

Informing the Patient: “The Whole Truth and Nothing but the Truth”

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Introduction to the Case: Dr. Ruth L. Fischbach

This year, for the first time, the Center for Bioethics has chosen a theme to carry out through the entire year. That theme is *truth telling* – a seemingly easy yet complex and at times difficult action to carry out. What is truth anyway? Is it in the eye of the beholder? And how much truth is it necessary to tell – all the truth and nothing but the truth? And what about the patients who may not want to hear the truth? Are they obligated to be told? What about cultural competency, beneficence, and non-maleficence?

We believe that truth telling is the essence of trust, yet medicine has not always subscribed to truth telling. Even in the last 50 years we have seen the pendulum swing from Novak’s study in the 1970s, where he found that 90 percent of physicians NEVER shared the diagnosis of cancer with patients, to his replicated study in the 1980s, when almost all of the physicians DID reveal the diagnosis, no matter what the circumstance. In the subsequent years, we have become more circumspect, appreciating that there may be extenuating circumstances when telling the absolute truth is not an absolute requirement

Dr. Kenneth Prager will present two cases with which the CUMC Ethics Committee has had to grapple. Both demonstrate the exquisite difficulty involved in knowing just how much to tell and when to tell it. No one can take us through these cases better than Dr. Prager.

Presentation of the Case: Dr. Kenneth Prager

In the first case described by Dr. Prager, a 70-year old Egyptian man only able to speak Arabic presented with evidence of bone cancer. A doctor was called to perform a biopsy to confirm the diagnosis but refused when the patient’s family told the doctor that they did not want the patient to know his diagnosis. They feared that the patient was emotionally weak and would lose his will to live if he knew what he was faced with. The family felt that only harm would come to the patient through the discussion of his diagnosis, and even the mention of the word “biopsy.” The family was not permitting a translator and, therefore, the doctor was forced to communicate via the family.

An Ethics Consult was called to discuss the family's wishes that the patient not be told of the possibility of cancer if the doctor went through with the biopsy. The Ethics consultant met with the patient's son, two nieces, and a nephew. Dr. Prager explained to the audience that the decision of who speaks to and for the patient is a very complicated issue that occurs frequently within hospitals. He emphasized that ignoring the family's wishes and speaking directly to the patient could be a violation of the ethics of that patient's culture. To do so, the physician would be denying the family their right and filial duty to protect their elder, as well as exposing the patient to information that to him is culturally unacceptable.

The patient's nephew worked as a healthcare worker in New York State and understood that the customs of the family were not the accepted practices in the US. He was able to explain to the staff that the circumstances surrounding the uncle's case were extenuating and the uncle would only be harmed by a truthful discussion of his diagnosis. The hospital team was informed that years earlier the patient had undergone a mastectomy in Egypt and was not told of his diagnosis for the same reasons. In that situation, the patient had never asked any questions pertaining to the nature of his illness. Eventually the family decided that they did not want a biopsy. Shortly thereafter, the patient was placed in a comfort care facility, where he was never told of his diagnosis.

Dr. Prager explained that Egypt and the US have very different norms when it comes to their communication practices with cancer patients. In Egypt, patients become very dependent upon their family and are not involved in decision making related to diagnosis or treatment. The family nurtures the patient and makes the decisions for him or her. Disclosing a serious diagnosis to a patient, by a doctor, is considered socially unacceptable and untactful. The family, however, is fully informed concerning diagnostic procedures and plan of care.

In the second case that Dr. Prager presented, an 84 year old Orthodox Jewish woman who was widowed was admitted to the hospital with end-stage lung cancer. She was frail and still very alert. Three months prior to her admission to the hospital she had been diagnosed through a biopsy with a mass that was causing pain on her chest wall. She had not been told of her diagnosis, and her sons insisted that she continue to be kept in this state of ignorance. Her illness had reached a stage where there was no cure, and only pain medication could be offered. The team learned that she was not only a Holocaust survivor, but that her parents and siblings had all been murdered by the Nazis.

As her lungs began to fill with fluid, it was recommended that she should be transferred home for hospice care. Instead, her sons requested that her chest fluid be drained. This was done and the patient remained in the hospital where she continued to become weaker and more sickly. The medical team asked the sons their thoughts on a DNR/DNI for their mother, as death appeared imminent for her and they had run out of options for treatment. The sons refused and insisted on intubation, even though their

mother had no chance of surviving her stay in the hospital. The team then approached the patient who said to direct all questions to her sons. She remained intubated in the ICU, until her death 3 days later. She never learned of her diagnosis.

Dr. Prager explained that there are many reasons people feel that it is best not to tell a patient bad news. The Hippocratic Oath that all doctors take states that “first, do no harm...” If telling a patient the bad news that he has an incurable disease, for example, would only upset him and provoke fear, then the truth could only hurt the patient. It appears that for many patients, their recovery is dependent upon their spirit and mood, and upsetting news may only impair the patient’s ability to fight the disease. Furthermore, some patients simply do not want to be told the truth if the prognosis is dire.

Over the past thirty years, doctors have radically changed their opinions regarding telling patients of a diagnosis of cancer. As Dr. Fischbach mentioned, thirty years ago when cancer was always viewed as a lethal disease, most doctors preferred not to tell the patients the diagnosis. As time elapses and cancer becomes a more treatable disease, doctors are more likely to tell cancer patients their diagnosis. This trend has come about for many reasons. A large reason is the idea of informed consent and the law that states that a doctor will be held liable for withholding any material facts that could help a patient make an informed decision. Disclosing a diagnosis is vital for informed consent. Additionally the “Patient Self-Determination Act” of 1991 furthered the patient’s right to make decisions concerning his or her health care. As technology has progressed, patients have become much more knowledgeable about illnesses and treatments due to the accessibility of information, for example, on the Internet.

There are many favorable reasons for disclosing a dire diagnosis to a patient. It helps promote a better doctor-patient relationship when patients know they can fully trust their doctor. When patients are informed, they are able to share their concerns with their families and in return their families are better informed and better able to offer supportive care. Additionally, research has shown that patients do not experience the emotional suffering that people fear may occur from learning their diagnosis. Lastly, patients are able to plan for their death and provide closure to their lives.

Cultural differences offer many opportunities for physicians to potentially clash with their patients and families concerning truth telling. Whereas in the United States our culture puts emphasis on individual autonomy and identity, many other cultures view a person as interconnected within his or her family and community. These cultures favor dependence over independence. In these situations, the families are there to protect the sick from bad things, such as making end-of-life decisions. These cultural differences pose problems for doctors often in terminal care issues, when they see the illness as happening to the family and not to the individual.

The manner in which a physician should tell a patient bad news varies greatly between cultures. In the US, physicians must learn ways in which to sensitively and compassionately talk with a patient when they have to relate bad news; however, many

of these methods are considered crude and hurtful by other cultures. In the US, a gentle approach by a physician would be to ask patients if they would like to know all the details of their condition; however, this would be a wrong action to make in many cultures because of the implications. Many cultures prefer ambiguity and indirectness, as opposed to our direct and often seemingly blunt and harsh approach. They feel that in order for a person to enjoy life, the person must continue living as before the diagnosis. If a physician tells patients that they are going to die, then we are condemning them to death while they are still living. This runs in opposition to the western belief that patients should know they are going to die so that they can live their life to the fullest and do everything they need to before they pass on, "live like you were dying." In these cultures, the belief is that it is possible to take care of a dying patient without needing to use the word "dying." In these cases, the physician should take into account the patients' needs and desires, while still respecting their cultural traditions.

This can cause physicians to feel as though they are compromising their professionalism and duty as physicians, although they may be respecting a patient's culture in lieu of the truth. This builds a tension between adhering to the traditional western values of autonomy and patient rights versus the respect for the patient's culture and values. Physicians often may feel that they are not honoring their ethical obligation to "do no wrong" to their patient if they do not provide their patient with the truth.

In general, many believe that the fewer the options that are available for a patient who is dying, the less critical it is for the patient to have total knowledge of his diagnosis and prognosis. If a patient has many options available and a better prognosis, however, then it seems more important for the patient to be knowledgeable about the options that are available.

Dr. Prager ended his presentation by stating that one of the elements in the art of medicine is knowing when, and how much patients want to know, and the optimal way to inform them if they so desire. Telling patients their diagnosis and their prognosis is not the end but the beginning of a sensitive and critically important dialogue.