

BIOETHICS

# Truth-Telling in a Culturally Diverse World

A. Jotkowitz, M.D., M.H.A.,<sup>1</sup> Shimon Glick, M.D.,<sup>1</sup> and B. Gezundheit, M.D., Ph.D.<sup>2</sup>

Department of Medicine, Soroka University Hospital and Faculty of Health Sciences, Ben-Gurion University of the Negev, Beer-Sheva, Israel.<sup>1</sup>  
Unit of Bone Marrow Transplantation, Cancer Immunotherapy and Immunobiology Research Center, Hadassah–Hebrew University Medical Center, Jerusalem, Israel.<sup>2</sup>

## ABSTRACT

Until recently physicians have been reluctant to disclose a poor prognosis to patients for fear of harming them with the bad news and/or taking away their will to live. In the last decades we have seen a reversal of practice among Western physicians, and most doctors readily disclose to their patients the full extent of their disease. This change is probably due to the emphasis on patient autonomy in the doctor-patient relationship and the lack of evidence that hearing the bad news impacts significantly on patient outcomes. This emphasis on complete honesty with patients might not reflect the practice in non-Western cultures. In disclosing a poor prognosis to a patient the physician must do so with cultural sensitivity, compassion and letting the patient decide how much he or she wants to know.

## INTRODUCTION

For thousands of years physicians have been debating about whether to disclose to patients a grim prognosis. Hippocrates instructs physicians to conceal “most things from the patient while you are attending him and many patients who receive a forecast of what is to come . . . have through this cause taken a turn for the worst (1). Oliver Holmes wrote in 1883 that “[y]our patients have no more right to all the truth you know than he has to all the medicine in your saddlebag. He should get only as much as is good for him” (1). Another nineteenth-century physician Worthington Hooker argued against the commonly held assumption that truth-telling harmed the patient and felt from a moral standpoint that lying was unacceptable (1). The American Medical Association code of ethics of 1940 states that: “a physician should give timely notice of dangerous manifestations of the disease to the friends of the patient.” Disclosure is recommended but not to the patient.

The primary justification for nondisclosure has been the fear that receiving the bad news could be harmful to the patient. In addition, many families and physicians want to shield the patient from the emotional strain of receiving the news. This attitude on the part of physicians, families, and patients reflects the paternalistic model of the doctor-patient relationship, which was the dominant paradigm until recently. In the paternalistic doctor-patient relationship the physician is the dominant member with unquestioned authority and the implicit ability to make decisions on behalf of his or her patients. In this environment there is really no need for patients to know the true extent of their disease, especially if this knowledge is thought to be harmful. In the last half of the twentieth century we have witnessed a paradigm shift in the theoretical basis and practical application of the doctor-patient relationship.

## AUTONOMY AND TRUTH-TELLING

Much of modern bioethics is built on the concept of autonomy. Beauchamp and Childress in their classic work *Principles of Biomedical Ethics* define autonomy as “personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice, such as inadequate understanding” (2). Two conditions are necessary for the exercise of autonomy. There must exist independence from controlling influences and the capacity for intentional action (2). The concept of autonomy as the focal point of modern bioethics was partly a response to the notorious experiments

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Correspondence to:

Alan Jotkowitz

The Moshe Prywes Center for Medical Education

P.O.B. 653

Beer-Sheva 84105

Israel

email: ajotkowitz@hotmail.com

performed by Nazi doctors on concentration camp inmates. These include Mengele's experiments on 1,500 sets of mostly young twins at Auschwitz and the infamous hypothermia experiments at Dachau where 300 prisoners were held in freezing water for as long as 7 hours resulting in 90 deaths. These human experiments were unique in biomedical science because death of the participant was an expected, and even sought-after, outcome, and, obviously, the subjects were unable to refuse to participate. The organized medical community was profoundly shocked by the involvement of physicians in these crimes and an international effort led to the development of the Nuremberg Code whose first principle states "the voluntary consent of the human subject is absolutely essential" for any research involving human subjects. This was followed by the World Medical Association Declaration of Helsinki in 1964, which provided recommendations to physicians on research involving human subjects. It asserts that the subject "should be informed that he or she is at liberty to abstain from participating in the study and that he or she is free to withdraw his or her consent to participation at any time." This document's focus is on research ethics and places major emphasis on the doctrine of autonomy and informed consent. The potential research subject has to be fully informed of the potential risks and benefits of the proposed research and must give his or her consent without undue coercion or pressure. In addition, there must exist no negative consequences of nonparticipation. Notwithstanding the almost universal acceptance of these principles, reports of cases of unethical research design and practices in clinical trials still plague the biomedical community.

Jay Katz and others have brought the concepts of informed consent and patient autonomy to the bedside and to the doctor-patient relationship. Katz argued in his classic work *The Silent World of Doctor and Patient* that patients have precious little say in medical decision-making relating to their health and quality of life. He attacked this way of practicing medicine as an assault on human dignity and an affront to autonomy (3). Clearly, there is a difference between the relationship of the researcher to his subject and the physician to his patient. The primary aim of the investigator is to advance science while the doctor wants to cure his patient. But, to the proponents of unlimited patient autonomy, this makes little difference. In both instances the research subject and the patient must give full consent to their treatment and anything less is unethical even if the physician believes he is acting in the best interest of the patient. However, according to Katz not only do patients have to consent regarding their treatment but they also should play the role of primary decision makers regarding their care. He also connects research ethics to clinical ethics by stating "as long as patients are viewed as significantly impaired to make decisions on their own behalf, the danger is great that patient-subjects' autonomy in research decision making will remain equally threatened" (4).

A striking example of the classic paternalistic attitude was the traditional hesitancy of doctors to inform patients of a diagnosis of cancer or any other disease with a grim prognosis.

Many patients were treated with toxic chemotherapy and even underwent surgery without knowing their diagnosis and, therefore, obviously were unable to give proper consent. Katz's new paradigm of honesty and an emphasis on patient decision making became accepted ethical doctrine in the West, as manifested by the UNESCO Declaration of Human Rights and Bioethics, and was slowly adopted by physicians. More recently, a large number of Western medical organizations ratified the Charter on Medical Professionalism, which states as one of its cardinal principles "physicians must be honest with their patients and empower them to make informed decisions about their treatment" (5). Another prominent proponent of autonomy has stated that "no competent patient in the United States has ever been forced to undergo medical treatment for his or her own good. No matter how tragic, autonomy should always win if its only competitor is the paternalistic form of beneficence" (6). Aside from the ethical arguments in favor of adequate disclosure to patients there exists no compelling evidence that informing patients of their diagnosis and prognosis is by itself harmful to patients. In addition, the pioneering work done by Kubler-Ross on understanding the dying process and the modern hospice movement all presuppose an understanding by the patient of his or her condition. Disclosure has been advocated for cancer patients with poor prognosis (7) and for informing Alzheimer patients of their diagnosis and prognosis (8). This trend toward truth-telling in medicine also has taken hold in pediatrics (9). The basis for this development is not autonomy as most ethicists still feel that children only have limited autonomy and the primary healthcare decision makers remain the parents but the feeling among experts in the field that it is better psychologically for the child to have an understanding of his or her disease. Disclosure in the pediatric setting also serves to create a trustful relationship between the child and health care team which is crucial to many children who are ill and for the health care providers.

There also is a movement afoot in the United States to extend the concept of disclosure to medical errors, something unheard of until very recently (10). This has been spurred on by the emphasis on providing quality of care in medicine and reducing medical errors and by some preliminary data that this policy will reduce malpractice claims as opposed to raising them (11).

The ethical justification for truth-telling also is supported by the current medico-legal environment in the Western world and particularly the United States. There exists legal requirements for complete disclosure in many states and the fear of malpractice has led many physicians to adopt this policy.

Recent studies reflect this complete reversal of physician attitudes toward truth-telling in the last thirty years. In 1961, 90 percent of physicians were opposed to telling cancer patients their diagnosis (12) and in the space of only 20 years there was a complete reversal of physician attitudes as in 1977 only 2 percent of American physicians were opposed to disclosure of a cancer diagnosis (13).

## CULTURAL DIFFERENCES AND TRUTH-TELLING

Notwithstanding the almost universal acceptance of the Physician Charter by organized medicine, there already has begun a backlash against the concept of unlimited human autonomy for a variety of reasons. We have previously argued (14) that the emphasis on autonomy might reflect a Western cultural bias and in other societies there is much less of an emphasis on personal autonomy and more of a shared decision-making model between patients, families, and physicians. Other physicians have expressed similar sentiments on the impact of culture on truth-telling (15–17). In many societies it is the children's responsibility to protect their parents from bad news and requiring individual informed consent prior to treatment is not culturally acceptable. In China, patients and physicians alike regard the family rather than the patient as having the primary decision making authority (18). An Indian physician in a symposium on transcultural dimensions of medical ethics reported from his country that a physician there was convicted for not imposing indicated treatment on a patient against his will and that both the public and most Indian physicians do not feel that informed consent is essential in order to treat patients (19). There also exists cultural differences on what it means to be alive that impact on the decision to disclose and some cultures (e.g., Native American) believe that talking about death can hasten it (20). Studies have also shown that patients from different cultures differ over whether physicians should tell a patient that he or she has cancer (21). In the Judeo-Christian tradition there also has been a hesitancy to fully disclose a poor prognosis to the patient. For example, Jakobovits has written that "the rabbis insisted on maintaining the patient's hopefulness not merely by withholding information of his imminent death, but by positive means to encourage his confidence in recovery" (22). Interestingly, there are data which suggest that when physicians are ill they often prefer a paternalistic model of treatment for themselves (23).

The Physician Charter also requires physicians to "empower" their patients, it does not adequately recognize that many patients do not want that power. An important book by Schneider makes the point that many patients are unable to make the complex decisions relating to their care either due to their current medical condition, cognitive state, or other reason (24). Several recent studies have demonstrated that seriously ill patients may have distinctly impaired judgment (25, 26). As practicing physicians it is obvious to us that a critically ill patient and/or their distraught family are not always in the best condition to make difficult decisions and therefore may lack one of the basic requirements for the exercise of true autonomy. In many instances they prefer to hand over that responsibility to their doctors. However, the patient's family does not have the right to hide the truth from the patient if the patient truly desires to be informed. The physician's primary responsibility is toward the patient and he or she must partner with the family to fulfill the patient's wishes.

In the era of globalization and mass communication it will be interesting to see the impact that modernization has on a culture's traditional mores regarding truth-telling. For example, as

mentioned previously many non-Western societies do not value unlimited personal autonomy and this could potentially lead to a clash with younger members of the society exposed to Western attitudes toward truth-telling. And likewise, Western cultures could certainly be influenced by models of shared decision-making common in other countries, either by immigration or direct observation of these traditional belief systems. This potentially could lead to personal ethical dilemmas for patients, their families, and physicians as cultural boundaries continue to blur around the world.

## COMMUNICATION SKILLS AND TRUTH-TELLING

So where does this leave the practicing physician? The bioethicists are pushing toward adequate disclosure; however, in many instances, the cultural milieu is pointing in the opposite direction. The answer might be found in the first lesson that one should be taught in medical school. Listen to the patient. Using all of the listening skills we should have learned in medical school let the patient tell us what and how much they want to learn about their disease. This approach is fully respectful of the patient's autonomy but also lets the patient decide how they want to exercise that autonomy.

No matter what the patient wants to hear it is obligatory upon us as physicians to know how to provide the information in a kind and considerate manner and if we don't know how to do it is incumbent upon us to learn. There are many programs available that can quickly teach an approach to breaking bad news and make most physicians competent in this area (27).

We also are well aware of the desire of many patients to remain hopeful even after receiving devastating news and the impact on the patient of taking away that hope. We do not know the therapeutic value of hope but scores of patient testimonials attest to its value in the eyes of the patient (28) and physicians must learn to deliver the worst news while enabling patients to retain some element of hope. Lastly, as members of a scientific profession more research is needed to help us better understand the desires and needs of our patients, the impact of culture and tradition on disclosure, the relationship between the patients psyche and outcome and how to provide the bad news in the most comforting manner.

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