

Communication and informed consent ... a story

E. Aitini MD

Someone knocks at the door.

My secretary pops her head in. “Excuse me doctor, the patient who tried to get in touch with you for an appointment is in the waiting room. Can I show him in?”

The door closes, only to open again thirty seconds later.

I get up and stretch out my hand to shake the newcomer’s. “Please, take a seat.”

He sits down in front of me. His facial expression is hard, and tense. His tone is angry, biting.

“There wasn’t even the suggestion of a meeting with me. I was told nothing. I only became aware of the diagnosis by reading my discharge letter from the ward where I had undergone surgery not only on my lungs, but which had also involved my heart. A *minor surgical procedure*,” he says sarcastically. “The surgeon contacted my wife and daughter and, without a minimum of compassion, told them that the situation was extremely grave and that probably I had about a month to live. You all pay lip service about how to communicate bad news, respect for patients, the attention that should be given to the psychological aspects ... but it’s all just talk, not something you actually put into practice.”

I feel the weight of these words, which are thrown at me in rapid succession almost without stopping to breathe.

An embarrassed silence conceals my discomfort, a surprise that I had not expected.

Alone, thin, his wife and daughter in the waiting room, his face dark, eyes resolute with no intention of giving up despite what he knows, however vaguely. “Until a week ago I hadn’t understood, or rather, no one had taken the time or trouble to explain my illness to me.

“It was not sufficient to know that I have cancer and that the situation was very grave. It wasn’t nearly enough.”

I feel unprepared, stunned. I have difficulty even choosing my posture and facial expression.

This more-than-justified aggression does not facilitate the start of useful communication, and I realize that my many years of announcing and re-elaborating bad news can only partly help me in this situation.

I try to understand what he expects of me. Does he want me to complete the information given to him a few days before by a surgical colleague regarding the characteristics of his illness? Illustrate treatment proposals, times, methods, collateral effects? Does he wish to continue to express his anger and irritation?

Using hand gestures and eye contact to accompany my words, I assure him that we have all the time necessary

to talk and that I am available and willing to listen for as long as he wants.

This seems to calm him. His tone of voice becomes slightly less aggressive. “Naturally, you understand how this has affected me. As soon as I arrived home from the hospital, I spoke to my family doctor who came to see me immediately. At that time I still didn’t know that my wife knew about the state of my health, and I was worried about how I could break this terrible news to her. However, when I started talking to my family doctor, my wife was present, and I realized that she already knew everything, or rather, she knew the dramatic news regarding my survival. My doctor advised me to get an appointment with you. Now, what can and should we do?”

The atmosphere in my office is now more relaxed; at least that objective has been reached, considering that talking with a patient who has advanced lung cancer about therapeutic proposals is not easy or simple when you factor in the results usually obtained. However, I begin to re-elaborate the bad news relating to his diagnosis and to describe the clinical experiments currently being carried out.

The patient is an educated man and completely understands the concepts of standard therapy, therapeutic protocol, and clinical trials.

We talk for a long time about various aspects of the treatment, the possible discomforts it can provoke, the effects it can have on his working life, his family life, and his relationships.

He asks if his wife and daughter can join us ... which they do. The meeting continues for another twenty minutes or so, and the patient accepts to take part in a controlled clinical trial.

A long time afterward, he tells me that it took him some time to understand the type of person that I was—because, from our first meeting, I tended to express cautious optimism. I offered possibilities and was very informal.

He felt the need to establish with certainty that I wasn’t excessively optimistic and that I would always be totally honest with him.

I had quite a few doubts about the matter of honesty for quite some time (and also with some difficulty), asking myself certain questions—such as what was the probability of survival or the percentage results of the therapy?

I have to confess that I have always tried to move the vision to other aspects, because presenting percentages cannot communicate certainty. Today, therefore, I still try

to involve patients more in the therapeutic program and everything that can be a consequence—advantages and disadvantages. Maybe he understood that percentages weren't that important for me in his case, or maybe he simply didn't like to talk about them.

At the end of our meeting, getting up to leave, with the date to begin the treatment fixed, the patient goes to the window and for a few moments seems to study the fir and birch trees running along the garden outside the day hospital. These are the first days of a mild November.

"Do you remember, doctor, when the schools started in early October? For years, those days marked the temporary end of my days playing in the sand beside the river and the beginning of an obligatory existence with exercise books, pens ..."

Naturally, I remembered that time only too well; it had marked each of my school years from nursery to high school. However, it was not that memory that gratified me; it was knowing that, for the first time since he had come into my office, my patient was talking about something other than his illness, taking possession of a memory, banal maybe, but part of his life.

"I was a bit of a rebel as a student; so much so that, when I was sixteen, my parents had to send me off to college. My years at university were much more congenial; 110 with honors in the first session in fourth year."

He leaves my office thanking me.

He is extremely precise in completing all the bureaucratic procedures involved in the controlled clinical trial.

When he returns the completed informed consent form, he asks if he can have a word with me on the subject. It seems quite normal that a teacher of philosophy has some questions or maybe only observations on such a delicate matter.

"I've read with great attention all the documents, and I think I've understood everything, even though I do think that some terms could have been replaced with easier-to-understand synonyms. In fact, I asked myself, 'Do they treat

only university graduates in that department?' Apart from the validity of the signature at the end of the form next to yours, how can you be sure that people have completely understood what they've signed? And if the information is not complete, the informed consent is not valid."

I recall the numerous meetings I attended, during which everyone had tried to contribute to solving that problem. I remember one of my colleague's proposals, which was to have the patient write down on a separate sheet of paper how much he or she had understood of the documents supplied and then to talk with the person again. We needed to explore their symbolic universe through communication, not only speaking, but also listening, convinced that this is part of the therapeutic process.

The patient reacted well to the therapy with a new biologic drug, and the collateral effects were contained. At the end of the program, we were able to verify a complete remission.

That spring passed, and then five more. Against all the odds, my patient got his life back.

Yet, every time, at each check-up, in different ways, he expressed his frustration, indignation, fear, uncertainty, and many other sentiments regarding the information given to his wife and daughter before it had reached him.

Legally, objectively, no one can deny or refute this right of a person who is ill. However, those concepts have never given me certainty, and they lead me to repeat that, if ever there were the need, no two lives are the same, just as no patient is comparable to another, each having the right to personalized communication with all the infinite variables that make each one of us different from another.

CONFLICT OF INTEREST DISCLOSURES

I have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and I declare that I have none.

AUTHOR AFFILIATIONS

*Department of Oncology, Suzzara Hospital, Mantova, Italy.