Communication in oncology

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Summary

Nowadays we are reminded everyday that breaking bad news to patients and families is one of the most difficult and demanding tasks that doctors have to face. Giving out bad news is something that makes us fear the unknown and move between different approaches, from downplaying the severity of the situation, to not caring about the consequences that our information will have on the patients' lives. The communication process between doctor and patient is also critical after the need of informed consent. Emotional support is fundamental to avoid patients feeling abandoned when coping with difficult situations. Ethical obligations and behavior codes must be learned and practiced by doctors to improve doctor-patient empathy.

KEY WORDS: communication in oncology, empathy, psychosocial needs, informed consent.

Introduction

Although cancer is increasingly a chronic condition, it is still perceived, emotionally, as a possible death sentence. As such, it disrupts the life of the patient and his family and abruptly changes his outlook and view of the future. The more unexpected the diagnosis is (as in the case of young subjects, in whom the gap between the subjective and objective reality is greater), the more drastic this change will be.

In the medical field, communicating bad news is a particularly complex task that demands not only sensitivity, but also other skills. Unfortunately, however, the teaching of communication and relational skills is not yet a part of medical training (1-3). The most useful communication skills in a helping profession are the following: listening, asking questions, and giving information. Listening is very different from hearing and the ability to listen is, of all the various skills, the one that, with the help of other sensory channels (sight for observation), allows us to access the other person's framework of reference. However, listening is also the most neglected skill and perhaps the most difficult to implement (4). An active listening situation is one in which operator and user exchange messages to ensure that what is said is being understood. Furthermore, the way in which we ask a question can be perceived, by our interlocutor, as a sign of our willingness, or otherwise, to open up to him. Whereas closed questions invite concrete answers, perhaps of only two possible kinds, and put the operator in a highly controlling position, open questions give the patient the possibility to speak freely (5).

The issue of communication in the field of oncology cannot be separated from a sociocultural analysis that seeks to set the concepts of illness, human transience and death within a broader framework. In today's telematic society, in which all aspects of knowledge seem to be easily accessible to all (democratization of knowledge) and images increasingly public and shareable (making our lives less and less private), it seems peculiar that it is still so difficult to impart unpleasant news of this kind. But the fact is that, in the Western world in particular, disease and death are excluded from our culture, as is the concept of vulnerability in general. In the past, death and disease were accepted with resignation as part of the natural order of things and were therefore topics that very much present in people's everyday lives. Nowadays, on the other hand, they are seen as taboos, which seem to have replaced the historical ones, such as sex or religion. Today, medical science is being asked to overcome disease rather in the way God was once called upon to protect us from all evils, and this goes some way towards explaining our embarrassment and difficulty when having to convey bad news (6).

Until a few years ago, it was possible to identify two main models of communication: in Latin countries there was a greater tendency to conceal the truth from the patient. This was done in a variety of ways, ranging from partial admissions or the providing of ambiguous or incomplete information to deliberate deception. It was believed that keeping the truth from the patient served to protect him and to prevent further suffering. The tendency in the English-speaking world, on the other hand, was always to inform the patient, sometimes in an abrupt and rather detached way.

Until 1995, the code of ethics left the physician considerable room for discretion when deciding how much information could be provided without having a negative impact on a patient's health status. But since the 1990s the need for informed consent for all procedures has changed the ethical and legal scenario: now the physician can no longer withhold information on the health status of the patient, who becomes his only interlocutor. Furthermore, information should now be conveyed using language that will not traumatize the patient and does not exclude elements of hope (Deont Cod. 1995, Article 29, Paragraph IV) (7,8). This turnaround also stems from judicial pronouncements that hint at some kind of equivalence between health and other commodities, which thus implies a need for consumer protection. However, there is no doubt that informing is not the same as communicating, and it is also clear that the patient's unwillingness to know can limit the efficacy of informed consent. Patient information in oncology, caught between moral, legal and practical/ethical issues, is in a particularly tricky situation. The increasing spread of defensive medicine has changed the balance of negotiating power (between physician and patient and between patient and healthcare facilities) which is the basis of the therapeutic alliance. Regardless of whether or not there is empathy between physician and patient, when detailed information is provided in order to meet an obligation, the patient is left with the burden of coming to terms with the diagnosis with the means at his disposal (9).

There are a number of possible obstacles to adequate conveying of information:

- · a fear of unnecessarily hurting the sick person;
- limited time available to devote to the patient;
- the belief that the physician's expertise should be limited the organic aspects of the disease and that the treatment of the emotional sphere calls for "other experts";
- feelings of inadequacy and helplessness on the part of the physician, and difficulties in managing complex issues (the physician has been trained to focus on healing and if this is unattainable, feelings of helplessness are triggered);
- the need of healthcare workers, so frequently exposed to pain and unpromising prognoses, to avoid distress through detachment or apparent insensitivity.

Professionals caring for a cancer patient must be technically skilled. In addition, however, they must always abide by the general rules of good manners, avoid contradicting each other, strive to communicate in the best way possible, and work with each other in a multidisciplinary approach that is never abstract but includes frequent reference to methods and actual proposals. In short, they need adequate knowledge, skills, attitude and methodology.

A word should also be said about the patient's family members, whose presence is not always helpful to professionals trying to carry out out their duties (10). There are different types of family member:

- those who are absent, both physically and emotionally;
- those who come between healthcare professionals and the patient, thus tending to exclude the latter from decision-making processes;

 those who behave in a constructive way, putting the good of the patient before their own needs and becoming active and valuable resources.

In 1997, the first handbook drafted by the CARE group (*Comunicazione, Accoglienza, Rispetto, Empatia* - Communication, Hospitality, Respect, Empathy) was published by the Italian Superior Health Institute (11,12). It teaches healthcare professionals how to talk to cancer patients in compliance with the basic rules of good manners; in fact, many practices still commonly seen on the ward can be ascribed to the absence of good manners and they have the effect of almost completely excluding the person who is the object of our professional commitment and should be the focus of our interest. Accordingly, it is good practice always to:

- introduce oneself to the patient, avoid using mobile phones while talking to him;
- observe a certain degree of formality;
- specify one's particular role in the multidisciplinary work;
- provide clear and understandable information (taking into account his cultural and psychological state);
- respect his right to privacy (avoiding speaking in front of others and asking explicitly whether he wants to speak in someone else's presence);
- avoid talking to other colleagues in front of the patient, thus excluding him;
- use accessible terminology;
- explain the reasons for the prescription of diagnostic tests, especially invasive ones;
- encourage the patient to express doubts or uncertainty;
- explain clearly why and when a certain medication should be administered.

How often do we deviate from this set of good practices? Every effort should be made to ensure that the patient and his family really perceive the physician's attention and consideration of the discomfort and distress associated with the disease. It is also important to avoid being too direct or excessively encouraging, especially if the timing is not right, and to avoid blaming the patient. Indeed, rather than judging the patient, the physician should try to appease any sense of quilt he may have. It is important not to show irritation or resentment if the patient or family members seek a second opinion, but to refer them to good quality centers. Patients who request a second opinion have often additional psychological needs (13). If one invites a patient to participate in a controlled clinical trial, one should explain the difference between this situation and the usual one, and also make it clear that if he does not wish to take part, there will be no reduction in the level of healthcare he receives (14).

It is also necessary to consider various organizational aspects of communication, for example guaranteeing appropriate space and time, and making sure the patient knows who his contact physician is and how he can be reached; in addition, given that a patient will often develop a deep sense of dependence on his physician, it is also essential to give him a reference telephone number, so that he need not feel abandoned to his own devices. One should not forget, however, that those who practice the medical profession also need support. Who supports the medical team? Those who work in a helping profession are notoriously subject to frustration and a sense of helplessness that may result in burnout syndrome (15,16). Characterized by a deep state of psychophysical exhaustion, burnout syndrome is the pathological culmination of a stress-generating process that is not adequately managed.

In 1847 The American Medical Association drew up the first code of medical ethics:

"The life of sick person can be shortened not only by the acts, but also by the words or the manner of a physician. It is, therefore, a sacred duty to guard himself carefully in this respect, and to avoid all things which have a tendency to discourage the patient and to depress his spirits".

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