of view through communication.

But what does it mean to communicate? "Communicate" comes from the Latin to have in common, to share, thus implying the idea of an exchange, of a reciprocal relationship and not of a mere transmission of aseptic information. It is made up of words, pauses, silences, gestures, and of expressions taking the form of verbal and non-verbal communication. Therefore, it is necessary to have an expressive capacity accompanied by a human capacity, for empathy and sociality. Thus the aspects of good communication emerge: the right thing to say, the most appropriate way to put the interlocutor at ease and gain their trust, respecting their culture, mood, times and needs.

Doctors, having to inform the patient in an accurate, complete and understandable way, cannot ignore the human connotations of what they are saying, transforming information into communication.

Therefore the "take care" concerns not only the disease but also the person, and the two aspects, scientific and anthropological, cannot be separated. Thus, a good doctor is not only a good clinician but also a good communicator. This aspect is then further enhanced in the communication of bad news.

In the 90s, the problem of communication in medicine has become evident, as well as the need for specific training for doctors. In 1992, in Italy, the National Committee for Bioethics (C.N.B.), in a document focusing on informed consent,[3] underlines that the doctor must possess specific communication skills to respond empathically to the different situations of clinical practice. A communicative ability is required that "is identified in the willingness to dialogue, listen, and exercise care that involves an accurate human understanding. [...] The C.N.B.. believes that adequate educational programs are required to acquire and develop this attitude".

The World Health Organization (WHO),[4] in 1993, affirms how effective doctor-patient communication is a foundation of good clinical practice and impacts disease outcomes, not only in physical but also in psychological terms. Several studies state that ineffective communication can affect the patient's psychophysical health and impact the economic aspect of public health. The WHO, therefore, invites countries to invest in training in terms of communication since the financial investment, time and resources, are less than the benefits for patients, doctors, medical faculties and the health system.

The Council of Europe, in 1999, "hopes for the introduction of cultural and university training on the doctor-patient and doctor-death relationship"[5]. The relevance of university education is recognized, and the European Union invites university institutes to take care on medical training not only about purely clinical knowledge but also in terms of communication with the patient. Another aspect in which to invest in training is the doctor-death relationship, thus inviting the doctor to become aware of this inevitable event of human existence, being able to discuss it with the patient in an empathetic way.

Recently, in Italy, the law n. 219 of 2017,[6] on informed consent and living, will, states in Article 1, paragraph 8 that "Communication is already time for care," and in paragraph 10: "The initial and continuing training of doctors and other healthcare professionals includes training concerning communication with the patient, of pain and palliative care," and entrusts the task to universities and scientific societies. The need for training is now no longer postponable.

Evidence acquisition

To gain an overview on what is considered bad news and how health practitioners deal with communication of bad news, authors started visiting the official websites of international organizations such as United Nations (lac.unwomen.org), World Health Organization (who.int/health-topics/women-s-health), Council of Europe (coe.it). The literature review was performed in the following international databases using as keywords "bad news" & "communication model" as well as "truth disclosure" & "death" & "terminal care" & "informed consent" & "teaching" & "training": PubMed, MEDLINE, Google Scholar, Embase and Scopus, considering publications and issues up to January 2022. A first screening of the articles was completed by reading their

headlines and abstracts to ensure that the topic and content was correlated with communication of bad news to patient. Potentially relevant studies which did not appear in the main search were also identified from the References of other articles.

Evidence synthesis

The literature on communication between health practitioners and patients documents the interest of the authors particularly focused on the communication of bad news, the effects that communicating bad news have on the doctor and the effects that receiving bad news have on the patient. Over time, three bad news communication models have been developed, each with its own characteristics. Results concerning each topic are discussed below.

What is bad news

"Communication is the cornerstone of good multidisciplinary medical care, and the impact of conversations regarding diagnosis, treatment and prognosis is indisputable."[7]

Communicating in medicine implies not only the transmission of information but the construction of a relationship of care between doctor and patient. This task, which by law is up to the doctor, has substantial implications for the patient and the professional, especially when it comes to bad news.

Bad news in medicine has different meanings that must be considered with particular attention; in the common imagination, a diagnosis of cancer or a reduction in life prospects is certainly bad news, but it cannot be limited to these conditions and a few others.

According to Fellowfield and Jenkins, any information that in negatively alters the patient's expectations about their present and future can be considered bad news.[8]

According to Sobpzak *et al.*, Polish authors, "it is any form of diagnosis that is related to a change of the organism towards a permanent state that requires continuous or long-term medical treatment, or a therapy that is aimed at pain control [...] therefore includes diabetes, coronary heart disease, allergy, tumors, as well as mental illnesses, genetic diseases and incurable and fatal diseases.[9]

It is essential, however, to remember that bad news is always in the eye of the beholder.[10] That means that the doctor, as such, cannot *a priori* determine which information for their patient is bad news, but has to be able to decide on it during the conversation, to express it and to discuss it in a professional, but serene and empathic way.

The diagnosis of a chronic disease, routine for the doctor and whose treatment has now been effectively consolidated over the years, may not be felt as bad news for the professional. Still, for the patient it can represent a condition of alteration in the conception of one's life.

It should be noted that lousy news becomes worse, the greater the difference between the patient's perception of reality (subjective reality) and the actual situation (objective reality). The professional's task is to make the transition between the two realities less traumatic.[11] What the listener hears depends not only on what the speaker says but on the subjective and social context of the listener.[12] This aspect of communication ambiguity is also fundamental in the context of bad news.

This sentence is exemplary: this tumors can be treated. The doctor refers to treatment as an action capable of prolonging the patient's life. The patient, however, realizes that there is the possibility of being cured, which implies a total recovery, thus the disappearance of the disease.[13]

Focusing on the social context of the listener, socio-cultural relationships and the patient's experience has to be considered.

A fatal diagnosis, for patients who are the only source of family income, can be related not only to the feeling of sadness but also to the feelings of anxiety, concern and fear for the family's fate once the sick person passes away.

Cultural differences can also significantly affect the healing path, as clearly emerged in this period of pandemic emergency: on the one hand, the "no vax" culture and on the other, the culture of those who have instead chosen to rely on science and get vaccinated. In recent months, it has been possible to see how important communication is in health. The voice of doctors must

be, on the one hand, precise and unambiguous in its contents in order not to confuse and create division and, on the other, be able to vary the vocabulary to be adequately understood by the entire population to which it is addressed, whose level of education is varied. In a situation such as the current one of great significant infectious risk, even setting up a routine therapy, such as anticoagulant therapy, which requires frequent hospital checks, could generate anxiety, fear and anguish because of the need to go to the hospital and risk contracting the virus.

Therefore, from an emotional point of view, bad news represents the irruption of something unexpected, and threatening, the implications of which are not exactly known, and which generates uncertainty, anxiety, fear, anguish, increases personal vulnerability, undermines the ability to control and the sense of continuity of one's existence.[14]

It is well known that bad news affects all areas of medicine, and doctors must use daily interface with various communication challenges, but it is more frequent in the oncology field. In the study proposed by Baile *et al.*, 65% of doctors working in the oncology field reports having to give between 5 and 20 bad news a month.[10]

Therefore, a difficult task for any doctor, is more relevant in the oncology field due to new diagnosis, relapse, metastasis, side effects of chemotherapy, radiotherapy and possible transition to palliative care. Communicating bad news is, therefore a particularly arduous task that requires, in addition to expressive skills also other skills, to be able to respond to the patient's emotions, to involve them in decisions, to help them cope with the stress created by the expectations of care, to involve different family members and solve the dilemma of how to leave hope in critical situations.[10]

Communication models

A review of the literature shows that there are three main models aimed at helping doctors and health care teams communicate the bad news: the NURSE protocol, the PERCS protocol and the SPIKES protocol.

In the NURSE protocol the main focus is on the empathic responses that the doctor provides during the interview.[14] NURSE is the acronym for:

- Naming Emotions: to name the emotion that is observed in the patient;
- Express Understanding: expressing understanding for the feelings;
- Showing Respect or prize for a patient's behaviour: showing respect for how the patient is dealing with the situation;
- Articulating Support for the patient: formulate supportive and non-abandonment sentences and statements;
- Exploring the patient's emotional state: frequently investigate the patient's emotional state.

PERCS, an acronym for Program to Enhance Relational and Communication Skills, developed in 2002 in Boston, is a multidisciplinary program based on a clear theoretical framework and aims to combine the teaching of specific communication skills with the cultivation of relational attitudes.[15]

The best-known model however is the SPIKES protocol,[16] a communication model customized to the patient's wishes.

This protocol, developed in 2000 by Baile *et al.*,[10] fragments the moments of communication into six fundamental steps that form the acronym SPIKES (Setting up – Perception – Invitation – Knowledge – Emotion – Strategy and Summary), in which the intervention starts from the exploration of knowledge and expectations to the communication of the truth respecting the rhythm and will of the patient.[11]

Thanks to its organized and schematic structure, it unequivocally facilitates the construction of a caring relationship in which the doctor and patient face the bad news by cooperating to deal with the emotional impact and reach a shared therapeutic plan.

Steps in the SPIKES protocol are the following:

1. setting up the interview. Start by preparing the physical context, developing a communication strategy and preparing to listen;

2. assessing the patient's perception. "Before you speak, ask". It is advisable to ask open-ended questions to evaluate the patient's perceptions and understand how much they already know and what idea they have about their disorders;

3. obtaining the patient's invitation. Invite the patient to express the desire to be informed or not about the diagnosis, prognosis and details of the disease; it should be considered that although most patients want to be fully informed, others may not have the same desire;

4. giving knowledge and information to the patient. Provide the patient with the information necessary to understand the clinical situation. Notifying them that bad news is about to be delivered can help make communication less shocking for the patient and facilitate the information process;

5. addressing the patient's emotion with empathic responses. Responding to the patient's emotions is one of the most difficult challenges in communicating bad news. This step shows the main task of facilitating the person to express their emotional reactions by responding to them in an empathic way;

6. strategy and summary. Discuss, plan and agree with the patient on an action strategy that considers possible interventions and expected results; leave time for any questions; evaluate how much the patient has understood by asking to summarize what has been said.

The impact of bad news on the patient

From a legal and ethical point of view, the doctor is responsible for informing the patient clearly and precisely. With time a gap was created between the willingness of the patient and family members to receive even unfortunate communications and the doctor's willingness to give them.[17]

To date, most patients prefer a practical and individualized approach to cancer with detailed information when talking about prognosis; this is even more true when dealing with young patients.[18] There is now a broad consensus of opinions on how patients want to receive bad news, of any kind: in a clear, honest, hopeful way, but not too blunt.[8]

It is essential to underline that the stress generated by the bad news can have a long-term impact, reduce the patient's ability to adapt and lead to anger with a greater risk of medico-legal disputes. Additionally, bad news miscommunicated can cause confusion, lasting stress, and resentment.[8]

Bad news, therefore, inevitably generate psychological damage.[10] By evaluating this damage, for example, in terms of anxiety, Zwingamann *et al.* have shown how the level of anxiety varies before and after the communication of the bad news and how this variation is less when the communicative approach used by the physician is more patient-centered.[19]

Empathy plays a fundamental role: it allows the best adherence to treatment and a lower incidence of complications. According to a study with diabetic patients, the incidence of acute metabolic complications was closely correlated with the physician's empathy measured according to validated criteria. This outcome can reasonably be related to creating a caring relationship based on the mutual understanding that leads to mutual trust.[20]

It is highly relevant, however, how the communicative method implemented not only influences the patient's perception of their illness but also affects the continuation and adherence to treatment. Many studies have shown a direct correlation between the physician's communication skills and therapeutic success. Sobczak *et al.* report, in their work,[9] how 50% of patients, following an overall negative evaluation of the doctor's behaviour, decide to change doctor or completely abandon treatment, unlike patients who evaluate the behaviour positively and of which 64% choose to continue the treatment with the same specialist. Also, the time dedicated to the visit is relevant. Patients who decide to continue the path they have taken tend to evaluate positively the time dedicated to communicating the bad news. At the same time, those who abandon the treatments believe that the time has been insufficient. This proves that the time dedicated to the visit correlates with the dynamics of the doctor-patient relationship. Finally, patients' negative feelings require psychological help, offered free of charge to patients diagnosed with cancer, which affects the hospital budget.[21]

The impact of bad news on the doctor

Doctors are the first to recognize that giving bad news is a task that could haunt also themselves for years to come.[8] This favors a nervous and uncomfortable communication that contributes to

reduce hope[18] or the use of vague or misunderstanding terms to try to hide their feelings.[8]

Coping with end-of-life problems is stressful for clinicians, and transitioning to palliative care is one of the most challenging tasks.[7, 15] Recalling the SPIKES protocol is already the first step; doctors should face these feelings, antechamber of emotional exhaustion, before communicating with the patient. This is why the elaboration of a mental plan is helpful, not only for young doctors, but also for those with decades of experience who report feelings of loss of hope and sadness.[22]

Focusing attention on oncologists, the most exposed to the communication of bad news, those who express an inability to communicate with patients have more significant stress and greater symptoms of burnout.[23]

Burnout is a psychological condition characterised by three dimensions: physical and emotional exhaustion, cynicism and depersonalization and low personal fulfilment according to the definition used by Messerotti *et al.* The relevant association is that doctors who limit the communication to the therapeutic success rate and therapy to be followed are at greater risk of burnout, respect to those who instead deal with emotional and quality of life issues in depth.[24]

Furthermore, physicians who emotionally feel incapacitated in front of a patient due to a failure to process the disease and death by themselves, are more likely to propose aggressive treatments. However, this behaviour leads not only to inadequate treatment as futile but also to a considerable economic impact on the health system. In addition, there is also an indirect cost that consists of the use of alternative treatments that expose the patient to possible drug interactions, increasing the induced chemo-radio side effects.[21]

It is therefore clear that improving communication skills leads to greater job satisfaction[23] and that doctors who are more comfortable communicating bad news are less stressed and have a lower risk of burnout.[10]

Discussion

From the analysis described above, it clearly emerges that international organizations have understood the importance and urgency of a specific commitment aimed at improving communication between health practitioner and patient. The WHO[4] underlined how a good communication between doctor and patient favors the outcome of a therapy and the psycho-physical well-being of the patient. The Council of Europe[5] has urged universities and hospitals to engage in training doctors for good communication. As mentioned, the recent law 219/17 in Italy[6] considers communication as a time of care and gives the responsibility for training to universities and hospitals. Therefore, the teaching of communication between doctor and patient and related techniques has now become no longer postponable.

The connection between the clinician's communicative empathy and the patient's outcome is not sufficient; it is important to learn: how to communicate bad news effectively.[19] Communication skills are not innate skills; they must be learned. The doctor must integrate their scientific training, which must be kept at a reasonable level and must include objective knowledge and skills (knowledge, know-how), with adequate training in communicative and relational skills that allow them to have a more prosperous and more human relationship with others (knowing how to be).

It is not sufficient even to learn by observing colleagues with more experience. Their communication difficulties could not have been overcome over time.[25] In addition, many doctors may unconsciously adopt inappropriate strategies for communicating bad news.[8] Therefore, reporting bad news can no longer be optional and has earned a place in the training curriculum. Communication that depends exclusively on the doctor's intuition can be harmful or reassuring and therapeutic,[12] and precisely because of its importance as a time for care, as reported in the Italian law 219/17, it cannot be entrusted to the instinct of the individual doctor.

Several works have shown how this skill can be taught, learned and made on one's own.[10]

It is essential to reflect on what the main objective of teaching is. It is the objective change in the communicative attitude,[14] and, given the difficulty of the fifth step (Emotion) of the SPIKES protocol, education is widely considered effective when it implements the physician's empathy.[12] According to Fallowfield *et al.*, the objec-

tive improvement of the clinician's performance must also be associated with a subjective improvement in one's communication skills.[25]

To implement this skill, several training programs have been developed. Baile *et al.*, in their work, demonstrate how the use of the SPIKES protocol in association with experimental role-playing techniques increases the confidence of teachers, fellows and medical students in applying the same protocol.[10] Although the role play requires trained actors to represent the different emotions that could arise in the patient, it is a highly functional tool as it allows you to experiment with different approaches and, carried out in a group, favors direct confrontation with colleagues. It also allows doctors to reflect on their own and the patient's emotions without the psychological pressure present during communication in a hospital setting.

A further example is the one proposed by the Back *et al.* study, who combined the use of the SPIKES protocol and the NURSE protocol by volunteer doctors, always in an out-of-hospital context, producing a marked improvement in communication skills. In this study, learning activities include hands-on sessions, guided discussions and the development of cognitive maps. The optimization of communication was and objectively observed by the patients and the doctors. A patient, after an interview with an appropriately trained doctor reports, "No one has ever talked to me like this" A doctor stated, "I feel less agitated, and my words are less intricate; I can focus on the person in front of me and find out what they need at that moment "[14]. Therefore, this model has completely hit what was seen to be the teaching goal.

Another training model is the intensive three-day course for doctors proposed by Fallowfield *et al.* An important feature of this type, of course, is the integration of different activities aimed at simultaneously developing skills, knowledge and awareness rather than sequentially. In addition, a model centered on the student-doctor is used, thus ensuring the possibility for individual participants to define learning objectives themselves, focusing on the difficulties they perceive and not just those observed by the researchers.[25]

Thus, structured training effectively leads to an improvement in bad news communication skills.[26]

Training concerns already structured doctors who annually have to update their training and postgraduates. Still, given the complexity of the topic, it is useful that this education starts already during the master's degree course, so it is also aimed at aspiring doctors. Medical students are attentive and motivated in learning and applying communication strategies.[27] This characteristic is common in both the biological and clinical triennium, and communication skills persist in some form during the progression in studies, especially when learned through direct experience but must be continuously put into practice as there is a progressive decline if they are not applied and practiced. Therefore, the need for continuous integration of the teaching of communication skills with the classical course of study is further reinforced. In addition, some skills such as "creating a personal connection with the patient," "eliciting the patient's point of view," and "checking / clarifying information" are more difficult to acquire and improve and therefore, teaching should be resumed over and over again.[27]

For what concern Italy, the Ministry for research and university asked for seminars on doctor-patient communication during the degree in medicine and surgery. We believe that legal medicine, which already has the duty to teach how to inform patients for good informed consent, has the excellent opportunity to make available its experience in the field to contribute to the correct teaching of doctor-patient communication, pending the establishment of real introductory teaching course integrated into the medical degree course.

Conclusions

The aim of the present work was to analyse the role played by communication in the medical-health intervention and how to transform it in a practical support for the health professions and the patient's outcome. The complexity of the doctor-patient relationship implies communicative exchanges, in which the effectiveness of the information provided by the doctor depends on the emotions felt in communicating it, and

the understanding of what is communicated depends on the patient's emotional state. It appears urgent, therefore, to create a training path that stems from the standardization of the results obtained from sector studies and that aims to replicate the socio-health practices considered to be of excellence.

Health reaches its best levels when the environment generates in people the ability to face life autonomously and responsibly. In this sense, health represents the culture and the degree of freedom experienced. The ideal would be to consider communication effectiveness — a good communication — indispensable for an adaptation process that expresses the citizen's ability to adapt to changes in the environment, to grow and age, to heal after a sickness, and to suffer and wait, more possible serenely, the death. On the other hand, the communicative ineffectiveness — or bad communication — could be identified in the solitude experienced by the patient, left to themselves and to their capacity for personal initiative.[28]

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