TO TELL OR NOT TO TELL THE TRUTH TO CANCER PATIENTS

BOGUSŁAW MACIEJEWSKI

Department of Radiotherapy, Cancer Center, M. Skłodowska-Curie Memorial Institute in Gliwice
Head: prof. dr hab. B. Maciejewski

There are many physicians by title, but very few by calling
Hipokrates

The physician-patient relationship is a significant component of the treatment strategy. Communication constitutes perhaps the most important process in medicine. Among various aspects of the direct relationship between the physician and the patient, conversations with the patient are among the most important. It is the duty of the physician to supply the patients with explanations. However, cooperation between the physician and the patient is not merely a question of mutual goodwill and readiness. It also depends on certain other factors, the nature of which may be associated with, for instance, knowledge and competence, i.e., the professional training of the physician for his work with patients. It is increasingly evident that medical knowledge must be supplemented by basic knowledge of psychology, so that the physician may make fuller use of the therapeutic power of words to enlist the patient’s psychological reserves.

One of the most popular and idealistic forms of the physician-patient relationship in modern society assumes that a good doctor takes care of patients with very serious diseases and provides treatments that lead for a cure. Such an idealistic model rarely happens in reality. Eliot Freidson pointed out that there is a conflict of interest, expectations and knowledge between medical professionals and patients. Patients prefer doctors who they can trust and also receive answers to their questions in a professional manner. It seems that this last aspect is crucial for patient engagement in the treatment process.

The physician-cancer patient relationship constitutes a most complex problem, and one of the most difficult aspects of this problem is sincere communication with the patient. Despite the passage of time this matter remains one of the most controversial questions. Among the main dilemmas is whether the patient should be told the truth. Most American physicians are willing to inform the patient who, they assume, has the right to learn the truth and decide whether the family should also be informed. Physicians in Europe, including Poland, are more in favor of telling the family first.

Both approaches raise many doubts, uncertainties, and moral dilemmas. Should the cancer patient be told the whole truth even when the disease is advanced and there is no chance of a cure? Or should the patient be cheated, should the seriousness of the situation be minimized by explanations that there is still hope, that within days the patient’s health is going to improve, while telling the whole truth to the family? Is such an attitude an expression of cowardice, mercy, conformity or pity? Is withholding the truth about the state of his or her condition from the patient a lie, a choice of a lesser evil or an act of grace? How can we separate truth and honesty with respect to the patient, who trusts us and listens with hope to our every word? According to what
criteria should the physician decide which approach is best for the other human being? Where is the boundary between the truth and the patient’s wellbeing? If someone were to ask whether the truth should always be expressed and never held back in the face of cancer, it would seem that absolute answers containing words like “always” and “never” would not fit.

It is hard to talk about the relationship between the physician and the cancer patient in Poland on merely moral and ethical grounds, without taking into account the political, social and cultural conditions that have influenced this system for decades. The notion of the summum bonum the highest good, and primum non nocere have become fundamental guidelines for Polish physicians, including oncologists. The use of Latin in Polish medical practice (histopathological diagnosis, patient records and autopsy reports), although it arises from tradition, has posed from the beginning a barrier of secrecy before the patient by coding information in an unknown language. This, indeed, has an impact upon the physician-patient relationship, and is the source of uncertainty, apprehension, fear, and suspicion. It is very seldom that a patient asks a physician to interpret and to explain Latin expressions.

At the beginning of the twentieth century Polish medicine was strongly influenced by well-known medical schools in Vilnius, Cracow, Vienna, Berlin and other centers with a long tradition of interest in research, anatomy, histology and humanitarianism. Medical ethics were highly respected, and physicians together with lawyers and teachers were on the highest levels of the social hierarchy. These traditions had an enormous impact on the physician-patient relationship; patients were treated with special care and dignity, and all patient rights were respected.

During the post-War period, with the introduction of Communism to the political stage in Poland, the good of the individual was replaced by the good of society, and the slogan “each one receives relative to his needs”, introduced by Communism, became an empty promise. A free health care system in general and free oncology services in particular were declared; however, this only apparently made medical assistance easily accessible.

A centrally managed administration, financing and organization of health care with low-budget expenditures led to a 40-year decay of the health care system from which it has been hard to recover. The patient frequently was treated mechanically and, although receiving treatment and medicines free of charge, had practically no possibility of expressing his or her needs despite the fact that this was legally guaranteed. Within the Communist system physicians were produced en masse, at first with assigned employment. During the first decades after the War their contact with the world of medicine was almost nonexistent. Low wages, generally low even today, and difficult living conditions for both physicians and patients had a negative impact on the relationship between the two groups. A Physicians’ Ethical Code did, in fact, exist, but it was far from perfect; and significant gaps in legal regulations seriously compromised the modest possibilities for respect of patients’ rights. Physicians and lawyers, similar to the other members of the intelligentsia, were pushed by the political system to the lowest levels of the social hierarchy, although society continued to hold them in high regard. This fact may to a large extent, be ascribed to the authority, knowledge and ethical standing of old professors who lived though the War and passed on their moral and humanistic values to the next generations of physicians. In view of such serious restrictions, it is surprising that the high educational level of physicians was maintained, so that their practical professional ability and knowledge did not differ from those of their colleagues from Western Europe. In such a social situation and with health care generally available (although it was of low quality), ethical, cultural and social differences generally vanished, and their impact on the physician-patient relationship disappeared. This is surprising considering the fact that although Poland has returned to a democracy, the centralized system of directory and financial distribution has remained despite the obvious need for change.

Disease remains a shameful matter. Cancer has been and frequently still is thought of as a death sentence, but such opinions have been changing over the last few years. Limited access to physicians, although the medicare system warrants the opposite, bad hospital conditions and shortages of drugs all have resulted in patients’ mistrust of prescribed therapies. A sociological survey indicated that as many
To tell or not to tell the truth to cancer patients

as 42% of those investigated declared that they “would go to the doctors as the last resort”, 63% used their own or their friends’ experience, and as many as 29% just waited for their symptoms to disappear. One-fifth of the people investigated used homeopathic remedies and chiropractors. Women still reluctantly participate in the national breast cancer prophylactic program although it is free and widely advertised. However, such a situation should not be surprising because contrary to constitutional assurances, the number of available medical procedures is still limited and the waiting-time for admittance to specialist is often very long.

Some studies indicate that as few as one patient out of five evaluated his or her contact with physicians as “good”. More than half considered the information obtained to be “insufficient and incomprehensible”. Another sociological survey suggested that the most effective psychological influence on the patient was the so-called egocentric communication style. This consists of autonomous physicians imposing their decision concerning their treatment upon the patient. Not having much of a choice and worried about possible loss of treatment, the patient often consents to the suggested treatment without further discussion or full knowledge about the procedure. In fact, the physician-patient relationship is asymmetrical and does not include a partnership, at least at the professional level, but it should proceed with no doubts existing at the emotional and psychological levels. The patient should be treated as a human and not as an object.

The physician-patient relationship has been slowly evolving over the last few years since Poland has become a democratic country. This is ensured by the revised physicians’ “Code of Ethics” as well as by the mandatory principle of informed consent. The empty slogans of “social care” and the old-fashioned medical insurance system should be infused with meaning to achieve the aim of providing meaningful health care. Meanwhile, a patient admitted to a doctor has to wait through the bureaucratic paper-work, including the types and codes of services are completed by the doctor. There are still many discrepancies between the declared and real-life accessibility of the health system. People are keen on the fast introduction of the patient-physician model proposed by Hohen der as “mutual participation”, in which a patient is a partner with the doctor and closely collaborates with him.

The political, historical, social and cultural circumstances of the physician-patient relationship presented here have influenced and are still influencing the answer to the question of whether the cancer patient should be told the truth. Some journalists report that patients in the United States are always told truth and such practices should hold in Poland. My impression from a number of visits to the US, however, is that this is not always the case, and the principle is not always upheld. Also, I doubt whether it would be proper to simply transfer this practice or legal principle to Poland. There is little probability that Americans are different from Poles and do not fear cancer. The scope and justification for telling the truth may differ, e.g., legal, economic, property matters, etc., but I believe psychological questions are rarely, if ever, considered.

There is much work to be done in Poland before people start to talk openly about cancer and discuss the disease with family, friends and specialists. For the last few years knowledge about cancer has been popularized by mass media but not too often. Besides the financial and organizational problems that have to be solved, there are many psychological and sociological customs that have to be changed, and all these activities need time to progress. In Poland as in other countries there are philosophical and ethical aspects of the doctor-cancer patient relationship that cannot be easily related to doctors’ unwillingness to start open communication with patients.

Everyday life again and again demonstrates to us that the cancer patient who asks about his or her condition and demands the truth, stating that he or she is strong and capable of withstanding anything, is in fact expecting denial, not the confirmation, of his or her apprehensions. Should we, then, tell the truth concerning the diagnosis? What verbal arguments does the physician have to aid him or her? In oncology many words like “if, maybe, and probably” are still used; the patient’s cure is simply expressed in probabilistic terms. Having many doubts as a young doctor I asked my mentor, a famous polish oncologist, when I should tell the truth to the patient. He answered that the truth can and has to be told only if the doctor’s knowledge and experience allow a treatment to be offered to the patient (e.g., surgery) which may lead
to a permanent cure. The strength of a doctor’s persuasion is usually enormous, especially when the patient trusts him.

What is the physician’s position with respect to the patient, if the physician offers only a chance, while homeopaths and chiropractors would freely promise to cure the patient with certainty? In what way should the physician behave toward terminal cancer patients, and how should he or she prepare the sick person for death? Even when given the opportunity of learning about one’s approaching death, a human being generally tries to avoid awareness of its inevitability. Is the physician to break this natural defense mechanism by telling the truth and depriving the patient of his or her hope? Who needs patients to be aware of the existence of their illness? Cui bono? The patient may die within a few months, but there are vastly different ways of living through this last period: depressed and in black despair, expecting the final stroke day after day; or living in a rather peaceful mood until the end. Seneca said “it is not death that we fear, but the thought of it”. Often times the escape from the consciousnes of death is a result of anxiety about the physical suffering associated with dying. The dominant role of ensuring the patient’s proper physical and psychological condition falls to the physician. Everyone feels safer and more certain knowing that he or she has someone who will help until the very end. I have had over 10 000 patients in my oncology practice, and only a few of them quietly and rationally prepared for death. I have witnessed many psychological breakdowns and have had a number of suicidal cases. However, at the opposite end, there was a group of very advanced cancer patients who were permanently cured. They passed through the doubts and only a few took up a conscious fight. We have many doubts, and we are not certain what the truth is in the end. The question of telling the patient the truth should also take into account the present situation in cancer research, which is decisively different from the advancement in, say, nuclear physics or space research. In the latter two cases the knowledge available is sufficient for the achievement of the solutions sought – e.g., space flights. What is now known about cancer cannot, however, constitute a basis for the establishment of a program that would offer a solution to the problem of prevention and treatment of this disease. Although research is actively continuing and progress is notable in, for instance, genetics and tumor biology, at the present stage of development the prospect of success is hard to determine. The complex nature of this disease constitutes an extremely difficult obstacle. Cancer is not a single disease, but it is found in many diverse forms, the nature of which are not yet precisely known. This makes any planning particularly complicated. Thus, one cannot foresee to what degree progress achieved with respect to one type of cancer can be helpful in fighting ano-
ther form. Only full control of this disease would, in my view, give the physician the right to tell the patient the full truth.

We still have a long way to go in fighting prejudices, preconceptions, uncertainties and stereotyped convictions. Thus, no single answer exists to guide the form the physician-patient relationship should take, nor is there a simple answer to the question of whether or not to tell the cancer patient the truth about their condition. There are no racial or religious prejudices among physicians. We do not consider the patient on the basis of what he or she represents, where he or she comes from or his or her educational and social status. Whether he or she is a VIP or a simple citizen, the patient’s condition is the decisive factor for a physician’s actions. The problem of telling the truth or withholding it and of legal responsibility depends on the patient’s good and still has to be solved by the physician with the aid of his or her own conscience.

REFERENCES


Received: 5.10.2007 r.
Address correspondence: 44-101 Gliwice, Wybrzeże Armii Krajowej 15