Truth-Telling Information and Communication with Cancer Patients in Turkey

Nuket ORNEK BUKEN, MD, PhD.*

* Department of Deontology and Medical Ethics, Hacettepe University, Faculty of Medicine, Ankara, Turkey.
e-mail: nuketbuken@hotmail.com

Summary

Within the scope of medical ethics, the subject of "telling the patient the truth" has undergone some important changes in our country in the last years. It cannot be denied that the information brought to light in the field of medical ethics has participated in the change that has been experienced in health care services in general and in physician attitudes towards cancer in particular. This change is in the form of patients taking an active role in the diagnosis and treatment for their illnesses and changing from physician-centered to patient-centered physician-patient relationships. In medical conditions such as cancer, illnesses in their terminal phases, and fatal illnesses, physicians experience a dilemma of whether or not to tell the truth. The inclination among physicians for telling the patient the medical truth can be characteristic of the country's health care policies and traditional physician attitudes, in the same way that differences can be seen in every country's own ethical, social and cultural structure. In addition to this the method of informing patients about their cancer diagnosis will also change with the patient's characteristics and the coping strategies that they use. The case study that will be presented in this article will discuss telling the cancer patient the truth with related ethical, social, and cultural elements, and some conclusions will be reached by evaluating the ethical-legal process and practical situations.

Key Words; Medical Ethics, Truth Telling, Physician-Patient Relationships, Physician Attitudes Towards Cancer, Ethical-Legal Process.

Introduction

Telling the patient the truth ensures that the correct information is given and the correct choice for the patient is made. Explaining the truth to the patient is more of a very complicated process than simply giving information. In this process the physician's attitude is important; a physician who has developed communication skills and knows approaches for informing can give desired messages that give the amount of information that the patient wants and when the patient is ready. The subject of truth telling may vary from country to country and culture to culture. The reason is reflected in different ethnic roots, religious beliefs, cultural differences and legal regulations (1, 2, 3)

Case Study

A 52-year-old male patient came to the emergency services with a complaint of involuntary movements that had begun with his left foot and spread to his leg. A presumed diagnosis of epilepsy was made in the neurologic evaluation and he was admitted to the hospital for further tests. The patient's EEG results were consistent with temporal lobe epilepsy and a total brain MRI revealed an edematous mass localized in the right temporo-parietal area. After consultation with the neurosurgical staff a decision was made that the mass was operable. After necessary preparations the patient underwent surgery, the mass was removed and sent for pathologic evaluation. The result was a adenocarcinoma metastasis with the lung as the probable primary site (4).

The patient was a young, lively architect. His one bad habit was to smoke nearly a pack of cigarettes a day and to drink a small amount of alcohol socially. He had played basketball until he was 30 years old and regularly played tennis. His wife who loved him very much hid the diagnosis of cancer from him. The guidance of the neurosurgeon, who explained that a metastatic cancer's prognosis is very bad, had an important part in this decision. The patient was told by his wife and physician that he had a blood clot that had been treated with surgery. Because no pathology was seen on chest films and at the patient's family's

insistence no further investigation was felt necessary and the patient was discharged. After surgery the patient's speedy recovery improved his morale. There was no hypertension, diabetes or secondary illness that could have caused the blood clot. The event was forgotten by everyone and no one was unhappy (4).

Seven months passed. Symptoms of coughing and bloody sputum appeared in the patient. A pulmonary medicine specialist was seen. This time a mass was seen on the chest films that were taken. A biopsy obtained from the mass with bronchoscopy revealed the adenocarcinoma of his brain metastasis's primary site and the patient was sent to an oncologist. Before the patient was seen by the oncologist he was warned by the patient's wife and the neurosurgeon not to tell the patient that the mass removed from his surgery was cancer. Whatever needed to be done to keep this information from the patient was to be done. The oncologist scathingly explained to the patient's wife all of the wrongs that were done in the dramatic side of this scene of excessive pressure. He told her that the patient still had a chance at recovery because there was no recurrence in the brain and there were no other metastases found outside the lungs. Of course he added that if the mass had been found in the lungs 7 months previously and treatment had been begun his treatment chance would have been higher than it was then (4).

The patient's wife did not like the warnings or recommendation from the oncologist. She was only concerned about how she was going to explain to her husband what she had kept hidden seven months previously. She tried to place all the responsibility on the neurosurgeon who did the surgery. However the surgeon had a relationship with the oncologist and told him the patient's wife had insisted that he keep the diagnosis secret. As a result the sides could not come to an agreement. The patient, who had an operable lung tumor with no other distant metastasis and no recurrence of brain tumor seen on the last MRI, was never seen by the oncologist and disappeared. The reason is probably because the patient's wife found another oncologist who was willing to keep the secret and condition from the patient. In fact in this entire event the patient has been out of sight. What is seen is his wife who has the authority to make decisions on his behalf, the physician and the patient's records.

Evaluation of the Case

It is necessary to emphasize four important points in this case. The first of these is that the patient was not told the truth and the probable results of this. In our case study, without determining how the patient would confront and react to a diagnosis of cancer by a professional, the truth was hidden from the patient by an amateur making a completely emotional decision. Here keeping the diagnosis secret from the patient was a situation that would hold someone responsible for the results and which needs to be given legal sanctions. This attitude that is said to be only for the benefit of the patient can never be considered right. The process that kept the patient who had possible treatment from receiving that treatment must absolutely be given legal sanctions.

In the physician-patient relationships in our country the one who is primarily responsible for making decisions about the patient's treatment is not the patient but the patient's next of kin. In particular when the diagnosis is cancer this situation is very clear. The family members who see that they have the authority to make decisions in the patient's place give their motives as the patient's morale, that is would negatively effect them psychologically, or that their condition would worsen if they were told their prognosis. Essentially the physician's negative attitudes also play a role in this understanding becoming taking hold. Sometimes the diagnosis is known by everyone except the patient but the patient is not able to receive this information without requesting it.

An important second point is the condoning of this situation by the neurosurgeon from the beginning where his decision to operate was made not by the sufficient and autonomous patient but without his knowledge by someone else. The patient's right to respect for his autonomy was abused and the physician's responsibility to get informed consent was not practiced. On the other hand the patient had the right to know the whole truth about himself. Interventions during medical care and decisions that are appropriate to ethical concepts and values require that the physician has great care and sensitivity. In fact the original problem, beyond what type of method and the kind of approach the physician should implement when faced with ethical problems, the medical pro-

fession's ethical side in its actual form is the endeavor and goal to pass on life.

The third important result is knowing the patient's treatment to leave him without it. The situations that need to be questioned is the search for the primary site in the period after surgery and the interference of the patient's wife's decision on giving necessary treatment to the primary site found in the lungs seven months later. There was an obstruction in the patient's meeting with his physician and making his own decision about treatment with his own free will.

The important final point however is the decision made by the neurosurgeon who removed the brain mass in the first surgery without consulting a specialist, an oncologist. The prognosis was wrongly interpreted and perhaps the patient's next of kin was wrongly directed. Both when the diagnosis was determined and when the neurosurgeon did not request consultation from an oncologist and a pulmonary disease specialist in jointly planning the patient's treatment program the attitude was one inappropriate to showing respect for the specialties. In this way a treatment process based on cooperation was obstructed from the beginning. This can create a situation where the physician is held legally responsible.

Physician Attitude towards the Patient with Cancer

Physician's attitudes towards patients with cancer have changed rapidly in recent years. In this change there has been a change in physician-patient communication models and an important patient-centered look that the field of medical ethics has brought to clinical medicine. Two separate negative attitudes have been defined for physicians who care for cancer patients. The first is the excessive guardian, protector, and paternalistic attitude in that the physician actually tries to prevent death, and is a denial of death. The other attitude again at the foundation is a denial of death, is the attitude of the physician who escapes from, distances himself from, the patient (5).

In oncologic illnesses telling the patient the truth is a process that is much more complex that simple information giving and requires effort. In cases such as cancer, illnesses in the terminal phase, some neurologic diseases, and AIDS, physicians and other health care workers experience dilemmas, arguments and problems on the subjects of whether or not to tell the truth or how to do this and who should inform. Like there are those who defend that the patient should be told the truth no matter what the situation there are also those who defend that the truth should be withheld to not cause harm. The thinking underlying the not telling the diagnosis to the cancer patient is the belief that the cancer patient will not be able to endure this information, that they will experience emotional problems and that it will negatively effect the prognosis of the illness. However informing the patient at every phase of the illness is important for patient adaptation. The foundation is the establishment of a participatory kind of communication that includes active listening to the patient and empathy. The subject of telling the patient the medical truth is effected by country's' sociocultural and economic structures and by medical practice and the form of health structures.

It is important how the patient and family, physician and ancillary health care personnel and society perceive the word cancer. Attention that focuses on the word cancer can do more than disturb the patient and the patient's next of kin. Today cancer is still the most feared disease in society because a significant part of society sees AIDS as an illness of those on the edge of society and not affecting them. In general, although incorrect, the word cancer is equated with death. The majority of patients and, in general, societies are tied to this wrong perception, are afraid of cancer and show similar reactions. However the truth is that the same type of cancer develops differently in different patients. The other side of this argument in spite of the fact that the course, complications and therapy are different in many different illnesses, it is acknowledged that cancer that is gathered under one disease name causes deep fear in patients and their next of kin and is equated with death. The duty of the clinician, without considering these exceptions, is to carefully analyze the person's cancer awareness and calculate their expectations. It is obvious how a person who has information gained from society by word of mouth and individual examples will respond to the diagnosis of cancer. Even if this person is in the

very early stages and has a good chance of recovery from the kind of cancer they have developed, they will be negatively effected by the diagnosis. For this reason it is important to inform. The life expectancy is much higher for patients who embrace life and do not lose their will to survive.

Some Inferences about Truth-Telling in Our Country

Together with the characteristics of the physician-patient relationship and the expectations of the physician and patient, is the physician's duty and responsibilities, the process of informed consent and ethical medical practice and whether or not it is consistent with legal standards. In this relationship, the goals of the physician-patient interaction, the physician's requirements, the role of the patient's values and the concept of patient autonomy are all extremely important.

In solving clinical ethical problems in our country the question can be asked of whether or not the guiding ethical principles' priority and evaluation is different from those in the West. Can the practices in the West that gives priority to the developed knowledgeable participation and the principle of respect for a person's autonomy as a part of that be left to the interpretation of one's culture and practices? When we look at these questions from the aspect of basic ethical principles we can say that it is necessary to agree on the concepts of universal values like respect for an individual's autonomy that has developed in the West. We cannot leave to the culture's own interpretation and practices the need to examine basic ethical principles; that is, the evaluation and structure of ethical principles in our country related to our subject will not be any different that in the US, Canada and Western European countries. However there can be a difference in the prioritizing and weighting of the principles. For example the principles of “do no harm and beneficence” take priority for us over the principles of “respect for autonomy and justice” because of the structure of society, our customs and traditions and our sociocultural structure. This situation also creates the substructure for hiding the diagnosis of cancer from patients. In that manner in oncology clinics that we have often witnessed where everyone knows the patient's diagnosis and the treatment that will be given except the patient not even one patient (even if they request) will be told the truth. The majority of the patient's next of kin (as in our case study) take an active role in the process of hiding the truth. As in other countries that have a clear paternalistic societal structure, in our country also the physician is generally the authority figure in the physician-patient relationship. In this way whether it is natural or not the relationship between physician and patient, rather than collaborative is more one directing the other. Because different examples of this type of relationship are often met in society in every area of life and it is something that has developed based on that, this type of physician-patient relationship is not regarded as strange and the majorities do not see a need to change the existing system. The majority of patients in our country during medical treatment are not in the position to be “knowledgeable and effective participants in the treatment,” they are people in the position of not knowing who gives them information about themselves or with which physician's treatment at which level they are responsible for or what their rights are. Conditions like cancer which require a continuous collaborative relationship between the physician and patient do not change this fact. Patients try to get information about the clinical diagnosis and treatment process from their nurses or interns or residents. However particularly in chronic illnesses it is a foremost condition for a “collaborative” type of relationship where the treatment method is chosen taking into consideration the patient's values and that the patient is informed about possible risks, the patient requests this information, makes the most appropriate choice based on their own values and knows their own rights in this process, requesting they be honored when necessary. In our country the patient accepts that the physician is the “authority” with information, experience and expertise. The patients do not think they have the right to ask questions, but that they have to answer every kind of question that is asked and that they are forced to accept every kind of treatment the physician recommends. Requests for information and desire for active participation in their treatment is minimal. Physicians also consider that patients generally have a lower sociocultural and intellectual level and for this reason there is no place for this time-consuming practice of informed consent, and continue the belief that they will always make the right decision for

the patient and that the social security system that the patient is bound to does not offer many choices for treatment. For this reason it is understandable that the situation is that most physicians are not skilled in cooperating with patients, in establishing or maintaining a collaborative relationship with patients and that patient also do not have any expectations. When a request for a relationship like this does not come from patients it is important for the physician to initiate it. However before everything the physician must believe that this kind of relationship is beneficial and that there is value in helping the patients be effective participants (6, 7).

Data from a Research Study Related to this Subject

Data from a limited research study done at Ankara University Medical Faculty Ibn Sına (Avicenna) Hospital related to the approach of physician candidates and physicians on the subject of informing patients about their diagnosis of cancer will shed light of the situation in our country. Although this study was only done at one hospital, because it is a referral center and teaching hospital it would not be wrong to say that it reflects the attitudes of physicians in our country. This study was done with a questionnaire given to 58 physicians and 150 medical students. In addition interviewing face-to-face 82 newly diagnosed cancer patients on different services their level of information was determined. At the end of the study it was seen that 52% of the physicians and medical students have a "protector, guardian" approach to the cancer patients. Also it can be accepted that the medical students having a paternalistic approach is an indicator that this attitude will not be changing in the near future in our country. In the face-to-face interviews with the patients the facts show that the patients had been informed at a level far below that of Western standards, 52 of the 82 patients did not have information about their disease (63.4%). It was seen that the patients who had a high chance of recovery had been informed at a higher rate than the others. The level of informing patients also increased with an increase in the patient's socioeconomic level and educational level (8).

When looking at the research results on the subject of truth-telling and general practice what are the reasons for the differences in the situation in our country from that in Western countries? Although there are signed international agreements at various levels in our country it can be said that the necessary legal foundation and control does not exist currently on this subject. On the other hand it seems that it will be difficult to change the "protector, guardian physician attitude" that our cultural and social foundation brings and that is supported by the Islamic religion's "fatalistic world view." In fact there is a large number of physicians who insist that it is not right to say "worrying" things to people with terminal illnesses. In addition during medical education physicians are not given sufficient information about "giving the patient bad news" and "informing the patient."

Legal Regulations in Our Country about Truth-Telling

When looking at legal documents related to truth telling in Turkey, we see that the decision is a sovereign understanding that is left entirely to the physician. However from the point of view of principles of medical ethics we see the principle of beneficence and doing no harm are given weight in evaluation.

When we look at these legal regulations' related articles that support the physician's paternalistic attitude, we can say that it is important that the 14th Article in the **Turkish Medical Deontology Regulation** is related to truth telling. According to this article it is necessary that the patient be clearly told their diagnosis and the necessary precautions that should be taken related to their diagnosis, however the disease's bad prognosis should be hidden from the patient. If the patient desires the possibility of the patient's abandonment should be considered and the diagnosis can be told to the family.

In the **Patients' Bill of Rights**, dated 1998, the 19th Article that is related to truth-telling, the decision about whether to tell the patient the truth is left entirely up to the physician. It states that *"When there is a possibility of worsening the patient's illness with a bad effect on the patient's spiritual make-up and when the course and result of the illness is serious it is advisable that the diagnosis be kept hidden from the patient."* In addition when the patient does not request it this kind of diagnosis is told to the patient's family.

Conclusion

Telling the truth is just one step in the physician-patient relationship and in the process of communication. There is an effect from many other factors in the cooperation of the patient with the physician in the process of mature communication. Telling the truth is an important step in treatment and we can never exempt ourselves from the responsibility to be honest with our patients by looking at our culture and our special situation. The most important condition of physician-patient relationships is mutual trust. The physician who makes important life affecting decisions for the patient should never be misleading. At the foundation of “collaboration” between physician and patient we again see the concept of “patient rights” in clinical medical activities emerging as a product of the relationship that is formed. When physicians tell patients the truth when making decisions related to their own bodies and lives they recognize their rights and human values and show respect for the patient’s rights. The cancer patient’s responsibility for his own health is closely related to his education, cultural situation, and economic status. For this reason patient/patient’s family education in society as well must be in the manner that will develop their level of responsibility for their problems and behaviors and will ensure that autonomy is a concept that is perceived by the patient.

In that case the subject that needs to be considered should not be “Should I tell the patient the truth?” but “How can I give the news in an appropriate manner?” It is necessary to give bad news in a manner that the patient can accept the information about the illness and by preserving hope. The physician giving the message that he/she is willing to talk, when the patient is ready to learn the truth about the diagnosis, giving the amount of information that the patient wants, being patient and tolerant, being honest, understanding the patient, are important in giving a guarantee to the continuity of the relationship.

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