Articles

Should Physicians Tell Patients the Truth?

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The medical literature suggests that most patients want to be told the truth about a diagnosis of cancer. Despite this evidence of their patients' wishes, physicians in many countries still hesitate to disclose this and other diagnoses. Physicians frequently ignore their patients' wishes when they consider the appropriateness of truth telling. A complete shift from nondisclosure to mandatory disclosure without considering patients' preferences may lead to serious harm to patients who do not want to be told the truth. Because physicians cannot satisfactorily treat patients without knowing their preferences toward disclosure of a diagnosis, I propose a simple strategy to break this long-standing ethical dilemma—physicians must develop the habit of inquiring about their patients' preferences.

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In Japan, the concept of informed consent has only recently been recognized.[1] Most Japanese physicians withhold important information about diagnosis and prognosis when their patients have cancer.[2-6] Articles in English-language journals suggest that many other countries face a similar dilemma.[7-13] Comparisons of patients' desires to be told a diagnosis of cancer and physicians' attitudes for disclosure show notable discrepancies. These comparisons suggest that patients are dissatisfied when physicians ignore their wishes.[3,8,10-15] Culturally specific attitudes of physicians and patients' families can be regarded as potential obstacles to meeting patients' wishes. Surveys also tell us that physicians should be aware that patients do not always want to be informed of a diagnosis of cancer. In some countries, many patients do not want to know the truth.[3,8,12,14,16]

Preferences for Disclosure of a Diagnosis of Cancer

How should physicians judge whether full disclosure is necessary? The criteria should not rest on physicians' preferences or their comfort, but should be in response to patients' satisfaction with current practice in their own countries. If most patients and their families are satisfied with the fact that patients are not informed of a diagnosis of cancer, then physicians need not change their attitudes. If patients are dissatisfied with current practice, it is problematic even though physicians may think that not telling the truth is good for their patients.

An international survey of 20 countries showed that oncologists estimated that a low percentage (<40%) of their colleagues used the word "cancer" or disclosed this diagnosis in Africa, France, Hungary, Italy, Japan, Panama, Portugal, and Spain.[11] In a survey in Japan, 67% of physicians would disclose the diagnosis to patients with early cancer, whereas only 16% would tell those with advanced cancer.[3] A 1991 survey of 1,171 Italian patients with breast cancer and their physicians showed that a minority of patients (47%) reported having been told that they had cancer.[13] In Spain, 42 of 167 cancer patients (25%) were correctly informed of their diagnosis.[10] A survey using several hypothetical situations evaluated variations in attitude among 260 European gastroenterologists to truth telling in cases of cancer. The results showed that gastroenterologists in northern Europe usually reveal the diagnosis to both the patient and the patient's spouse, but some would inform only the spouse with the patient's permission. They would conceal the truth if the cancer had metastasized. Gastroenterologists in southern and eastern Europe usually concealed the diagnosis from patients, in many cases even when the patient asked to be told the truth.[9]

In Greece, 500 healthy people were asked whether they would want to be informed of a diagnosis of cancer. A third of respondents replied yes, a third said no, and a third answered that it depended on the circumstances.[12] In 1986 an Italian public television survey showed that a sample population representative of the entire nation was more or less equally divided in its preference for truth telling in medicine.[8] In a survey of 1,023 patients who underwent upper gastrointestinal endoscopy in Japan, 58% of them wanted to be informed of the diagnosis if they had stomach cancer.[14] A survey of 183 outpatients in Japan revealed that 54% of them wanted to know a diagnosis of cancer.[15] A survey in a Spanish hospital reported that 71% of hospital health workers would want to know their own diagnosis should they suffer from cancer.[10]

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These data indicate that many patients want to be informed of a diagnosis of cancer. Although the numbers are limited, a discrepancy exists between patients' preferences and physicians' attitudes. Physicians may need to consider changing their attitudes based on patients' desire to know the truth.

Which Patients Should Be Told the Truth?

It is often argued that truth telling depends on the patient. The objective is to divide patients into two groups based on physicians' assessment of their patients' capacity to cope with the truth. One group includes patients to whom physicians can tell the truth without concern, and another includes those who physicians fear may be harmed by a full disclosure of information. The underlying assumptions are that the word "cancer" connotes death, that patients would be so desperate that they could not make autonomous decisions, and that they should be protected from this despair.[8,9]

In general, physicians decide to tell patients their diagnosis after carefully considering a patient's age, sex, personal history, occupation, family and social background, character, religion, and physical condition.[6,7] Physicians may be more comfortable discussing a diagnosis of cancer if the patient has a stable personality, strong family support, and religious beliefs. They may not inform patients of a diagnosis of cancer if the patient is female, older, less educated, or unemployed. Many Japanese physicians think that disclosure of a diagnosis of cancer should be determined in this way—case by case. As a result, no distinctive standard of disclosure has yet been established.[17] Because no standard criteria or widely accepted methods predict a patient's ability to cope with this serious situation, leaving the decision to physicians' impressions risks being biased by the physicians' own perceptions of cancer and death and own personalities. Even if this strategy is useful in identifying patients who can tolerate the diagnosis of cancer, it does not mean that physicians can distinguish between patients who want to be informed of their diagnosis and those who do not.

Physicians also regard the prognosis as an important factor in deciding whether to disclose a diagnosis of cancer. Many physicians would inform their patients about having early cancers, but are reluctant to disclose a diagnosis of incurable advanced cancer.[6,9] No evidence exists, however, that disclosure leads to despair. The data available consist of reports of patients in the United States where most patients have been satisfied with full disclosure.[18,19] A Japanese oncologist reported his impression that full disclosure to terminally ill cancer patients was not followed by depression or mental instability and seemed to result in improved terminal care.[20]

Another factor is the wishes of a patient's family. In Japan, Greece, Italy, and southern and eastern European countries, it is common to disclose a diagnosis of cancer first to a patient's family.[8,9,12] Some physicians would disclose a diagnosis to a cancer patient only when the family allows them to do so. Israeli oncologists are often faced with a spouse or children of a patient who insist that they must not disclose to the patient that he or she has cancer.[21] In a survey of patients' families in Spain, most patients' relatives preferred to avoid the word cancer and sometimes insisted that physicians not tell the truth to the patients.[10] An Irish physician also reported that it is appropriate to discuss the diagnosis first with the family.[9] A family would judge how and when they want to let a patient know in Ethiopia.[22] A belief held by many Chinese is that the sick are entitled to be treated as children and deserve protection.[23] In Japan, once a patient gets sick, the family usually treats the patient as incompetent. Physicians must ask whether they themselves and the patients' family are adequate substitute decision makers. Of 100 patients with breast cancer in Japan, 83 accepted disclosure of their own diseases, but only 21 advocated disclosure in the case of a family member.[24] A survey of 546 patients who knew they had cancer reported that two thirds desired a direct explanation, but only a third of their families wanted them to have it.[25] Several surveys on Japanese physicians showed that Japanese physicians are three to five times more likely to want to be informed of a diagnosis of cancer than they are to give this information to their patients.[3,26]

Both physicians and patients' families may assume that a patient will not tolerate a diagnosis of cancer—although they can.[26] The perceived discrepancy between what physicians and families want for themselves and for their patients may distort their assessment of patients' preferences. One survey done in Japan reported that physicians have practically no knowledge of their patients' preferences toward disclosure of a diagnosis of cancer.[27] A series of surveys done in the United States supported this conclusion.[28]

Who Should Decide?

Physicians need to recognize that some patients want to keep their right not to know information they may find intolerable. It would be paradoxically paternalistic for physicians to convey a diagnosis of cancer to patients who stated that they did not want to be informed. When offering truth, physicians must recognize that patients' choices should be respected not because they or others agree with those choices, but simply because it is the patients' right not to know.[16]

Being diagnosed with cancer is a uniquely personal disaster for many patients. First and foremost, it affects their own life; no one, including physicians or families, can take over their burden. Diagnostic information regarding one's body and life belongs to the person to whom it refers, not to family or physicians.[22] Therefore, a patient's wish to know or not to know the truth is the most important factor in determining disclosure.

Unlike many American patients, those from some cultures may be reluctant to express their wishes to their physicians. Physicians have to consider the factors that keep their patients from expressing their wishes in their own countries. Traditional paternalistic physician-

It is my custom to ask patients directly if they would like to be informed of a diagnosis of cancer should it develop. Some patients want to be informed; others do not. Physicians cannot predict whether patients would want this information. Even your family may not be able to predict what you want.

You are the only person who knows how much information you need. I want to respect your wishes to know or not to know the real diagnosis, even if it is against your family's wishes. **These questions have nothing to do with your current medical condition.** I will ask these questions periodically as long as our relationship continues. You can change your mind at any time. Please note that this is **not** a survey. These are your actual medical decisions and will be made part of your medical record.

I recommend that you keep a copy of your answers and discuss your decisions with your family immediately. If you have any problems with your family, please let me know.

- Would you want to know a diagnosis of an early and potentially curable cancer if it should develop?
  YES NO I do not know

If you chose I do not know or NO, to whom should we tell the diagnosis?

- Would you want to know a diagnosis of incurable cancer and its prognosis?
  YES NO I do not know

If you chose I do not know or NO, to whom should we tell the diagnosis?

- We will abide by your answers when we decide what and how much we should tell you. Is this acceptable to you?
  YES NO I do not know

If you chose I do not know or NO, what would you want us to do?

- Should we tell you a diagnosis of cancer even if your family insists that we not tell you?
  YES NO I do not know

If you chose I do not know or NO, what would you want us to do?

- Once you decide that a physician should tell a diagnosis of cancer to your family or whomever you choose, but not you, we will discuss your treatment with them and withhold all information from you. Is this acceptable to you?
  YES NO I do not know

If you chose I do not know or NO, what would you want us to do?

- We would like to know how much information you would want should cancer develop. Please choose one of the following:

Diagnosis only
Diagnosis and prognosis
All of the above and choices of treatment (operation, chemotherapy, other) with their side effects and success rates of treatment
All of the above and choices of life-sustaining treatment (if the disease should become terminal) with their side effects and success rates of treatment
Other

Signature:

Figure 1.—A sample questionnaire is shown for patients undergoing routine cancer screening.

patient relationships,[6,8] physicians' power over patients,[29] requests by patients' families, and reluctance to question or discuss must be reconsidered.[30] For example, a Russian patient noted ". . . the doctor gives you medicine and you take it. No questions."[31(p334)] French patients rarely question the prescribed treatments.[32] Patients in Japan do not usually expect to be equal participants or involved in health care decision making.[33]

How can physicians know the minds of patients who are reluctant to ask or discuss medical issues, especially serious ones? Physicians must take the initiative to ask them if they want to know their diagnosis, even if it is unfavorable. If patients prefer to know their diagnosis, physicians also should ask them how much information they would like about the prognosis and whether they want to join the discussion of their own treatment. These questions must be asked in a systematic manner at the beginning of the patient-physician relationship—before any examinations and laboratory tests are done. For example, physicians can interview patients who undergo routine cancer screening or periodic health examinations. These questions can be asked along with the medical or personal history to avoid raising suspicion that the physician thinks that the patient has cancer. It is necessary to repeat these questions periodically because the answer given when patients are healthy may not predict patients' wishes when they are really ill. A sample questionnaire is included (Figure 1).

This inquiry might also be useful for American physicians who deal with patients from countries where physicians are paternalistic and withhold a diagnosis of cancer. By inquiring early in the relationship, physicians could decide whether to tell the truth based on patients' stated preferences. These patients may be reluctant to say what they really want to do; their expression of preferences might be subtle and indirect, and they might hesitate to refuse their physician's recommendation. It is also important to remember that physicians cannot predict patients' preferences solely from their cultural backgrounds. Many articles regarding attitudes of people from diverse cultures are available and provide characteristics of particular cultures, but it is doubtful that those data can serve as accurate guidelines to assess each patient in the clinical setting. Patients vary from one another even when their cultural origin is identical. These differences would require American physicians to pursue careful assessment of the desire for disclosure in patients from other countries.

Usefulness of This Strategy

It should be noted that meeting patients' preferences does not ensure their satisfaction with medical practice. It is possible that patients may regret asking to be informed of their diagnosis because of the grave nature of the information, the burden of lengthy discussions about prognosis, complications, and treatment, and consideration of life-sustaining treatment. Furthermore, we cannot know whether patients who have been unaware that they have had cancer are dissatisfied with the fact that they were not informed of their diagnosis. We also cannot anticipate the degree to which patients with cancer can be satisfied with the disclosure based only on their desires to know it when they are well.

Given this unpredictable situation, physicians should base their attitudes toward truth telling on their patients' wishes. The smaller the discrepancy between patients' desires to be told the truth and physicians' willingness to tell it, the more likely patients are to be satisfied with their physicians' practices. It is difficult to satisfy patients by ignoring their preferences.

A proposal to elicit patients' preferences toward the disclosure of a diagnosis of cancer should be validated in an appropriate manner. If my proposal is effective, patients will be satisfied with this strategy. Clinical research should be conducted to reveal its effectiveness. Methods that include randomization and case-control comparison are considered unethical, however. If investigators fail to give patients in the control group an opportunity to express their preferences about medical information, these patients may be deprived of an opportunity that would benefit them.

An alternative research method is a descriptive survey of all patients who are told a diagnosis of cancer based on their wishes. The outcome variable would be the patients' satisfaction brought on by the disclosure of a diagnosis of cancer. We need to ask patients directly if they are satisfied to have been told the truth or whether they regret their decision and would have preferred not to know. Lack of data regarding the satisfaction of uninformed cancer patients makes it impossible to quantitatively compare patients' satisfaction with or without the disclosure. Therefore, the utility of this strategy can be shown only by presenting data regarding the satisfaction of patients who are told a diagnosis of cancer based on their own preferences.

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