Bioethics for clinicians: 7. Truth telling

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Abstract

The standard of professional candour with patients has undergone a significant change over the past 30 years. Independent of their obligation to disclose information necessary for informed consent, physicians are increasingly expected to communicate important information to patients that is not immediately related to treatment decisions. The purpose of truth telling is not simply to enable patients to make informed choices about health care and other aspects of their lives but also to inform them about their situation. Truth telling fosters trust in the medical profession and rests on the respect owed to patients as persons. It also prevents harm, as patients who are uninformed about their situation may fail to get medical help when they should.

Mr. S is 26 years old and has recently joined a family physician’s practice. He had an episode last year of unilateral arm weakness and visual blurring without headache that resolved within 12 hours. He was referred to a neurologist, who did several tests. Mr. S was subsequently told not to worry about the episode and thought no more about it. He has had no similar episodes since. In his medical records is a letter from the neurologist to the previous family physician stating that Mr. S almost certainly has multiple sclerosis. In the letter the neurologist explains that in order to prevent excessive worry he does not inform patients in the early stages of multiple sclerosis of their diagnosis.

What is truth telling?

In the practice of medicine, truth telling involves the provision of information not simply to enable patients to make informed choices about health care and other aspects of their lives but also to inform them about their situation. Patients may have an interest in medical information regardless of whether that information is required to make a decision about medical treatment. Truth telling requires accuracy and honesty: as Cabot wrote at the turn of the century, physicians should strive to create a “true impression” in the mind of the patient. Thus, truth telling requires that information be presented in such a way that it can be understood and...
patient's well-being.6 Good communication is required for its own sake and that "nondisclosure can itself affect the knowing that information can have value to patients for their own medical records, the Supreme Court of Canada acknowledged that physicians have about them. Not telling the truth can harm patients in many ways. Patients who remain uninformed about their condition may fail to obtain medical attention when they should. They may also make decisions affecting their lives that they would not make if they were aware of their condition. In addition, telling patients their diagnosis early in the course of a serious illness such as multiple sclerosis can be helpful simply because "some people find comfort in the knowledge that physicians can name their problem."9

Not telling patients the truth about their condition may entail deceiving them. Lack of candour or outright deception, even when well intentioned, can undermine the public's confidence in the medical profession.1

Law

Legal aspects of physician–patient communication are discussed in earlier articles in this series (see sidebar). Truth telling goes beyond disclosure for the purpose of assisting the patient in making treatment decisions and includes the broader notion of the accurate and honest communication of information. Canadian courts have dealt with lack of physician candour with regard to patient access to medical records, mishaps occurring in the course of treatment and the practice of "shielding" patients from bad news. In discussing the right of patients to gain access to their own medical records, the Supreme Court of Canada acknowledged that information can have value to patients for its own sake and that "nondisclosure can itself affect the patient's well-being." Good communication is required after treatment as well as before. For example, failure to tell a patient about the accidental puncture of his spleen during a lung biopsy was held to breach the physician's duty to inform the patient, particularly because the patient had asked what had occurred during the procedure. The judge concluded that litigation arose from a "less than satisfactory physician–patient relationship" precipitated by the lack of candid interchange following the mishap.7

A physician was found negligent in a case involving nondisclosure to the patient of his risk of having acquired HIV infection from a transfusion. A family physician's desire "not to worry" a pregnant woman with information about serious but unlikely risks to the fetus after she contracted chicken pox proved an ineffective defence in a negligence action taken by the woman.7

Indeed, many legal actions result from communication difficulties between physicians and their patients. Some patients who sue report having felt rushed or ignored during visits;1 patients who are dealt with in this way are less likely to have their informational needs met than those who are given the time and opportunity to voice their concerns.12 Effective and timely communication is essential to good care and can reduce the risk of malpractice claims.11

Physicians may be unsure whether to provide patients with statistics related to a prognosis. A court in California found no negligence in a physician's failure to disclose the precise statistical risk of death within 5 years to a patient with pancreatic cancer before the patient gave consent for experimental therapy. The court did not find, "as a matter of law," that any particular type of information must be disclosed, but it adhered to "the patient-based standard of disclosure" whereby "adequate information" must be given to enable the patient to make "an intelligent choice."14

The Supreme Court of Canada has granted that there may be narrow exceptions to truth telling, for example when the patient's emotional condition is such that the disclosure of bad news could cause harm.15,16 The most relevant test for nondisclosure is "whether the disclosure would in itself cause physical and mental harm to this patient."17 Physicians should start from the assumption that all patients are able to cope with the facts, and reserve nondisclosure for cases in which more harm will result from telling the truth than from not telling it.

Policy

The CMA Code of Ethics recommends that physicians provide patients with whatever information that will, from the patient's perspective, have a bearing on medical care decision-making and communicate that information in a way that is comprehensible to the patient.18

Empirical studies

Physicians

In a landmark study conducted in 1961, 90% of a sample of 219 US physicians reported that they would not disclose a diagnosis of cancer to a patient.19 Of 264 physicians surveyed almost 20 years later, 97% stated that they would disclose a diagnosis of cancer.20 This indicates a
complete reversal of professional attitudes toward truth telling, at least in the context of a diagnosis of cancer. Cultural values appear to influence physicians’ attitudes toward truth telling. In one study, US physicians who reported that they commonly tell cancer patients the truth said that they did so in a way that was intended to preserve “hope” and “the will to live,” both valued notions in US society. The findings of another study suggested that gastroenterologists from southern and eastern Europe were less likely to be candid with patients than their North American counterparts.

Patients

The literature suggests that most patients want to be informed about their situation. For example, in a 1957 study involving 560 cancer patients and their families, 87% of respondents felt that patients should be told the truth about their illness. In a study done before any treatment existed for multiple sclerosis, many patients with the disease felt they had a right to know what was wrong with them. Some were angry about being asked why they wished to know. One wrote: “Do I have to explain why? Just so that I know.” A survey conducted in 1982 indicated that 94% of patients wanted to know everything about their condition, 96% wanted to be informed of a diagnosis of cancer and 85% wanted to be given a realistic estimate of their time to live, even if this were less than 1 year. Other studies showed that over 90% of patients wanted to be told a diagnosis of Alzheimer disease and that over 80% of patients with amyotrophic lateral sclerosis wanted to be given as much information as possible.

Attitudes toward disclosure can vary from one cultural context to another. For example, in one study, a greater percentage of Korean-born patients preferred to be given less information than did US-born patients.

Outcomes

Truth telling increases patient compliance, reduces the morbidity such as pain associated with medical interventions and improves health outcomes. Informed patients are more satisfied with their care and less apt to change physicians than patients who are not well informed.

Some studies suggest that truth telling can have negative consequences. For example, the diagnosis of hypertension may result in decreased emotional well-being and more frequent absence from work.

How should I approach truth telling in practice?

Truth telling can be difficult in practice because of medical uncertainty and the concern that bad news might harm the patient. It can also be difficult when medical error occurs and when the patient’s family is opposed to truth telling.

The pervasive uncertainty in medicine can and should be shared with patients. Telling patients about the clinical uncertainties and the range of options available to them allows them to appreciate the complexities of medicine, to ask questions, to make informed, realistic decisions and to assume responsibility for those decisions.

Predicting what information a patient will find upsetting, or foreseeing how upsetting certain information will be, can be difficult. Patients may indicate, explicitly or implicitly, their desire not to know the truth of their situation. When such desires are authentic they should be respected. It is possible to deliver the truth in a way that softens its impact; many books provide practical suggestions on telling bad news. The truth may be brutal, but “the telling of it should not be.”

Physicians should disclose the occurrence of adverse events or errors to patients but should not suggest that they resulted from negligence. The admission of error is not an admission of substandard practice. Negligence is a finding made in court, not by physicians or their colleagues.

Telling the truth can defuse resentment on the part of the patient and reduce the risk of legal action. People sometimes sue physicians out of a “need for explanation—to know how the injury happened and why.” Truth telling at the time of the misadventure can ensure that an injured patient seeks appropriate corrective treatment promptly. Such frankness may thus foster, rather than undermine, the patient’s trust in physicians.

In some cultural settings patients with terminal illnesses may waive their right to know about their situation or transfer that right to family members. Physicians should explore such waivers sensitively with their patients to ascertain whether they are authentic requests. Patients should be explicitly offered the opportunity to be told important information. When a patient has a serious illness such as cancer, it may be helpful to document his or her preferences regarding the involvement of family members. Families who resist disclosure of the truth should be counselled about the importance of truth telling, much as they might be counselled about the appropriate management of any medical problem.

It is important to bear in mind that substantial variability exists within cultures and that cultural values can change. For example, in Japan, where medicine has traditionally been very paternalistic, the National Cancer Centre decided in 1995 that cancer patients must be given a form describing their disease and various side-effects of treatment.
The case

If the neurologist seriously considered multiple sclerosis as a likely or working diagnosis he was not justified in withholding this information from Mr. S. A general worry about causing anxiety is not sufficient to exempt a physician from his responsibility to tell the patient the truth. Physicians need not and should not wait for near certainty before they disclose information to patients. If Mr. S is not told about his condition and makes a decision that he would not otherwise have made, his physicians could be held responsible if gal liability for any untoward outcome that resulted. Likewise, Mr. S’s physicians could be held responsible if he failed to avail himself of new and potentially beneficial treatments were his condition to worsen.

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References