COMMUNICATING BAD NEWS DURING AN OFFICE VISIT

TRANSmisión de malas noticias en la consulta

A. Guerra-Tapia, A. González-Guerra

"Who taught you all this, Doctor?"

"I learned it by suffering."

Albert Camus, The Plague.

It’s not always so easy to sit in the doctor’s chair. Accurate diagnosis and appropriate treatment—the objectives of the medical interview—are the result of previous training that requires effort, study, and dedication. To achieve these goals we are trained, first in medical school and then in hospitals during our postgraduate internship and residency, through a system that has been in place in most health care systems for decades. However, the most difficult moment in our medical practice is when we have to deliver bad news.¹

I asked one of my residents what she felt the first time she had to inform relatives of the imminent death of one of her patients. The moment came while she was on call in the dermatology department and a patient with terminal metastatic melanoma developed irreversible multiorgan failure.

"I wanted to hide. I couldn’t look the patient’s relatives in the eyes. I didn’t know what words to use. In the end, I cried along with them."²

It is quite possible that my resident had unknowingly hit upon a rather good way to communicate bad news: she was kind, empathic, and coherent. But if instead of having to use her intuition she had received specific training, she would have been more efficient and would probably have managed the situation with less suffering for all concerned. But we doctors are not taught how to break bad news. Developing this communicative skill involves answering a series of questions:

What Is Bad News for a Patient? Is It the Same or Different for the Physician?

Patients often come to us with considerable anxiety over a condition that we consider to be of little significance. It may be terrible for them, however, if the disease (which we know is not fatal, will not be transmitted to offspring, and is not contagious) has a negative impact on their future, that is, if it interferes with the fulfillment of their hopes in life. For certain ethnic groups, for example, the presence of barely noticeable vitiligo can constitute an impediment to marriage, although for the physician such a diagnosis may seem of little importance.

How Much Information?

Not all patients want to know; not all patients want to know everything. When we give bad news we must initiate a process of accompaniment. Insinuation, silence, and indirect truths can be used to minimize the impact of the news, allowing patients to construct their own new reality, one that they can live with. There is no set recipe that can ensure success. We professionals all develop our own strategies on the basis of our own perceptions and experience. No medical activity is more a matter of art and less a question of science.
We must remember that while patients have the right to be informed, they also have the right not to be. Too much information is just as dangerous as too little.

Defensive medicine often leads us to give exhaustive information that can be (unintentionally, of course) almost cruel. For example, to give information about statistical survival rates can be devastating for patients if they happen to be in a group with a poor prognosis. This knowledge worsens their quality of life and has a negative impact on the future course of their disease. Yet it is also true that incomplete information can keep patients from doing things they would have done if they had known the whole truth. Incorrect management of such situations can even lead to lawsuits.

What to do, then? Perhaps the 2 basic rules—the 2 pillars on which we can lean—are that we must always answer the questions that patients formulate (“Doctor, can this cancer spread to other parts of my body and kill me?”) and that patients should know everything they need to in order to participate in diagnostic and therapeutic decisions concerning their own disease (“We can use methotrexate, which might damage your liver, or cyclosporine, which can harm your kidneys. Both are effective, but they carry risks that we will have to deal with together.”)

Until quite recently, the sharing of information was governed by the principle of beneficence or paternalism—doctors themselves judged what their patients should know. Patients could thus be kept ignorant of the true nature of their disease, the risks involved, and their prognosis. While in some cases a doctor may still withold information concerning certain details that might jeopardize the recovery of a patient who is unstable, high-strung, or seriously depressed, nowadays the sharing of information is governed by the principle of autonomy—that is, patients themselves take decisions on everything concerning their disease and must affirm their knowledge and acceptance of any tests or treatments that carry risks by signing an informed consent form, now in general use.

The law establishes that the physician has the obligation to reveal all pertinent facts that might affect the rights and interests of the patient. This new way of treating disclosure is not, however, without dangers. Negative details are often explained in a way that is radical and almost cruel and that can leave patients submerged in a deep depression that in no way favors their health. We must not forget that alongside the right to information, Spanish law also recognizes the right not to be informed (Law 41/2002 on rights and obligations in matters of information and clinical documents).²

In order to adapt our practice to this law, we must take into account what patients already know about their disease, what else they want to know, and what their concerns and expectations are. For example, they may already know that they are going to die and what worries them is whether they may lose their mental faculties in the time prior to death. They might need to know approximately how much longer they have to live in order to put their affairs in order. They might want to know whether they can travel to a place they have always wanted to visit or if they can have sexual relations. Perhaps they are looking for the answers to a host of other questions of which we may be totally unaware. The information we share will not be the same in every case and should be focused more on the patient’s concerns than on scientific precision.

How to Do It?

Before giving bad news, we must consider 4 conditions that need to be met:

1. We need a complete and correct evaluation of the seriousness of the disease and its prognosis. Here there is no room for doubt or confusion.

2. We must consider the particularities of each patient, including such elements as personality, work situation, and economic status. Religious beliefs are an important psychological support and for this reason it is crucial that we be aware of our patients’ faith.

3. We must plan in advance how we will deal with the family. As family members may visit one by one, on different days and at different times, it is often necessary to give information individually to each of them. Each may interpret explanations differently and this can create confusion; it is thus useful to try to identify a sole leader or ally with whom to communicate. Some families put doctors on a pedestal and trust them completely. Some are uninterested and try to shirk their responsibility to care for the patient. Others are aggressive and make threats against the physician “if things go badly.” Denial of the problem and unrealistic hopes are a major obstacle. While we must nourish hope, we must not lie. There is also the “insenstive” family, the kind in which a member, upon hearing the words “you have a tumor,” will ask outright, in front of the patient, whether it is malignant, has spread, or may be fatal. This is where we must remember the right not to be informed. Not all patients want complete and direct information about their disease and they may prefer to be informed gradually. Such patients are the ones that remain silent and look pained in the face of their relatives’ questions. We must always remind such relatives that for the moment we will answer only the questions posed by the patient—the party concerned—and that we will speak to them at some other time, after the visit, if they wish. This reply, given politely but firmly, is usually effective. At the other extreme is the family that begs the physician to hide the diagnosis from the patient, or to lie outright, in order to spare the patient suffering. Of course, the law guarantees patients the right to be informed and we must provide the information if they request it explicitly. The best we can do is to omit some information, but we must never lie.

4. We should also consider the doctor-patient relationship, in which the degree of mutual trust, past experiences, and the participation of other professionals all play a role. While it seems that a strong doctor-patient bond facilitates the communication process, in some cases it increases the emotional tension and frustration of the physicians, who cannot spare their patient’s suffering. Moreover, technological developments and changes in the organization of medical practice have increased the number of professionals involved in managing a disease. Patients may receive the same information from
different sources—the dermatologist, the surgeon, or the radiologist. The coordination and definition of the role of each member of the medical team in delivering bad news thus becomes an inescapable challenge.

If all these factors are taken into consideration, we will achieve genuine communication—something more intense and personal than mere information, which could be dispensed by a robot. Our way of sharing information with patients, as the first step in the communication process, is a therapeutic tool and, like all tools, we must learn how to use it. The ability to communicate is not a gift, but rather a skill that can be learned.3

Practical Steps:

1. Analyze the context. Consider the questions of when, how, with whom, and how long to take. We must try to find an environment free of distractions and interruptions. We should be seated comfortably and close to the patient. At least 3 chairs are needed. One is for the patient, 1 for a relative, and 1 for the physician. We must not rush, so we should find an office that will be available for a reasonable length of time.

2. Consider the starting point. What does the patient know? What does he or she want to know? We should find out what the patient wants to know and provide the answers ("Would you like me to tell you more about your illness?") We must accept possible silences, evasive answers, or a refusal to be informed, but always offer another possibility ("I can see that you don’t feel like talking now, but I’ll be here when you do.")

3. Share the information. For this, we must do the following: a) Pay attention to nonverbal communication (gestures, postures, looks). Such clues arise from an emotional process. We should look patients directly in the eye, but we must be careful not to stare, as that might frighten them. Our facial expression should express seriousness, but not severity. Gestures should be kind, but not overly cheerful. We should speak in a neutral tone, with a firm voice that is neither authoritarian nor tremulous. Our manner should express confidence and be unhurried. We also need to be prepared for the possibility of patients taking their anger out on us, following the impulse to “kill the messenger.” The best response will be a serene and understanding one. b) Pay attention to verbal communication (words). Spoken words express a cognitive process. The most important elements here are our opening remarks, in which we formulate our main statements, questions, and answers. We must present the facts as objectively and concretely as possible. We can omit some details when the information poses an immediate and serious threat to the physical or psychological integrity of the patient (for example, when there is a risk of suicide), to public health (for example, the risk that a patient may inform the media that he or she has a very contagious disease, creating social alarm that makes preventive measures more difficult), or if there is a therapeutic need to do so. Difficult expressions and technical terms should be avoided, unless we are going to clarify their meaning immediately, for example: “pustules, that is to say, pimples.” Technical terms are an economical way of communicating among experts. However they are only useful to patients when they are understood; otherwise, they are nothing but empty and useless words. During the interview, comprehension should be checked regularly: “Do you understand what I mean?” c) Listen. It is a good idea to encourage patients to express their feelings and to listen attentively if they interrupt us. Listen with an attitude that is not judgmental or moralizing. Listening in this way, even to the silences, is known as “active listening” and is a very effective tool in human communication.

4. Empathize, don’t sympathize. We must try to imagine how the other person might feel without letting it affect us personally. It is good to be well practiced in giving support and to learn to empathize with our patients’ emotions without identifying with their anguish. Repeated failure in adapting to individual situations can lead to physician burnout.

5. Propose care and follow-up. We cannot change bad news, but we can offer positive advice and constant emotional support both to patients and to their families. There is always something that can be done—leave a door open to hope ("We can start eliminating the affected areas," “At least, the lymph nodes are not affected.”) We should try to manage uncertainty without setting specific time limits ("Time will tell how things are going."). We can also reinforce the role of the family as a resource of support ("You seem to be a very close family," “I can’t help noticing how concerned your children are about you”) and provide information about the social support available from support groups, patients’ associations, etc.

And finally, we always have our intuition to fall back on, just as my resident had hers. If there comes a time when you don’t know what to say, the best thing is to say nothing. Silence is often more eloquent than words. The ability to listen actively—to use everything at our disposal to understand our patients, to really pay attention to them and show it—can be more important than what we want to say and how we say it.4

As the old Arab saying goes, "He who does not understand a look will never understand a lengthy explanation."

References