

Communication in Cancer Care (PDQ®)-Health Professional Version

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Overview

Communication between clinicians and patients is a multidimensional concept and involves the content of dialogue, the affective component (i.e., what happens emotionally to the physician and patient during the encounter), and nonverbal behaviors.

In oncology, communication skills are a key to achieving the important goals of the clinical encounter.[1] These goals include the following:[2-4]

- Establishing trust and rapport.
- Gathering information from the patient and the patient's family.
- Giving bad news and other information about the illness.
- Addressing patient emotions.
- Eliciting concerns.

Effective and supportive communication can assist the patient and his or her family in navigating a successful transition to palliative care.[5] Moreover, the need for truly informed consent and the patient's right to health care information and compassionate care create ethical, legal, and humanistic mandates for competency in oncology communication.[6]

In this summary, unless otherwise stated, evidence and practice issues as they relate to adults are discussed. The evidence and application to practice related to children may differ significantly from information related to adults. When specific information about the care of children is available, it is summarized under its own heading.

Current Clinical Trials

Use our [advanced clinical trial search](#) to find NCI-supported cancer clinical trials that are now enrolling patients. The search can be narrowed by location of the trial, type of treatment, name of the drug, and other criteria. [General information](#) about clinical trials is also available.

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Unique Aspects of Communication with Cancer Patients

Most studies of provider-patient communication have focused on primary care or general internal medicine settings. Although many of the findings may be applicable to oncology, several unique elements present in oncology are not present in many other medical settings. Cancer is a life-threatening illness. Although recent treatments have increased the hope for cure or at least the arrest of the disease, the diagnosis of cancer results in significant fear, uncertainty, and commitment to often arduous, expensive, and complex treatments. Therefore, communication and the provider's relationship with the patient and the patient's family are particularly important in providing support through the crisis of cancer.

Cancer care can also be emotionally taxing on the oncologists who must frequently give bad news and deal with dying and death. Because of reimbursement issues, medical visits have become shorter while patients' desires for information have increased.[1] Patients regard their oncologists as one of the most important sources of psychological support,[2] while oncologists receive almost no training in communication and the interpersonal dimensions of patient care.[3]

Communication research in oncology has begun to change this landscape by demonstrating the association of good communication skills with the following:[4]

- Enhanced patient satisfaction.
- Compliance with treatment.
- Increased patient knowledge.
- Enhanced accrual to clinical trials.
- Better transition of patients from curative to palliative treatment.
- Decreased oncologist stress and burnout.

The scientific study of communication skills in oncology, however, is still in its infancy. Three key concepts have nonetheless emerged in defining the importance of interpersonal and communication skills in the interaction of providers with cancer patients and their families:

- A patient-centered approach best describes the most effective way of providing comprehensive cancer care,[5] and communication skills training can no longer be considered an optional skill.[6]
- The communication between the oncology clinician, patient, and patient's family is associated with important outcomes of care.
- Communication skills are not innate, do not necessarily improve with clinical experience, but can be taught and learned.

Several reports provide an overview of these issues.[7-11]

Patient-Centered or Patient-Focused Care

The patient-centered model of care emphasizes the importance of the clinician's relationship with the patient and the patient's family as a therapeutic tool, endorses shared decision making as a key component of treatment, and emphasizes clinician understanding and addressing of patient concerns and information needs as important in promoting patient well-being and quality of life.[12,13] Interpersonal and communication skills are essential in achieving these goals and are also associated with other important clinical outcomes for the patient, the patient's family, and the medical team. These skills are especially important in highly charged emotional situations such as transitioning the patient to palliative care and at the end of life.

Patient Information Needs

Imparting information to the patient can serve the following key functions:

- Grant patients a sense of control.
- Reduce anxiety.
- Improve compliance.
- Create realistic expectations.
- Promote self-care and participation.
- Generate feelings of safety and security.

Many patients actively seek information and identify acquiring information as a priority. In one study,[14] with 12 specific information and support topics listed, patients chose information as their greatest need. Ninety-seven percent of patients wanted more feedback on the progress of the cancer; 88% wanted more information on the probable future of their illness; and 91% wanted more information about their illness. Another study [15] found that 83% of the female breast cancer patients interviewed wanted as much information as possible; 16% wanted limited information; 91% wanted to know their prognosis before beginning adjuvant treatment; and 63% wanted their oncologist to ask them whether they wanted to know their prognosis. Patient needs may, however, shift to an emphasis on support immediately after the first consultation. A study has shown that 63% of patients wanted more assurance that they would be looked after; 59% wished for greater reassurance and hope; and 59% expressed an increased need to talk about their worries and fears.[14] In several studies, information-seeking has been found to have beneficial effects on increased compliance, increased patient satisfaction, improved quality of life, and reduced distress.

[14,16,17]

Although many patients have high information needs, some patients want less information about their cancer. Research increasingly supports clinical experience in clarifying that patients differ in the amount of information they want and need about their cancer care.[18] In addition, patients' information needs may change at different points on the disease and treatment trajectory, with patients who have advanced disease desiring less information about their illness.[14] It is often difficult for providers to accurately estimate or provide the amount or type of information that patients want, leading to patient dissatisfaction with the amount or type of information they receive.[19-22] Thus, it is important for a clinician to ask how much information a patient wants.

Research has attempted to characterize different information styles in a variety of ways. One of these is monitoring and blunting.[23] Monitors actively seek information, whereas blunters avoid or distract themselves from information. For example, one study [24] found that having a monitoring style was related to a preference for detailed information, participation in medical decision making, and patient question-asking. Thus, patient information style may greatly affect patient communication preferences and patient interactions with health care providers. This area warrants additional study and has implications for how patients adjust to their cancer experience.

Participation Styles in Decision Making

Participation style in decision making represents how much patients want to be involved in the decision-making process related to their cancer. Studies of patient desire to participate in treatment decisions have yielded conflicting results, largely depending on how participation in decision making is defined. Participation can range from the patient actively engaging in the decision-making process, to the patient wanting the doctor to make the ultimate decision.[25] The desire to participate in treatment decisions is associated with locus of control, which describes how an individual tends to attribute control. Patients with an internal locus of control seek information to control their own destinies, whereas those with an external locus of control tend to passively accept their lot.[26]

Because research shows that a range of patient decision making exists, increasing participation for all patients may not be the most effective strategy. One study [27] categorized patients with early-stage breast cancer into the following groups:

- Delayers, who consider at least two options, but their deliberation is perfunctory and they immediately prefer one option.
- Deferrers, who accept their doctors' recommendations without a significant degree of reflection.
- Deliberators, who weigh the pros and cons of each treatment and do not make a choice until they have considered all the relevant information and have found an alternative with which they are satisfied.

Another study [28] identified the following four patterns to describe how patients' emotional styles affected treatment decision making:

- Passive.

- Avoidant.
- Panicked.
- Rational.

Passive decision makers allowed directive physicians to make treatment choices for them. They responded more to the caring attitude of their provider and the need to have someone to believe in rather than to an opportunity for autonomous decision making. Women with breast cancer using an **avoidant** style of decision making refused to actively confront their diagnosis or participate in planning their cancer treatment.

Panicked patients were so fearful when confronted with a diagnosis of cancer that they could not participate in decision making, whereas **rational** decision makers were able to control strong feelings of fear and engage fully in decision making.[28]

Results of another study found that whereas most well people preferred to play an active role in decision making, very sick people preferred the doctor to make decisions,[14] suggesting that seriously ill people may prefer a degree of paternalism in their care because an active role in decision making may take more physical and mental energy than these patients can afford. Alternatively, there may be a limit to the amount of negative and pessimistic information people can absorb before their capacity for coping is seriously compromised.[14]

Although the categorization of patients into various participation styles appears to offer some useful predictive power for defining communication patterns, the issues are complex. It has been suggested that to match the provision of information and support with the expressed needs of patients, patients should ideally be queried frequently about their needs.[14,29] Information and involvement preferences may also be affected by factors such as a change in disease status and the behavior of the physician during consultation. [28] Individualizing treatment discussions to patients' preferred decision-making styles rather than encouraging decision-making autonomy is likely to maximize outcomes for patients with cancer.[30]

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Important Outcomes of Communication

Patient Satisfaction

Patient satisfaction reflects how well patient health care needs, expectations, or preferences are met. The measurement of satisfaction with patient care is complicated by a patient bias to skew responses in favor of high satisfaction scores. In oncology, some studies support the concept that communication skills are related to patient satisfaction in several areas. Specifically, several studies relate patient satisfaction to psychological adjustment, including patient satisfaction with the amount and kind of information provided at the time of diagnosis;^[1] clinician willingness to discuss treatment options;^[2] patient perception of the oncologist as caring, attentive, or emotionally supportive;^[3-5] and patient rating of communication with the physician. Basic communication skills have also been related to satisfaction in other studies,^[6,7] which have demonstrated that among gynecology and medical oncology patients, satisfaction was associated with attentiveness, interest, and friendliness and with providing information. These findings among oncology patients parallel those found in other medical specialties.

Informed Consent

Informed decision making is an essential component of the ethical practice of prescribing cancer treatments and conducting research. However, fully involving patients in clinical decision making is a challenging task for physicians, who nonetheless have been urged in recent years to take a less legalistic and more interactive approach with patients in explaining treatments.^[8,9] The aim of informed consent is to emphasize more effective communication between patients and physicians, where information disclosure and patient participation in decision making are the goals rather than the notions of an administrative requirement to have patients sign a document or to protect a physician from legal liability.^[10] Such a dialogue would also allow the clinician to determine how much information a patient actually desires and would respect the patient's right to shun information that might be unwanted.^[10,11]

There are few data to describe how oncologists practice informed consent, and there are inadequate

guidelines for communicating with patients about treatment decisions.[12] The best information comes from studies of communication in clinical trials, which show that oncologists scored poorly on measures of the quality of the information provided to the patient and explanation of randomization, implicitly expressing favoritism of one treatment over another;[13] that physicians overestimate patient satisfaction with specific treatment information;[14] and that not all patients understand the unproven nature of the treatment.[15] Inflexibility in the timing of information may represent a physician barrier to clinical trial recruitment. For example, treatment of breast cancer for patients on clinical trials cannot begin until the patient has signed the informed consent form. This requirement effectively compels physicians to reveal information to patients soon after the diagnosis is confirmed. Sixty-one percent of the physicians in one study [16] explained that they would have preferred to tell patients about their diagnosis and prognosis in small increments. They argued that patients need time to absorb the shock of the diagnosis before hearing a detailed description of the uncertainty of treatment options but that the need to obtain informed consent constrained their schedule for disclosure to patients.[16]

The reason that eligible patients decline participation in clinical trials has been explored in several studies, which reflect many of the issues surrounding inadequate communication. In one study, patients were found more likely to participate in clinical trials when their physicians were cordial, able to establish trust and rapport with the patient, and attentive to patient concerns.[17] Other than increasing monetary incentives to the investigators conducting the studies, few interventions have been successful at finding ways to improve accrual to clinical trials in oncology, including an intervention study to improve communication about randomized clinical trials [18] and an intervention program designed to increase the enrollment of rural American patients who have cancer.[19] A pilot study that examined barriers to the participation of African American patients with cancer in clinical trials concluded that factors associated with religion, education, and income rather than race may be major barriers to clinical trial participation.[20] The authors of the study concluded that interventions that target education and income could increase the recruitment of African American oncology patients onto clinical trials.[20] More work in this area is needed to increase the participation of all oncology patients in clinical trials, regardless of race or educational and income level.

Interventions to improve the informed consent process also show that having a study team member or educator spend more time talking one-on-one with the patient to improve understanding of clinical trials are more successful than the use of multimedia or enhanced consent forms.[21] One study using a staged approach in which parents or guardians consented to more limited segments of treatment showed promise. [22]

Malpractice Claims

A small number of physicians appears to generate a disproportionate number of lawsuits.[23] Although there are a number of risk factors for malpractice claims—including physician specialty, number of patients seen, and physician characteristics—they do not seem to be predicted by the characteristics of a physician's patients, the technical aspects of care, or the complexity of care.[24] Rather, patient dissatisfaction—especially with the interpersonal aspects of care—seems to be an important determining factor. These interpersonal aspects include the following:[25]

- Time spent with the patient.

- Ability of the physician to meet patient expectations for care.
- Ability of the physician to convey information to the patient.
- Physician concern for patient worries.
- Friendliness and courteousness of the physician.

Other but more scarce research has suggested that communication skills are also related to patient retention, compliance with treatment, practitioner burnout,[26] collaboration among oncology teams,[27] and increased difficulty in transitioning to palliative care.[28]

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Factors Affecting Communication

Age, Race, Ethnicity, and Communication

An important area of communication problems centers on the differences in communication between doctors and older women versus doctors and younger women. Better patient-physician communication has been associated, particularly for older and disadvantaged patients, with the following:[1]

- Patient choice about treatment.
- Satisfaction with care.
- Quality of cancer care.

A study examining health care disparities in older patients with breast cancer found that older age and Latina ethnicity were negatively associated with physician provision of interactive informational support; these patients received less interactive informational support from their physicians than did younger patients.[2] The authors concluded that improving the quality of communication at the level of patient-physician interaction could be an important avenue to reducing age and ethnic group treatment disparities among patients with breast cancer.[2]

Research suggests that older patients with breast cancer who receive less-than-definitive care have higher recurrence rates and higher mortality rates than other women and remain at greater risk for receiving less-than-definitive treatment. In one investigation, patients aged 80 years and older reported receiving markedly less information about treatment options than did younger patients, were less likely to state that they were given a choice of breast cancer treatment, and were less likely to initiate communication or to perceive that their surgeons initiated communication.[1] Another study [3] also highlighted the importance of communication between older patients with breast cancer and their physicians. Investigators found that although older women obtained information regarding breast cancer from different sources, they relied most heavily on their physicians for information. Despite this expectation, the knowledge about the importance of patient-physician communication, and the increasing use of breast-conserving surgery (BCS), older breast cancer patients undergo BCS less frequently than do younger women. In addition, within older populations, radiation therapy is sometimes omitted after BCS. Even though many factors could explain these patterns of care,[4] it is possible that the quality of communication between older patients and their oncologists contributes to the observed treatment variability—although the traditional medical standard of care might account for physicians who do not recommend BCS,[4] in addition to a possible geographic preference for recommended treatments.[5] Nevertheless, a study has shown that discussing treatment options with physicians increased the probability of an older woman receiving definitive primary breast cancer therapy (defined as modified radical mastectomy or BCS with axillary dissection and radiation therapy).[1]

Several studies have investigated the relationship between race and communication in oncology. One study of 405 newly diagnosed cancer patients reported that physicians spent more time in relationship building with white patients than with nonwhite patients.[6] Another study found that black patients with lung cancer received significantly less information from their doctors and were less likely to prompt their doctors for information.[7] These patients also had lower postvisit trust in their physicians.[8] Clearly, this is an area of neglected importance in communication skills.

Socioeconomic Status

Younger and more educated patients are most likely to take an active role in medical decision making. Some researchers have observed that low-income women who are not as well educated do not communicate as well with their physicians about their treatment preferences or concerns and fears.[4,9-11] Being unmarried, having a lower socioeconomic status, and having treatment options discussed less frequently are risk factors

that, in addition to older age, predicted receiving conservative primary tumor therapy.[11] Limited financial resources have been shown to be a barrier to receiving radiation therapy after lumpectomy. Transportation to and from a radiation therapy facility is another impediment. Additionally, research data suggest that differences in physician-patient communication patterns could contribute to variance in BCS rates among income strata.

Influence of Culture/Ethnicity/Language

Using culturally appropriate approaches to communicating about cancer may lessen levels of distress for the patient and/or members of the patient's family. Developing an awareness of cross-cultural practices regarding cancer disclosure issues allows the clinician to become more sensitive to the expectations of culturally and individually diverse cancer patients. When discussing diagnoses and treatment options with patients from different cultures, it is important for clinicians to consider how to balance a commitment to frank discussion and a respect for the cultural values of the patient.[12]

In general, patients whose dominant culture is derived from a Western philosophy subscribe to certainty, predictability, control, and obtainable outcomes.[13] This culture has engendered an approach that fosters self-determination and autonomy in making treatment decisions.[14] This patient-centered society values having fully informed patients who make accurate assessments about their health as a cultural prerogative. [12] Western cultural assumptions exist about what is good and just in medical care. One such assumption is the principle of self-determination and its importance in enabling patients to make autonomous treatment decisions.[15]

On the other hand, patients in Italy, China, and Japan;[14] patients in Spain;[16] patients in Tanzania;[17] and Korean Americans and Mexican Americans believe that there is a positive value inherent in nondisclosure of diagnosis and of a terminal prognosis.[14-16] In the family-centered model of medical decision making, such as that found among Mexican Americans and Korean Americans, among Ethiopian refugees, and in Italy, autonomy is seen as isolating.[14,16] Patients with an Egyptian background believe that dignity, identity, and security are conferred by belonging to a family and dealing with illness within a family context.[18] Navajo culture provides another example of diverse cultural attitudes toward illness. Navajos feel that order and harmony are disrupted by receiving negative information;[14] receiving an unfavorable diagnosis and prognosis is seen as a curse.[16]

In some cultures, the negative stigma associated with the word cancer is so strong that the use of the word can be perceived as rude, disrespectful, and even causal. A study investigating the puzzling factors and solutions of family-related barriers to truthfulness with patients who have terminal cancer was conducted through a nationwide survey conducted in Taiwan. The results showed that families believe it is unnecessary to tell aged patients the truth, and patients can be happier without knowing the truth.[19] For Ethiopian refugees who are diagnosed with cancer, it is important to tell the family first but also important not to give unfavorable information at night so as to avoid the burden of a sleepless night.[16] An awareness of the use of nonverbal communication in some cultures and the psychosocial impact of terms such as cancer is helpful. Often, phrases such as malignant tumor or growth are less inflammatory and are more readily accepted,[16] as is approaching loaded topics indirectly. Thus, it is essential to assess and consider patients cultural beliefs when communicating with them about their cancer.

A study of the breast cancer experience of Asian American women [20] found that a lack of knowledge about breast cancer, cultural factors related to beliefs about illness, gender role and family obligations (e.g., self-sacrifice), and language barriers contributed to Asian American women's apparent lack of active involvement in their care.

As described above, cultural background greatly influences many aspects of the communication process. Although some cross-cultural descriptive studies have been conducted, especially on the views about disclosure of the diagnosis, relatively little is known about the specific influence of culture on the interaction between patients and their health care practitioners. How cultural variables might affect the information patients want, patients' preferred and assumed participatory styles, and other aspects of the interaction warrant future study.

The Patient's Family

Families can help patients make better decisions about their care.[21] Some therefore believe that patient-centered approaches emphasizing patient autonomy in medical decision making should be shifted to family-centered approaches because most decision making in health care is carried out in the context of family care and obligation.

Health care professionals are valued when they establish a structured and ongoing dialogue with family members about the following:[22]

- Treatment goals.
- Plans of care.
- Expectations regarding patient outcomes.

Caregivers report that specific and tailored direction is supportive and reduces the uncertainty they experience as they provide care.[22] Family caregivers must be considered an integral part of the advanced cancer care partnership.[22] In one investigation, being welcomed into the medical setting was a simple action that was greatly appreciated by caregivers and allowed them to move on with unfolding events.[23] In taking a legitimate place in the cancer scenario, caregivers may more easily attend to their own needs alongside those of the patient.[23] Ideally, however, the physician should check with the patient to determine his or her desires about the level of involvement that caretakers should have in making decisions.

(Refer to the PDQ summary on [Family Caregivers in Cancer: Roles and Challenges](#) for more information.)

Other Communication Barriers

Unless directly invited, many patients are often reluctant to ask important questions about their disease and its treatment. Some researchers have found that indirect cues signaling informational and emotional needs are far more common from patients than direct requests for information or support. Concomitantly, doctors readily respond to direct expressions of need but find it difficult to detect and respond to indirect behaviors cueing patient needs.

The indirect forms of communication that are particularly difficult for many doctors to detect and respond to

include the following:[24]

- Allusions.
- Paraverbal expressions (e.g., auditory pitch and tone).
- Nonverbal behaviors (e.g., facial expression and posture).

Patients may assume that their doctors will tell them whatever is relevant; others worry about appearing foolish if they reveal their ignorance by asking questions; and some feel guilty about taking too much of the busy doctor's time.[25,26] In the absence of explicit discussion, physicians may make incorrect assumptions and unilateral decisions about patients' information needs and preferences, incorrectly assessing their own information-giving behavior.[27] Other barriers to communication may include the multiple specialists that patients see; the multiple clinicians and others that the patient may see within the treatment team (e.g., physician, mid-level practitioner, nurse, billing office clerk, patient advocate); the challenges posed by variations in education level, cultural differences, and ethnicity; and the anxiety that often accompanies an initial or high-stakes interview (e.g., disclosure of restaging results), which may affect patient comprehension and understanding.

Nurses as Advocates for Patients and Their Families

Nurses play an important role in supporting patients through the crisis of cancer and play an important role in today's multidisciplinary cancer team. They perform key functions at almost every stage of the cancer trajectory. Clinic and inpatient nurses are frequently the first clinical contacts for patients and family members and, through their initial interactions, set the tone for the support the patient will receive throughout his or her care. Nurses are important sources of information about procedures, treatments, and other aspects of patient care. Spending more time with the patient than do physician members of the treatment team, nurses are frequently the most trusted member of the cancer team when it comes to obtaining information, and they serve as advocates for the patient when important and sensitive questions such as "How bad is it?" or "How long do I have to live?" arise. Nurses must also attend to patient and family emotional needs after bad news is given and deal first with other emotionally draining situations, such as angry patients or family members or patients who are withdrawn and depressed. Advanced practice nurses provide direct patient care, often acting as physician extenders and managing much of the day-to-day care of the patient.

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Communication Along the Disease Trajectory

Basic Communication Skills

Communication with the patient and family entails a number of essential skills, which can be remembered as five E's:[1]

- **E**ngaging the patient.
- **E**liciting the patient's understanding/current concerns.
- **E**ducating the patient.
- Addressing **E**motions.
- **E**nlisting the collaboration of the patient and caregiver.

These skills serve the following purposes:

- Developing rapport.
- Establishing patient understanding of their condition and important concerns.
- Providing information about the illness and treatment.
- Responding to emotions using empathic, validating, and clarifying responses.
- Enlisting the patient and family in the treatment plan.

An online lecture titled "Communication and Interpersonal Skills in Cancer Care" further explains these basic skills and may be found on the website of the [International Psycho-Oncology Society](#).

The application of basic communication skills to a number of oncologic challenges—including breaking bad news, shared decision making, and dealing with depression and challenging patients—has been outlined.[2]

Clinicians should remember that many patients are anxious about medical visits. Putting patients at ease will

allow better assimilation of information; and the skills of inquiring about the patient's point of view, listening without interrupting, and being empathic will be perceived as supportive and caring. As one study [3] found, the first few moments of the interaction are especially important in forming lasting impressions; a friendly handshake and making eye contact are important first steps in creating trust and rapport. Sitting down puts the health care provider at patient eye level and invites discussion rather than one-way conversation; asking the names and relationships of others in the room acknowledges their potential role as allies in the care of the patient. Inquiring briefly about the patient's hometown, family, or other personal aspects of life helps shift the focus from patienthood to personhood. Not interrupting while patients are talking and acknowledging the importance of their concerns conveys respect for their point of view.

Delivering Bad News

Giving bad news is a frequent and significant communication challenge for oncologists. Moreover, a typical oncologist in practice may give bad news thousands of times over the course of a career. Increased cancer survival now means not only that information regarding the state of the disease and its response to a multitude of treatments over time must be communicated effectively to the patient, but also that adverse information related to irreversible and potentially irreversible side effects, complications of the illness, and the treatment and diminished prospects for the future must be disclosed.

This process is made difficult by the following factors:[4-9]

- Oncologists are rarely trained in techniques for giving bad news.
- Physicians often experience negative emotions such as anxiety and fear of being blamed when they must tell patients that treatment has not worked.
- Physicians may react to patient emotions by offering false hope or premature reassurance.
- Physicians may omit important information from the disclosure.
- Patients may process information through a repertoire of coping strategies or styles called denial or blunting, which may include avoiding asking questions, being overly optimistic about the outcome, and distorting information to put it in a better light.

Diagnostic Disclosure and Discussions About Prognosis

When there was little in the way of effective anticancer treatment, physicians shied away from disclosing the cancer diagnosis for fear it would send a patient into a mental tailspin.[10][Level of evidence: II] Disclosure of a cancer diagnosis progressed from the physician-centered paternalistic approach to doctor-patient communication in the 1950s and 1960s, to full disclosure by the late 1970s.[11] Improved treatment modalities, changing societal attitudes and, in the United States, legislation enforcing the patient's right to informed decision making drove physician-patient communication in a more open or disclosing direction.[12] Consequently, today in North America and many Western countries, there is total open disclosure regarding the presence of cancer, although physicians frequently do not discuss the prognosis unless a patient asks. The reluctance to truthfully disclose a terminal prognosis persists in southern Europe, including Italy and Spain.[13] For patients, however, not discussing the diagnosis may engender feelings of isolation, anxiety, lack of autonomy or control, psychological abandonment, mistrust, suspicion, and a sense of betrayal. On the other hand, open discussion of the diagnosis decreases uncertainty, improves participation in decisions

about care, allows access to psychological support, encourages self-care, and allows the patient to begin planning for the future.[12]

Although honest disclosure can have a negative emotional impact in the short term, most patients will adjust well over time. Gratitude and peace of mind, positive attitudes, reduced anxiety, and better adjustment are some of the benefits that patients report from having been told about a diagnosis of cancer. Because uncertainty is a major cause of emotional distress for patients, relief from uncertainty can, in itself, be therapeutic;[14] some believe that over time, patients achieve a psychosocial objective correlative of order within the context of chaos theory.[15] When bad news is given tactfully, honestly, and in a supportive fashion, the patient's experience of the conversation is less stressful. Not being told about the severity of their condition or not having the opportunity to express their fears and concerns may lead patients to believe that nothing can be done to help them or may prevent them from understanding their disease.[16];[17][Level of evidence: II] On the other hand, a patient who is told bad news bluntly by a practitioner who is trying to quickly complete the difficult task of sharing bad news will likely feel extremely frightened and unsupported. Being told that there is nothing more to be done can engender feelings of abandonment.[17] One study [18] [Level of evidence: II] surveyed 497 cancer patients regarding their experiences receiving their cancer diagnoses.

Significant predictors of patient satisfaction with the conversation included the following:

- Perceiving the physician as personally interested.
- Being able to understand the information given.
- Being informed in the proper environment (doctor's office).
- Having more time invested in discussing the information.

Although most patients wish to have complete and accurate information regarding their condition, many patients feel that the news is forced upon them unless their right to have the news given according to their preferences is acknowledged by the physician (e.g., "Are you someone who wants to know all the details about your condition?").

A study [19][Level of evidence: II] of 351 patients who had a variety of cancers at different stages and who were seen at M.D. Anderson Cancer Center elicited patient communication preferences when they were given bad news of the initial cancer diagnosis or recurrence. The highest rated elements included the following:

- The doctor being up-to-date on the latest research on the patient's cancer.
- The doctor informing the patient about the best treatment options and taking time to answer all patient questions.
- The doctor being honest about the severity of the condition.
- The doctor using simple and clear language, giving the news directly, and giving full attention to the patient.

Differences were noted in patient preferences based on sex, age, and level of education, underscoring the

importance of tailoring the discussion to the individual patient. Cancer type did not predict patient preferences. It is important for a physician to elicit patient perspective on his or her condition because many incorrect beliefs can be clarified for the patient's benefit.

One protocol or method of disclosing bad news is represented by the acronym SPIKES,[4] an approach that comprises the following six steps:

- **S**—**S**etting up the interview (choosing the right location, establishing rapport).
- **P**—Assessing the patient's **P**erception of the medical situation.
- **I**—Obtaining the patient's **I**nvitation (asking the patient's permission to explain).
- **K**—Giving **K**nowledge and information to the patient.
- **E**—Addressing the patient's **E**motions with empathic responses (addressing emotions that might occur during bad news disclosure and strategizing a treatment plan).
- **S**—**S**trategy and **S**ummary (summarizing the plan for the patient and family).

The SPIKES method is useful because it is short, is easily understandable, and focuses on specific skills that can be practiced. Moreover, this protocol can be applied to most situations of breaking bad news, including diagnosis, recurrence, transition to palliative care, and even error disclosure. This method also includes reflective suggestions for physicians on how to deal with their own distress in being the messenger of bad news. In an innovative qualitative study focused on communicating bad news related to cancer recurrence, [20] patients with diagnoses of gastrointestinal cancers during the previous 2 years listened to audio recordings of oncologists using the SPIKES approach (with standardized actors) and then identified what they liked and disliked about the communications. Three major themes were identified:

- Recognition, which involved the physician acknowledging or reflecting the patient's emotional response, without becoming overly emotional or offering platitudes.
- Guidance, which referred to the physician remaining in charge of the dialogue, pointing out the patient's strengths, and offering positive recommendations.
- Responsiveness, which involved the physician moving back and forth between providing "recognition" and providing "guidance," using an interacting, rather than lecturing, style.

Patients consistently noted that they did not like the physician beginning the communication of bad news with words such as "unfortunately."

Whereas most physicians in Western countries tell their patients that they have cancer, information about prognosis is less commonly presented. Most cancer patients report that prognostic information is of great importance to them. If patients are actively encouraged to ask questions, prognosis is the one area in which they desire information and actually increase their question-asking.[21] In one study,[22][Level of evidence: II] prognostic information that was rated as most important by women with early-stage breast cancer included knowing the probability of cure, disease stage, and chance of curative treatment and receiving 10-year survival figures comparing receipt and nonreceipt of adjuvant therapy. Probability of cure and knowledge of disease stage were also identified as high-priority needs in another study of women with early-

stage breast cancer.[23][[Level of evidence: II](#)] However, patients clearly vary in their desire for prognostic information, and patients with more advanced cancer may be less inclined to receive information about their life expectancy;[24] many others may be ambivalent. It has also been shown that physicians and their patients who have advanced cancers often overestimate the probability of survival.[11] Thus, there is considerable controversy about how to discuss prognosis with patients; a number of articles have made valuable suggestions.[24-28]

Transition to Palliation and End-of-life Care

Communicating with dying patients can be complicated by practitioners' own reactions such as anxiety, sadness, and frustration,[7] combined with the historic tendency in Western medicine to focus on cure. The data from one study suggest additional reasons. Physicians strive to achieve a delicate balance between providing honest information and doing so in a sensitive way that does not discourage hope.[29] Physicians may fear that the revelation of a grim prognosis may psychologically damage patients' hopes and may diminish their will to survive through a form of prophecy. This fear is consistent with a Western cultural assumption that one needs hope to battle cancer. Physicians are also uncomfortable with putting odds on longevity, recurrence, and cure because they do not know when or how individual patients will die.[11] In one study,[30][[Level of evidence: II](#)] hope was a constant theme of the respondents. However, many patients do not measure hope solely in terms of cure, but hope may represent achieving goals, having family and oncologist support, and receiving the best treatment available.[30,31]

The value of end-of-life discussions is not solely psychological. In addition, aiding patients with end-of-life discussions through this kind of communication has an impact on health care costs. In a large study of people with advanced cancer, patients who reported having end-of-life discussions with their physicians (n = 188) had significantly lower health care costs than did patients who did not have these discussions (n = 415). This was demonstrated by a reduction in resuscitation, ventilator use, and intensive care stay. There was no difference either in survival time or in the likelihood of receiving chemotherapy for patients who discussed end-of-life preferences with physicians (n = 75) and those who did not (n = 70). Higher costs were associated with worse quality of life at death, as rated by the patient's caregiver (hospice nurse or family member).[32] [[Level of evidence: II](#)]

Patients facing death have myriad concerns that include the following:[33-36]

- Leaving children and other loved ones behind.
- Decline in the socially based aspects of one's identity.
- Being unable to fulfill normal roles.
- Fear of burdening loved ones.
- Loss of control.
- Deterioration in personal appearance.
- Needing help with intimate personal care and routine activities of daily living.
- Worries about mental awareness.
- Pain and management of symptoms.

- Quality of life.
- Dignity.
- Achieving a sense of completion.
- Having a good death.
- Abandonment.

During transitions, patients want their oncologists to provide biomedical information, show that they care about them as individuals, and balance hope with realism. One study [37] identified several communication strategies to accomplish this, including “ask-tell-ask” and “hope for the best, prepare for the worst.” A number of patients are grateful for the opportunity to talk about questions of death, though they often have few opportunities because many patients find that the medical staff is afraid of or uncomfortable with talking about death and dying,[31] which exacerbates feelings of isolation and separation.

Saying goodbye to patients is an area discussed in an article that provides practical suggestions for communicating with the patient at the end of life.[38] The authors suggest that saying goodbye is an important way for the oncologist to achieve closure with the patient by acknowledging the importance of the relationship and expressing appreciation to the patient.

Strategies for Delivering Bad News

When existential concerns are translated to the clinical setting, the optimal method of breaking bad news becomes a primary concern. Giving bad news abruptly has been found to increase its negative impact.[39] Patients also report particularly negative reactions as a result of the following circumstances:

- News delivered over the telephone or in the recovery room.
- Doctors withholding information.
- Clinicians’ failure to provide information about the availability of additional help.
- Information given bluntly and factually (e.g., “You have a terminal cancer and you have 6 months to live”).[40]

Patients also report that letters and tapes of the bad news consultation are helpful and may increase their level of satisfaction with and retention of the information provided.[14]

One survey found that most physicians do not have a consistent plan or strategy for breaking bad news to their patients.[39] Among a sample of physicians who attended an annual meeting of the American Society of Clinical Oncology, 22% reported that they did not have a consistent approach to the task of delivering bad news to patients, and 51.9% reported that they had several techniques or tactics but did not have an overall plan. Determining what patients believe to be important in the interaction may help refine the current guidelines and yield specific, evidence-based recommendations for facing this challenging task.[4]

Some general guidelines and recommendations for how bad news interviews should be conducted have been published.[4,19,41-43] However, these recommendations have usually taken the form of practical advice

formulated on the basis of anecdotal experiences or opinions with little empirical foundation. For example, in one review of more than 300 articles from the published literature between 1973 and 1993, only 23.2% of authors reported descriptive data on breaking bad news, and almost two thirds were opinions, reviews, letters, case reports, or non-data-based descriptive studies.[39] Although there are some subtle differences between approaches recommended for giving bad news, there are also many common elements. For example, each of the strategies referenced above recommends giving the news in an appropriate setting (quiet place, with uninterrupted time), assessing the patient's understanding of their illness, providing the information the patient wants, allowing the patient to express emotions and responding appropriately, summarizing the information provided, and coming up with a plan for the next step(s). Additional research is needed to empirically support these techniques.

Research also suggests that the structure and content of the consultation influences the patient's ability to remember what has been said in the following ways:[16]

- Patients usually recall facts provided at the start of a consultation more readily than those given later.
- Topics deemed most relevant and important to the patient (which might not be those considered most pertinent to the doctor) are recalled most accurately.
- The larger the number of statements made by a doctor, the smaller the mean percentage recalled by the patient.
- Items that patients manage to recall do not decay over time, as do other memories.

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Communicating with Children About Their Cancer

In seriously ill adults and also in children, uncertainties about the future often provoke a profound sense of loss of control. Studies show that children wish to be informed about their illness and plans for treatment.[1]

Although children's information needs may be age-dependent, most will worry about the impact of the disease and medical treatments on their daily lives and on others around them. Studies also show that when information, even if unfavorable, is withheld from children, the silence exacerbates the child's fears and fantasies.[2] While not all terminally ill children want to talk specifically about death or the dying process, when they realize that their future is limited, they adapt by shifting their focus to a more immediate future such as the next holiday or a significant event.[3] Some children also have a surprising awareness of the fact that they are going to die. Children have asked questions such as the following:

- "Is it going to hurt?"
- "Will I be able to breathe?"
- "Will an angel come and take me away?"

Sometimes children will act out their concerns with disruptive behaviors. When communication barriers are addressed, these disruptive behaviors often disappear.

What Do Children Understand About the Concept of Death?

According to classical developmental theory, children do not fully comprehend the irreversibility of death until the approximate ages of 11 years to 16 years.[4] However, even much younger children understand the principle of cause and effect; most children with fatal illnesses—even those as young as age 3 years or 4 years—pick up cues from the physiological changes in their bodies as well as the reactions of parents and hospital staff and thus have an advanced understanding of disease and the concept of death.[5] Dying children are also aware of the short time they have left, especially adolescents who are acutely focused on the future. Thus, approaching a child with a preconceived notion of what a typical child of that age can understand about death is not always helpful in a clinical setting.[6]

Discussing Terminal Illness with Children

Strategies for discussing end-of-life issues suggest that it is useful to formulate specific skills to be embodied in discussions that often begin long before a child is terminally ill.[5] The following strategy, which can be remembered as six E's, may be used as a guide for health care providers who communicate with dying children and their family members:[7]

- **Establish** an agreement concerning open communication with parents, children, and caregivers early in your relationship with them. Begin by exploring the attitudes of the child's caregivers about sharing medical information with the child and answering any concerns they might have.
- **Engage** the child at an opportune time. A newly diagnosed serious illness or the occasion when a child takes a turn for the worse are medical events that should trigger discussion.
- **Explore** what the child already knows and wants to know about the illness. This will allow you to correct misperceptions and misunderstandings about the medical facts and to give information according to the child's desire for information.
- **Explain** medical information according to the child's needs and age.
- **Empathize** with the child's emotional reactions.

- **Encourage** the child by reassuring him or her that you will be there to listen and be supportive.

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Training in Communication Skills

Training Providers

Some believe that effective communication between doctor and patient is a core clinical skill that should be taught as rigorously as other medical sciences are taught.[1] Underlying this belief is a growing body of research and development of guidelines acknowledging that physicians need not be born with excellent communication skills but can learn as they practice various other aspects of medicine.[2]

Clinicians specializing in cancer acknowledge that insufficient training in communication and management skills is a major factor contributing to their stress, lack of job satisfaction, and emotional burnout.[3,4] Unfortunately, few oncologists or nurses have received adequate formal education in communication skills using methods likely to promote change, confidence, and competence.[3,4] On the other hand, good physician-patient communication is associated with the following:[3,4]

- Adherence to drug regimens and diets.
- Pain control.
- Resolution of physical and functional symptoms.
- Control of blood sugar and hypertension.
- Good psychological functioning of patients.

Most (80%) patient-physician communication studies involve primary care physicians (i.e., family medicine physicians, general internists, or pediatricians). However, approximately 20% of studies in one review [5] used

cancer providers, revealing a trend of inadequate training in patient communication for oncologists and other health professionals who deal with cancer patients, particularly with respect to giving bad news and handling strong, emotionally charged interview contexts.[5,6]

One group of authors believes there are four tasks in teaching effective practitioner–cancer patient communication:[7]

1. Defining and distributing a comprehensive, evidenced-based curriculum.
2. Recruiting faculty and/or local practitioners who embrace this curriculum and employ it in practice.
3. Anchoring the curriculum in evidence-supported behaviors to promote effective interventions and focusing clinical controversies on the spectrum of naturally occurring communication styles that arise when working with patients.
4. Employing longitudinal reinforcement.

Given a well-developed and broadly accepted curriculum, the next step in establishing a successful communication program is to create surroundings that maximize the opportunity to learn, practice, and internalize the curriculum. Longitudinal learning programs that utilize a cohesive faculty result in more meaningful incorporation of curricular elements into the practice styles of learners.[7]

Various approaches to training physicians to communicate with cancer patients have been instituted to meet these guidelines. One approach is a program titled Oncotalk,[8] a communication skills program built around evidence-based educational techniques. In an intensive 4-day retreat focused on communication at the end of life, medical oncology fellows are exposed to didactic material that incorporates specific interviewing skills. They then interview standardized patients while they are observed by trained facilitators, who act as coaches to help the oncology fellows recognize and deal with obstacles and challenges in the encounter. The curriculum encompasses basic communication skills such as how to respond to emotional concerns and affect and communication skills along the disease trajectory, including the following:[8,9]

- Giving bad news.
- Conducting a family conference.
- Managing the transition from curative to palliative therapy.
- Responding to requests for futile treatments.

Societies such as the American Society of Clinical Oncology (ASCO) have developed and adopted specialized curricula for communicating with older cancer patients.[7] Several authors have published positive results from randomized trials or other outcomes assessments of communication skills training in oncology.[10,11]; [12,13][Level of evidence: I][14,15]

Other approaches that have been used to enhance the communication skills of physicians include the following:

- A skills-based approach that designs structured training activities to teach communication skills.[16]

- Development of an innovative assessment instrument to facilitate curricular mapping of palliative care education.[17]
- Efforts to enhance residents' knowledge, skills, and attitudes needed for effective palliative care.[18]
- Listening to the patient and responding with care as a model for teaching communication skills and to frame the patient-physician relationship around trust and respect.[19]
- The use of serial standardized patient-based assessments of medical students' acquisition of core clinical skills.[20][[Level of evidence: II](#)]

Nurses in Communication with Physicians

In general, nurses spend more time with patients than do their physician counterparts. Nurses play a vital role in supporting the patient through the crisis of cancer. Nurses are frequently left to pick up the pieces after physicians have delivered bad news or explained information about an illness. Questions such as "How bad is it?" or "How long do I have to live?" are often posed to nurses by patients who either are reluctant to bother the doctor or feel uncomfortable about asking for information. Nurses play a vital role on the treatment team, advocating for patients and acting as intermediaries for patient requests or concerns. Thus, teamwork between physicians and nurses is essential. However, role and status differences between nurse and physician can sometimes make communication challenging.

While nurses receive a fair amount of training in communication and interpersonal skills during their undergraduate years, it is widely recognized that for oncology nurses, advanced training in communication skills and subjects such as death and dying are highly desirable. Research suggests that these training programs are useful and well-received.[21]

Training Patients in Communication Skills

Although less common than interventions for providers, a number of interventions have been designed to help cancer patients navigate their health care issues and improve communication with their providers. The goals of these interventions have varied across studies and have included outcomes such as the following:

- Increasing patients' question-asking in the consultation.[22-24]
- Increasing recall of the information discussed in the consultation.[25,26]
- Increasing patient satisfaction.[27,28]
- Improving patients' psychological adjustment.[26,29,30]

These interventions have met with varying degrees of success, but most are quite labor intensive.

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Current Clinical Trials

Check NCI's PDQ Cancer Clinical Trials registry for U.S. supportive and palliative care trials about [communication in cancer care](#) that are now accepting participants. The list of trials can be further narrowed by location, drug, intervention, and other criteria.

General information about clinical trials is also available from the [NCI website](#).

Changes to This Summary (02/01/2018)

The PDQ cancer information summaries are reviewed regularly and updated as new information becomes available. This section describes the latest changes made to this summary as of the date above.

Editorial changes were made to this summary.

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The lead reviewers for Communication in Cancer Care are:

- Mary K. Buss, MD, MPH (Beth Israel Deconess Medical Center)
- Larry D. Cripe, MD (Indiana University School of Medicine)
- Esme Finlay, MD (University of New Mexico)
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