Physicians who diagnose and treat cancer have an enormous responsibility. They not only have to be aware of the medical aspects of cancer screening, diagnosis, and treatment, but also have the difficult task of talking about these issues with their patients.

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Dr. Peter Angelos’ introductory chapter, "Physicians and Cancer Patients: Communication and Advance Directives," in Ethical Issues in Cancer Patient Care (Kluwer Academic Publishers, 2000) discusses the changes in physician attitudes toward physician-patient communication about cancer diagnoses over the past several decades.

Dr. Angelos traces the history of such communication from the 1950s model of paternalistic medical practice to the modern paradigm of shared decision making. He then points to new areas where further change is necessary in order to expand patient autonomy in cancer care.

A Look Back to the 1950s

To explore the complex history of physician-patient communication about cancer, Dr. Angelos reviews a series of articles published in major medical journals in the 1950s and early 1960s that illustrate the ethical dilemmas of physicians treating cancer patients during that time.

In the 1950s, many physicians faced unavoidable patient mortality resulting from cancer. Many physicians believed that patients should not be told of a diagnosis of cancer unless exceptional circumstances arose. Physicians often feared the psychological response of the patient—the sudden shock and devastation patients might experience and the loss of hope in a possible cure.[1]

At the same time, significant progress in cancer treatment was under way, and an early diagnosis began to provide more hope for the cancer patient. Public educational efforts began to focus on providing information to lay people about cancer. Experts in the field prepared pamphlets describing various cancers and their warning signs in order to help patients turn to physicians at appropriate times and ultimately achieve earlier cancer diagnoses.[2]

Some physicians felt that such educational efforts resulted in "mass cancerophobia" among the public and that funds should be redirected to basic cancer research.[3] Others believed that physicians should reveal the complete truth and that "fear, delay, and ignorance are the allies of cancer."[1]

The debate about disclosure of cancer diagnoses spurred a series of studies on what physicians actually chose to reveal to their patients and on patients’ preferences for disclosure.

In a study of 444 Philadelphia physicians, Fitts and Ravdin found that most physicians surveyed did not regularly discuss a cancer diagnosis with their patients.[2] Many physicians stated that terms other than "cancer" should be used when discussing the disease with patients.

Some chose to include additional comments, many of which supported nondisclosure of the cancer diagnosis. One physician included an anecdote about a patient who was in apparent good health until he learned of his cancer diagnosis; he subsequently lost interest in life and headed down a
steady and rapid decline until his death.

In a 1961 study by Oken, 90% of surveyed physicians at Michael Reese Hospital in Chicago stated that they preferred not to disclose a cancer diagnosis to their patients.[4] Even those who chose to reveal a cancer diagnosis often used alternative terminology instead of "cancer" or "malignancy."

The respondents also suggested that their preference for nondisclosure was based primarily on experience. However, additional questions in the survey suggested that, in fact, physicians seemed to make such decisions on the basis of a priori emotional and personal factors.

The researchers concluded that physicians’ reasons for nondisclosure lacked a scientific basis and that further studies needed to be done to explore the success of various physician strategies for disclosure.

Studies of patients suggested that the overwhelming majority would prefer to know if they had cancer. In Kelly and Friesen’s study of 100 cancer patients and 100 patients without known cancer, 89% and 82%, respectively, said they preferred to know about having cancer.[1]

In a survey of tumor clinic patients and their families at the University of Wisconsin Research Hospital, Samp and Curreri found that 87% of those answering the question said that patients should be told if they have cancer.[3] In addition, the majority of respondents were supportive of cancer educational efforts; they said they believed that more cancer education should be done and that cancer education can save lives.

Thus, Dr. Angelos illustrates the conflict between physician practice and patient preferences. This clash of viewpoints can be attributed to the paternalistic model for physician practice, in which physicians perceive themselves as possessing adequate knowledge to make decisions for patients.[5]

It is important to point out that although physicians went against patient preferences during this time period, they believed that they were making the best decisions for the benefit of the patients. According to this model, patient benefit and medical benefit were identical concepts.

Shift From the Paternalistic Model

Dr. Angelos then turns his attention to the shift from such paternalistic oncology practice to the rise of the practice of involving patients in the medical process. By 1979, when Novack and colleagues replicated Oken’s study, they found that 97% of respondents preferred to disclose patients’ cancer diagnoses.[6]

This reversal in physician attitudes demonstrates the prevalence of the new paradigm of shared medical decision making for clinical practice. In this paradigm, patient benefit is viewed as a separate entity from medical benefit; therefore, to achieve patient benefit, physicians must consider the patient’s own beliefs and goals.

Achieving the ideal of shared decision making requires explicit communication between cancer patients and their physicians, as this case illustrates.

The case, which began in 1981 and was settled in 1993, is discussed by Dr. Peter Angelos in Ethical Issues in Cancer Patient Care (Kluwer Academic Publishers, 2000).

The family of Miklos Arato sued his treating physicians after Mr. Arato’s death from recurrent pancreatic cancer for not disclosing to him a "statistical prognosis" for his disease. The case was ultimately decided in favor of the physicians on appeal to the California Supreme Court.
Based on the patient's lack of explicit questioning regarding his life expectancy, the physicians believed that the patient did not wish to discuss this topic and felt that statistical information might lead to the patient losing hope.

Thus, without an ongoing exchange of information and explicit discussion of patient and physician perspectives, the physicians in this case seemed to have slipped into the previous paternalistic paradigm and withheld statistical information from the patient.

Shared decision making includes increased autonomy for the patient and a respect for patients’ priorities and decisions about their health care. Instead of assuming that physicians have the full authority to make medical decisions for their patients, today's practitioners clearly believe in sharing the diagnosis of cancer with their patients and are thereby beginning to integrate the patient into the decision-making process.

Although this shift in physician attitudes has brought about more explicit physician-patient communication, the shift to shared decision making in current practice is not yet complete (see box). The dilemma of how to provide the best care for cancer patients has shifted from the question of whether to disclose a diagnosis of cancer to the question of the amount and type of information to be disclosed, as well as the ways in which information is presented to cancer patients.

**Advance Directives**

Dr. Angelos argues that the use of advance directives can play a significant role in improving physician-patient communication and in expanding patient autonomy.

Currently, patients have the option to prepare living wills in order to communicate their preferences in case they are no longer able to participate in the decision-making process because of their illness. Alternatively, they may select someone to assume durable power of attorney for their health care and to make health care decisions when they can no longer do so.

These two types of advance directives can be categorized as formal advance directives. However, patients frequently use informal advance directives, in which they communicate their wishes to friends or family members without formalizing their plans in a legal setting.

The Patient Self-Determination Act (PSDA) was passed in 1991 to encourage the use of formal advance directives by requiring hospitals with Medicare participation to present information on advance directives to all patients admitted to the hospital. Despite this effort, few patients currently use advance directives.

Dr. Angelos discusses his and Johnston’s findings that only a small number of patients undergoing high-risk procedures (esophagogastrectomy for esophageal cancer and Whipple procedure for pancreatic cancer) had an advance directive when they were admitted for the procedure.[7]

The lack of advance directives among cancer patients suggests that additional discussion of these issues is necessary between patients and their physicians.

Dr. Angelos suggests that these discussions begin early in the series of physician visits both in primary care and oncology practice, providing longer time for the patient to think about and discuss his or her wishes with friends and family. In some cases, it may be easier for a nurse or social worker to raise these issues with the patient.

With the high number of new cancer diagnoses (an estimated 1.2 million in the United States last year) and the current high lifetime risk of developing cancer (1 in 2 men and 1 in 3 women),[8] physician communication with patients about cancer will touch upon all segments of society.

To practice medicine according to the current shared decision-making model, physicians need to offer explicit information about cancer diagnosis, treatment, and prognosis to patients.
At the same time, ongoing discussion must be undertaken to explore patients’ values and beliefs regarding serious illness, and their wishes must be respected throughout treatment and in end-of-life issues.

The establishment of an open, good physician-patient relationship is necessary to allow the patient to exercise autonomy and share in decision making. The difficulties of establishing such a relationship and effectively communicating with patients indicate that the transition from the medical paternalism of the 1950s to today’s model of shared decision making is incomplete.

Sensitivity to patient values and expanded discussion about advance directives during the course of treatment may lead to increased use of advance directives and explicit understanding between the patient and physician that will help complete this transition.

References:

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