

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

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Overview

This summary provides oncology clinicians with an overview of key topics in communication in cancer care. The goal is to facilitate more effective communication between cancer clinicians and the patients and families they care for. The summary explores the following topics:

- Discussion of the literature on the goals and importance of high-quality communication.
- Overview of common communication models.
- Demographic and cultural influences on communication.
- Evidence on education and training in cancer communication for clinicians.
- Communication challenges in oncology and methods used to approach them.
- Considerations for communication in pediatric oncology.

The literature on communication in cancer care is actively evolving and, to date, much of it has been descriptive, observational, and/or qualitative. When possible, controlled/randomized data have been included.

Communication research is also particularly vulnerable to bias and other confounders, an issue discussed further [below](#).

Communication involves an exchange of information and a means of connection between two people or parties. The relationship between the clinician and the patient embodies both aspects of communication. Patients with cancer desire information about their disease to make choices about cancer treatment and, ultimately, to live their lives more fully. In addition, most patients look to their oncologist and other cancer clinicians for guidance and support. Frequently, the information that oncologists share with patients is serious in nature and may evoke strong emotions from patients and caregivers. Effective communication requires oncologists to convey information in a manner that patients can understand, manage emotional responses to the information provided, and help patients make sound medical decisions.

Patient-clinician communication is defined by its bidirectional nature, with each participant giving and receiving information. Patients and their families are often greatly invested in their personal relationship with their oncologist, and the intensity and longitudinal nature of these relationships is likewise an aspect that attracts many clinicians to the field of oncology.

Goals and Importance of Communication

Effective communication may impact health outcomes, though it remains challenging to demonstrate direct causal relationships between communication techniques and outcomes and/or identify the precise elements of patient-provider communication in oncology that result in improved physical, emotional, and other health care outcomes. Although the body of oncology-specific communication research is growing, level I evidence supporting specific tools or interventions from randomized controlled trials remains limited. Notably, studies on communication may have several confounders, including recall bias, self-reporting bias, and multiple influences on

understanding. Communication research also suffers from a lack of standardized and validated communication assessment measures, while rigid and/or specific approaches to communication may fail to adapt to social and cultural differences in communication.

Despite these challenges in the literature, investigators have proposed links between good patient-centered communication skills—focused on defining and attending to the specific information needs of the patient, fostering trusting relationships, and addressing both cognitive and emotional needs in communication—with the following patient- and system-related outcomes:[1]

- Enhanced patient satisfaction.[2]
- Increased quality of life.[3,4]
- Reduced patient anxiety and improved symptom control. [4-7]
- Adherence with treatment recommendations.[8]
- Enhanced accrual to clinical trials.[9]
- Improved disease-related understanding.[10]
- Improved prognostic awareness.[11,12]
- Receipt of care consistent with the patient's stated preferences, particularly at the end of life.[12,13]
- Decreased oncologist stress and burnout.[14]

Conversely, there is also evidence to suggest that patient dissatisfaction with poor communication may lead to negative outcomes, such as increased malpractice suits. A small number of physicians appears to generate a disproportionate number of lawsuits.[15,16] 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.[17] Rather, patient dissatisfaction—especially with interpersonal

aspects of care such as the physician's friendliness and courteousness, ability to convey information to the patient, and concern for patient worries—seems to be an important determining factor.[18]

In the best-case scenario, a communication event results in knowledge creation for both parties, allowing clinicians to help guide and support patients in making decisions aligned with their goals and values, and empowering patients to participate more actively in their health care.

References

1. Ong LM, Visser MR, Lammes FB, et al.: Doctor-patient communication and cancer patients' quality of life and satisfaction. *Patient Educ Couns* 41 (2): 145-56, 2000. [[PUBMED Abstract](#)]
2. Zachariae R, Pedersen CG, Jensen AB, et al.: Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. *Br J Cancer* 88 (5): 658-65, 2003. [[PUBMED Abstract](#)]
3. Lorusso D, Bria E, Costantini A, et al.: Patients' perception of chemotherapy side effects: Expectations, doctor-patient communication and impact on quality of life - An Italian survey. *Eur J Cancer Care (Engl)* 26 (2): , 2017. [[PUBMED Abstract](#)]
4. Pozzar RA, Xiong N, Hong F, et al.: Perceived patient-centered communication, quality of life, and symptom burden in individuals with ovarian cancer. *Gynecol Oncol* 163 (2): 408-418, 2021. [[PUBMED Abstract](#)]
5. Mack JW, Fasciano KM, Block SD: Communication About Prognosis With Adolescent and Young Adult Patients With Cancer: Information Needs, Prognostic Awareness, and Outcomes of Disclosure. *J Clin Oncol* 36 (18): 1861-1867, 2018. [[PUBMED Abstract](#)]
6. Shin JA, El-Jawahri A, Parkes A, et al.: Quality of Life, Mood,

and Prognostic Understanding in Patients with Metastatic Breast Cancer. *J Palliat Med* 19 (8): 863-9, 2016. [[PUBMED Abstract](#)]

7. Lin JJ, Chao J, Bickell NA, et al.: Patient-provider communication and hormonal therapy side effects in breast cancer survivors. *Women Health* 57 (8): 976-989, 2017. [[PUBMED Abstract](#)]
8. Jacobs JM, Pensak NA, Sporn NJ, et al.: Treatment Satisfaction and Adherence to Oral Chemotherapy in Patients With Cancer. *J Oncol Pract* 13 (5): e474-e485, 2017. [[PUBMED Abstract](#)]
9. Albrecht TL, Eggly SS, Gleason ME, et al.: Influence of clinical communication on patients' decision making on participation in clinical trials. *J Clin Oncol* 26 (16): 2666-73, 2008. [[PUBMED Abstract](#)]
10. Weeks JC, Catalano PJ, Cronin A, et al.: Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med* 367 (17): 1616-25, 2012. [[PUBMED Abstract](#)]
11. Lobb EA, Halkett GK, Nowak AK: Patient and caregiver perceptions of communication of prognosis in high grade glioma. *J Neurooncol* 104 (1): 315-22, 2011. [[PUBMED Abstract](#)]
12. Liu PH, Landrum MB, Weeks JC, et al.: Physicians' propensity to discuss prognosis is associated with patients' awareness of prognosis for metastatic cancers. *J Palliat Med* 17 (6): 673-82, 2014. [[PUBMED Abstract](#)]
13. Tang ST, Wen FH, Hsieh CH, et al.: Preferences for Life-Sustaining Treatments and Associations With Accurate Prognostic Awareness and Depressive Symptoms in Terminally Ill Cancer Patients' Last Year of Life. *J Pain Symptom Manage* 51 (1): 41-51.e1, 2016. [[PUBMED Abstract](#)]
14. Graham J, Ramirez A: Improving the working lives of cancer clinicians. *Eur J Cancer Care (Engl)* 11 (3): 188-92,

2002. [\[PUBMED Abstract\]](#)

15. May ML, Stengel DB: Who sues their doctors? How patients handle medical grievances. *Law Soc Rev* 24 (1): 105-20, 1990.
16. Brueck M, Salib AM: Strategies for Acing the Fundamentals and Mitigating Legal and Ethical Consequences of Poor Physician-Patient Communication. *AMA J Ethics* 19 (3): 289-295, 2017. [\[PUBMED Abstract\]](#)
17. Stelfox HT, Gandhi TK, Orav EJ, et al.: The relation of patient satisfaction with complaints against physicians and malpractice lawsuits. *Am J Med* 118 (10): 1126-33, 2005. [\[PUBMED Abstract\]](#)
18. Hickson GB, Federspiel CF, Pichert JW, et al.: Patient complaints and malpractice risk. *JAMA* 287 (22): 2951-7, 2002. [\[PUBMED Abstract\]](#)

Models of Communication

Few would dispute that patient-oncologist communication has both desirable and undesirable consequences. The topics and verbal or nonverbal communication behaviors that reliably lead to desirable consequences—or away from undesirable consequences—remain largely a matter of speculation, despite a proliferation of communication skills training interventions and a growing number of empirical studies. The question, however, is of great importance to the interested oncology clinician. The consensus is that the current status of patient–oncology clinician communication is suboptimal and often leads to undesirable consequences for the patient.

For example, an often-cited, large, cross-sectional study of patients with advanced-stage cancer demonstrated that only 38% recalled discussing their end of life (EOL) preferences with a clinician. Those who did were less likely to receive intensive medical treatments (intubation, resuscitation, and intensive care

unit admissions) and more likely to enroll in hospice. Furthermore, more aggressive medical treatment was associated with lower quality of life.[1] Many other observational studies confirm the low rate of conversations about EOL and the negative consequences of not having these conversations. Left unanswered is the question of what clinicians can do differently to improve health care behaviors and outcomes. For more information, see [Planning the Transition to End-of-Life Care in Advanced Cancer](#).

Oncology clinicians acknowledge that they feel unprepared for communication with patients, especially those who may be near the EOL. They identify as additional impediments inadequate time during the average clinic visit for these difficult conversations and the emotional challenges inherent in these conversations. Communication skills training can increase clinicians' confidence, improve certain communication behaviors, and lead to better patient satisfaction.[2] However, these and other interventions do not consistently improve other measures of communication or actual health care choices and consequences.

One explanation for the limited impact of communication interventions on patient outcomes is that models of patient-oncologist communication may not accurately reflect what happens before, during, and after encounters between patients and oncology clinicians. There are several reasons this may be the case:

- First, models reflect an ideal. In some cases, the ideal is based on ethical principles derived from research oversight rather than clinical medicine.[3] Informed consent is one example of a model based on what should happen rather than what may actually be happening.
- Second, models represent the potential relationships between variables of interest. A model may reasonably describe what happens with the measured variables but not accurately capture what happens during communication and

the mechanisms that link it to outcomes.[4]

- Third, definitions and measures of communication quality are not standardized.[5,6] Measures of patient, caregiver, and clinician perceptions of communication assess participants' subjective experiences and likely capture constructs that are distinct from the content of the communication encounter. Objective assessment of communication content and behavior requires investigators to manually code audio or video tapes of patient-clinician communication encounters, a process that may be perceived as intrusive by research participants and resource-intensive by investigators.

Many but not all studies, for example, suggest that patient expectations or prognostic understanding influence treatment decisions.[7,8] The different definitions and measures of prognostic expectations, however, may mean that related but unidentified factors are important.[9] Finally, often the data are derived from cross-sectional studies. Causal inferences are common but may not be accurate absent confirmation in a well-designed prospective trial.

That said, models are potentially useful heuristics, problem-solving techniques that use self-education to improve performance. They provide oncology clinicians with a broad sense of the goals of communication and required skills. Familiarity with the more common models also gives oncology clinicians a framework to evaluate new data and modify their approach to communication. This section describes and evaluates briefly the two dominant models of communication: shared decision making and patient-centered communication. Each model has advantages and provides a potential road map to better communication. No data allow clinicians to favor one model over another.

It is worthwhile to mention two less commonly discussed but potentially important models. The first is Cognitive-Emotional Decision Making (CEDM). One review proposed CEDM based on

the potential interaction between emotions and cognition during decision making.[10] The authors' model synthesized three well-established concepts. First, emotions inform patients' decisions. The idea that decision making is a cognitive exercise in which the patient compares the relative risks and benefits of options is incomplete. Patients often use emotional cues—what they are feeling—to evaluate the relative importance of the risks and benefits. Second, people cope with health threats by evaluating the salience of the threat and the resources available to meet the threat. Third, people develop internal representations of the meaning of illness, and their representations influence how they evaluate and adhere to recommendations. There has not yet been empirical testing of the CEDM model. However, the model warrants mention since it recognizes emotion and coping as intrinsically relevant to the decision-making process.

The second type of model focuses on explaining the causes of behavior change. Social Cognitive Theory and the Theory of Planned Behavior are two examples.[11,12] Their relevance comes from the idea that if improvements in communication are to lead to improvements in health care outcomes, then we must understand how communication changes behaviors. For example, how do conversations lead a patient to forgo cardiopulmonary resuscitation and enroll in hospice? The models recognize that people seek positive outcomes while they try to avoid negative outcomes. Communication is one influence on the patient's deliberations around strategies and efforts to prepare for change and then act accordingly. The models further posit that there are several modifiable mediators, e.g., knowledge, beliefs, perceived communication competence, and skills, to effect behavior change.

Shared Decision Making

Shared decision making (SDM) was an ideal initially proposed to engage the patient in health care decisions. Prior to that, physicians tended to act as if they alone had the information necessary to formulate a diagnostic and treatment plan independent of the patient but in the patient's best medical

interest. In contrast, SDM models rest on the premise that both patients and clinicians make essential contributions to the decision-making process. Neither knows enough to make a sound decision independent of the other. Clinicians are experts in diseases and treatments. Patients are experts in their values and the trade-offs they are willing to accept. Clinicians may describe options for treatment or care and the anticipated benefits or harms, including their likelihood. However, only the patient can determine the importance of the benefits and harms since such judgments require some sense of the patient's values and goals.

Widespread integration of SDM into patient-oncologist communication has lagged for several reasons. First, there is no consensus about what verbal and nonverbal communication behaviors are essential to SDM. Systematic reviews of the relevant literature published in 2006 and 2019 concluded that there is no unified model of SDM.[\[13,14\]](#) The 2019 publication identified 53 different elements mentioned in at least one of the 40 articles analyzed. The most common elements included: make the decision, elicit and integrate patient preferences, tailor information, and deliberate about options and their benefits and harms with the patient.

A second reason relates to patients' general satisfaction with communication, regardless of whether there is evidence of SDM. For example, investigators followed 14 patients with advanced cancer with in-depth interviews and observations of outpatient clinic visits.[\[15\]](#) They found little evidence of SDM; however, patients rated communication encounters favorably.

A third reason relates to uncertainty about the best way to train clinicians in SDM behaviors and support implementation. The training question will likely remain relevant absent a consensus about the key attitudes and skills necessary to introduce SDM into clinical encounters. Many tools to support SDM, such as decision aids, have been tested and generally show improvement in measures of patient satisfaction and reduction

in decisional conflict. These effects are modest, and improvements in patterns and consequences of health care choices are rarely seen.[16] In addition, decision aids and other tools are not widely used.[17]

At present, SDM is essentially a laudable goal of communication in search of a method. Few would disagree that patients should be fully informed of the options and their potential harms and benefits to the extent that they desire. Once informed, patients then should have an opportunity to integrate their values and goals into their choices.[18] Clinicians can play a valuable role in SDM by helping patients recognize the implications of each option for the patient's values and goals.[19]

Patient-Centered Communication

The National Cancer Institute commissioned communication scholars Ronald Epstein and Richard Street to evaluate the status of patient-centered communication in cancer care as part of its strategic plan to integrate social, psychological, and communication research with biomedical research. The resulting monograph presents an aspirational and comprehensive model of what patient-centered communication might accomplish. This model proposes six core functions of communication: foster healing relationships, exchange information, respond to emotion, manage uncertainty, make decisions, and enable patient self-management.[20]

The most direct evaluation of the impact of patient-centered communication on patient outcomes is the Values and Options in Cancer Care (VOICE) trial.[21] The design of the intervention and the outcome measures were based on Street's Ecological Model of Patient-Centered Communication and four key communication goals (engaging patients and caregivers, responding to patient concerns, informing patients about treatment choices, and framing prognosis). The model suggests that interventions should target the mutual interactions between patients and oncologists rather than focusing on individual communication behaviors. In addition, the intervention should

be sensitive to the social and clinical contexts relevant to the success of the intervention.

The VOICE trial was a cluster randomized clinical trial conducted at multiple clinics. A total of 118 patients were enrolled in the prerandomization period and 265 patients after physician randomization to either the intervention (n = 130) or control (n = 135) groups. The primary outcome was a composite measure based on an analysis of audio recordings of clinical encounters. The composite measure scored behaviors related to patient engagement and evidence of clinicians responding to emotion, informing patients about prognosis and treatment choice, and providing balanced information. The secondary outcomes included proximal measures of communication outcomes, e.g., the human connection scale, and distal outcomes such as aggressive treatment or hospice enrollment. The intervention improved communication behaviors, as assessed by the composite measure, without changing secondary outcomes.

Conclusions

Models of communication articulate laudable goals and provide a high-level road map for communication in cancer care. Patients, caregivers, clinicians, and researchers seem to share a common understanding of the goals.[\[22\]](#) The missing details, however, hamper the development of curricula and effective interventions. In the meantime, clinicians may choose to organize or explain their communication strategies using models and modify as new evidence clarifies the communication behaviors that are most impactful.

References

1. Wright AA, Zhang B, Ray A, et al.: Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 300 (14): 1665-73, 2008. [\[PUBMED Abstract\]](#)
2. Moore PM, Rivera S, Bravo-Soto GA, et al.: Communication skills training for healthcare professionals working with

people who have cancer. Cochrane Database Syst Rev 7: CD003751, 2018. [\[PUBMED Abstract\]](#)

3. Agledahl KM, Førde R, Wifstad A: Choice is not the issue. The misrepresentation of healthcare in bioethical discourse. *J Med Ethics* 37 (4): 212-5, 2011. [\[PUBMED Abstract\]](#)
4. Street RL: How clinician-patient communication contributes to health improvement: modeling pathways from talk to outcome. *Patient Educ Couns* 92 (3): 286-91, 2013. [\[PUBMED Abstract\]](#)
5. Epstein RM, Franks P, Fiscella K, et al.: Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Soc Sci Med* 61 (7): 1516-28, 2005. [\[PUBMED Abstract\]](#)
6. Street RL: The many "Disguises" of patient-centered communication: Problems of conceptualization and measurement. *Patient Educ Couns* 100 (11): 2131-2134, 2017. [\[PUBMED Abstract\]](#)
7. Zafar SY, Malin JL, Grambow SC, et al.: Chemotherapy use and patient treatment preferences in advanced colorectal cancer: a prospective cohort study. *Cancer* 119 (4): 854-62, 2013. [\[PUBMED Abstract\]](#)
8. Mack JW, Walling A, Dy S, et al.: Patient beliefs that chemotherapy may be curative and care received at the end of life among patients with metastatic lung and colorectal cancer. *Cancer* 121 (11): 1891-7, 2015. [\[PUBMED Abstract\]](#)
9. Cripe LD, Rand KL, Perkins SM, et al.: Ambulatory Advanced Cancer Patients' and Oncologists' Estimates of Life Expectancy Are Associated with Patient Psychological Characteristics But Not Chemotherapy Use. *J Palliat Med* 21 (8): 1107-1113, 2018. [\[PUBMED Abstract\]](#)
10. Power TE, Swartzman LC, Robinson JW: Cognitive-emotional decision making (CEDM): a framework of patient medical decision making. *Patient Educ Couns* 83 (2): 163-9,

2011. [\[PUBMED Abstract\]](#)

11. Prochaska JO, Velicer WF: The transtheoretical model of health behavior change. *Am J Health Promot* 12 (1): 38-48, 1997 Sep-Oct. [\[PUBMED Abstract\]](#)
12. Bandura A: Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev* 84 (2): 191-215, 1977. [\[PUBMED Abstract\]](#)
13. Makoul G, Clayman ML: An integrative model of shared decision making in medical encounters. *Patient Educ Couns* 60 (3): 301-12, 2006. [\[PUBMED Abstract\]](#)
14. Bomhof-Roordink H, Gärtner FR, Stiggelbout AM, et al.: Key components of shared decision making models: a systematic review. *BMJ Open* 9 (12): e031763, 2019. [\[PUBMED Abstract\]](#)
15. Brom L, De Snoo-Trimp JC, Onwuteaka-Philipsen BD, et al.: Challenges in shared decision making in advanced cancer care: a qualitative longitudinal observational and interview study. *Health Expect* 20 (1): 69-84, 2017. [\[PUBMED Abstract\]](#)
16. O'Connor AM, Stacey D, Rovner D, et al.: Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* (3): CD001431, 2001. [\[PUBMED Abstract\]](#)
17. Légaré F, Adekpedjou R, Stacey D, et al.: Interventions for increasing the use of shared decision making by healthcare professionals. *Cochrane Database Syst Rev* 7: CD006732, 2018. [\[PUBMED Abstract\]](#)
18. Katz SJ, Belkora J, Elwyn G: Shared decision making for treatment of cancer: challenges and opportunities. *J Oncol Pract* 10 (3): 206-8, 2014. [\[PUBMED Abstract\]](#)
19. Witteman HO, Julien AS, Ndjaboue R, et al.: What Helps People Make Values-Congruent Medical Decisions? Eleven Strategies Tested across 6 Studies. *Med Decis Making* 40 (3): 266-278, 2020. [\[PUBMED Abstract\]](#)
20. Street RL, Makoul G, Arora NK, et al.: How does

communication heal? Pathways linking clinician-patient communication to health outcomes. Patient Educ Couns 74 (3): 295-301, 2009. [\[PUBMED Abstract\]](#)

21. Epstein RM, Duberstein PR, Fenton JJ, et al.: Effect of a Patient-Centered Communication Intervention on Oncologist-Patient Communication, Quality of Life, and Health Care Utilization in Advanced Cancer: The VOICE Randomized Clinical Trial. JAMA Oncol 3 (1): 92-100, 2017. [\[PUBMED Abstract\]](#)
22. Bomhof-Roordink H, Fischer MJ, van Duijn-Bakker N, et al.: Shared decision making in oncology: A model based on patients', health care professionals', and researchers' views. Psychooncology 28 (1): 139-146, 2019. [\[PUBMED Abstract\]](#)

Informational Versus Emotional Aspects of Communication

One major aspect of communication is informational. Patients come to cancer clinicians because they are experts who can provide information about their illness. However, the role of the cancer clinician is more than presenting facts and data. While many patients want a share in decision making,^[1] most expect recommendations from their doctor on how best to treat their illness. This form of communication includes some synthesis of information about the cancer and guidance for the individual patient.

For many, cancer is a serious, perhaps terminal diagnosis. Hearing information about cancer often evokes an emotional response from patients and their families, which may cloud their ability to fully hear and process information. One approach to education about communication advocates that clinicians' responses to patients' emotional responses can enhance communication.^[2]

References

1. Lee SJ, Back AL, Block SD, et al.: Enhancing physician-patient communication. Hematology Am Soc Hematol Educ Program : 464-83, 2002. [[PUBMED Abstract](#)]
2. Back AL, Arnold RM, Baile WF, et al.: Approaching difficult communication tasks in oncology. CA Cancer J Clin 55 (3): 164-77, 2005 May-Jun. [[PUBMED Abstract](#)]

Demographic and Cultural Considerations in Cancer Communication

Both patients' and providers' demographic and cultural characteristics, backgrounds, and experiences can influence communication preferences and styles and may, in turn, affect clinical outcomes. Demographic factors with a potential to affect communication in cancer care include, but are not limited to, age, gender and sexuality, race and ethnicity, and socioeconomic status. Cultural factors such as language, family structure, religion and spirituality, and even the culture of medical practice are also relevant.

A patient and his or her providers often have different demographic or cultural backgrounds and identities. Frameworks proposed to help guide providers in approaching the care of patients with backgrounds different from their own include the concepts of cultural competence and cultural humility. Some medical literature has suggested moving away from the idea of cultural competence, which encourages providers to study the values, beliefs, and behaviors of certain cultural groups, in favor of cultural humility, which promotes a "lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and nonpaternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations."

[1,2]

A wealth of oncological and nononcological literature explores demographic and cultural influences on communication, though like the bulk of communication literature in general, it leans toward observational and qualitative studies and is vulnerable to bias and overgeneralization. A comprehensive review of this literature is beyond the scope of this summary; however, some demographic and/or cultural trends relevant to communication in cancer care are noted in the literature, some of which is referenced in the table below.

Demographic Influences on Cancer Communication

Table 1. Demographic Influences on Cancer Communication

Demographic Influences	Special Considerations
Age (i.e., pediatric, young adult, middle-aged, older adult)	• Younger patients tend to speak more and ask more questions in encounters with oncologists.[3]
	• Oncologists address the emotional aspects of illness more with younger patients.[3]
	• Older adult patients are at higher risk of sensory, functional, and cognitive deficits that affect communication.
	• Cancer patients >65 y have stronger preferences for written health information and phone calls versus emails and text messages, compared with younger patients. [4]
	• For more information about pediatric

	<p>communication, see the Communication in Pediatric Oncology section.</p>
<p>Gender and sexuality (i.e., male, female, transgender, nonbinary, LGBTQ+)</p>	<ul style="list-style-type: none"> • Women have more prognostic discussions with their providers and may have better prognostic understanding than men.[5]
	<ul style="list-style-type: none"> • Women may be more interested than men in discussing emotional, social, and spiritual aspects of their illness and care.[6]
	<ul style="list-style-type: none"> • LGBTQ+ patients may worry about sharing information about their sexual orientation or gender identity with providers but report improved alignment with providers, well-being, and quality of care when they do.[7]
	<ul style="list-style-type: none"> • Oncologists report a desire to engage in open, nonjudgmental communication practices with LGBTQ+ cancer patients, but cite a lack of experience with transgender patients in particular and a fear of offending patients as barriers to providing affirming care.[8]
<p>Race and ethnicity (i.e., American Indian or Alaska Native, Asian, Black/African American, Hispanic/Latino, Native Hawaiian or Pacific Islander, White, multiracial)</p>	<ul style="list-style-type: none"> • Racial and ethnic minority patients consistently report unmet informational needs, and physicians underestimate the amount of illness-related information that minority patients want.[9-11]
	<ul style="list-style-type: none"> • Oncologists spend more time building communication with White patients than with racial and ethnic minority patients.[3]
	<ul style="list-style-type: none"> • Black cancer patients are more likely than White cancer patients to report dissatisfaction with patient-physician communication and report feeling less respected by their clinicians.[12-14]
	<ul style="list-style-type: none"> • For more information about language barriers, see the Language and the use of interpreters section.

Socioeconomic status (i.e., high, middle, low)	<ul style="list-style-type: none"> • Oncologists may demonstrate less patient-centered communication relating to the illness experience for patients of lower socioeconomic status.[15]
	<ul style="list-style-type: none"> • Patients of lower socioeconomic status are less likely to have follow-up care discussions with oncology providers.[16]
	<ul style="list-style-type: none"> • Oncologists give more biomedical information to and spend more time relationship-building and providing psychosocial counseling for affluent patients. [3]
LGBTQ = lesbian, gay, bisexual, transgender, and queer.	

Health literacy

In addition to the demographic and cultural disparities noted above, a patient’s health literacy level can also have a significant impact on cancer communication. The U.S. Department of Health and Human Services defines personal health literacy as “the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.” Low health literacy has been frequently linked to worse health outcomes. Cancer patients with low health literacy may misunderstand details of their disease or treatment plan, which may, in turn, contribute to over- or under-treatment and poor adherence to a treatment plan.[17]

Health literacy is distinct from general literacy, though it is important to note that health information is often presented at a relatively advanced reading level. Lower education levels are associated with poor health literacy, but providers should not assume that patients with high educational attainment also have high health literacy, as many do not.[17,18] Older age has also been associated with poor health literacy.[19]

Various working groups and studies have sought to identify best practices for communicating with patients with low literacy skills. Recommendations include the following:

- Change the communication skills of the health care provider rather than those of the patient. The provider should bear primary responsibility for ensuring that patients understand their medical situation. Health literacy training for providers may be effective.[20]
- Use plain language that is free of medical jargon. Audiovisual aids may help, though complex technology may inhibit patients. Written information should be at the fifth-grade level or lower.[21,22]
- Health navigators and ombudsmen may help empower patients with low literacy skills.[23]
- Limit information given to patients at each interaction, especially if information is emotionally charged.
- Repeat important information, and use teach-back strategies to improve communication outcomes.[22]
- Make information and illustrations culturally relevant, and use the language(s) spoken by the target population.

Interventions to overcome disparities

While the causes of the disparities noted above are multifactorial and systemic in nature, greater provider awareness of implicit bias, the effects of structural racism, and social determinants of health is an important first step in reducing inequalities in care. While providers have an imperative to provide culturally sensitive and equitable care, patients can also be encouraged to communicate their concerns with their oncology providers to make their visits more patient centered.[15] Clinicians can strive to improve follow-up discussions and follow-up care in an effort to improve communication and patient outcomes.[16,24,25] Using clinical navigators may also help empower patients to communicate better with their oncologists.[26]

Cultural Considerations in Cancer Communication

Various cultural factors such as language, family structure, and religion/spirituality may impact communication preferences and practices for both patients and providers. These factors are important to consider when practicing culturally sensitive care.

Language and the use of interpreters

Health care organizations should provide language assistance services for all patients who primarily speak a language different than their provider's. Ideal services should include bilingual staff when possible and professional interpreters at each step of the visit and at no cost to the patient.[27] Clinicians should not use a patient's family members or friends to interpret, as they may not communicate all information accurately and may be uncomfortable communicating emotionally difficult information. Professional telephone interpreters are about as accurate as in-person interpreters, [28] but in-person interpreters are preferable for conveying sensitive information, such as bad news or chemotherapy consent. Effective communication with a patient through an interpreter may be facilitated by a few key strategies:[29,30]

- It is helpful for the provider to introduce himself or herself to the interpreter before the encounter and briefly preview the planned conversation.
- In a bedside or office encounter, the interpreter should be positioned next to or slightly behind the patient.[30] If the patient is deaf and a sign language interpreter is used, the interpreter should be positioned so that the patient and interpreter have a full view of each other's face and hands.
- Speak directly to the patient or family member while the interpreter is present. Avoid speaking about the patient in the third person.
- Speak in simple, brief phrases and avoid medical jargon.

Family roles in cancer care and communication

There has been a dearth of studies on the adaptive patterns of families in response to cancer, though research in this area is growing.[31] Family members of cancer patients often find themselves thrust into the medical environment with little or no time to emotionally and psychologically incorporate the diagnosis of a life-threatening illness into their lives.[32] Just as each cancer patient reacts to cancer differently, the family system reacts differently. Interaction between the cancer patient and the family unit must be constructed, redefined, negotiated, and renegotiated along the illness trajectory.[33]

Families react to the illness of their loved ones in various ways, but it is common for families to experience communication challenges. One study examined the phenomenon of avoidance of family communication about cancer.[34] In this study, interviews with 50 caregivers and 26 families were audiotaped and transcribed. Two-thirds of families (65%) experienced communication difficulties. Participants' narratives pointed to three distinct thought processes that contributed to the phenomenon of avoidance: avoidance of psychological distress, desire for mutual protection against harmful situations, and belief in positive thinking.

In a randomized trial, investigators interviewed male and female cancer patients and asked how the family was affected by the cancer diagnosis. Almost all expressed the importance of concealing feelings of distress and unhappiness, stemming from a need to protect family and friends and to act normal. Also important were factors such as maintaining or returning to familiar routines and roles.[35]

Opening up lines of communication and encouraging mutual disclosure about cancer-related issues may be effective at reducing distress in relationships for cancer patients. One study of 148 couples facing breast cancer showed that reciprocal self-disclosure during cancer discussion was associated with lower levels of psychological distress.[36]

Another study suggested that family-focused psychotherapy may also help increase patients' and their family members' cancer-related communication. The study data was gathered from a large randomized controlled trial examining the effect of family-focused grief therapy on family bereavement outcomes. In the study, 257 patients and family members reported on their perception of cancer-related communication after each therapy session using a self-disclosure scale. Participants reported more cancer-related communication on average during therapy sessions compared with baseline; however, the long-term therapeutic effects on depressive symptoms and bereavement in family members depended on the listener's perceived responsiveness (responsiveness defined as "to what degree participants perceived the family as caring, understanding, and accepting of their communication"). Participants who perceived their families as highly responsive had lower depression and bereavement scores after the patient's death if they had more cancer-related communication in the therapy sessions, while more communication was actually associated with worse bereavement outcomes for families who perceived low responsiveness.[37][[level of evidence: I](#)]

Expectations for the role of family members in cancer care and communication with the patient and providers regarding the disease course and treatment plan vary among cultures, as well. Some cultures place greater emphasis on communication with the family unit as a whole, while others focus more on individual patient independence and autonomy. While providers and researchers should use caution when attempting to generalize about specific cultures' communication preferences, some of the literature identifies certain culturally relevant patterns, including the following:

- Families from Asian cultures may wish to be more involved in determining what information is presented to the patient and how it is delivered.[31]
- Latino families and patients may expect family members to be heavily involved in medical decision making throughout

the illness trajectory.[31]

- African American patients may also rely heavily on family input with regard to medical decision making and for coping with their illness.[31]

Clinicians practicing cultural humility respectfully elicit from the patient and family not just information needed to make an accurate diagnosis, but also identify what matters most to them and negotiate mutually satisfactory goals for treatment.

Communicating about spirituality in cancer care

Spirituality is an important source of strength and coping for many people facing cancer. Research indicates that both patients and family caregivers commonly rely on spirituality and religion to help them deal with serious physical illnesses, expressing a desire to have medical staff acknowledge or address specific spiritual and religious needs and concerns.

[38,39] For a detailed discussion of this topic, see [Spirituality in Cancer Care](#).

References

1. Epner DE, Baile WF: Patient-centered care: the key to cultural competence. *Ann Oncol* 23 (Suppl 3): 33-42, 2012. [[PUBMED Abstract](#)]
2. Tervalon M, Murray-García J: Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. *J Health Care Poor Underserved* 9 (2): 117-25, 1998. [[PUBMED Abstract](#)]
3. Siminoff LA, Graham GC, Gordon NH: Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. *Patient Educ Couns* 62 (3): 355-60, 2006. [[PUBMED Abstract](#)]
4. Saied A, Sherry SJ, Castricone DJ, et al.: Age-related trends in utilization of the internet and electronic communication

- devices for coordination of cancer care in elderly patients. *J Geriatr Oncol* 5 (2): 185-9, 2014. [[PUBMED Abstract](#)]
5. Fletcher K, Prigerson HG, Paulk E, et al.: Gender differences in the evolution of illness understanding among patients with advanced cancer. *J Support Oncol* 11 (3): 126-32, 2013. [[PUBMED Abstract](#)]
 6. Seifart C, Riera Knorrenschild J, Hofmann M, et al.: Let us talk about death: gender effects in cancer patients' preferences for end-of-life discussions. *Support Care Cancer* 28 (10): 4667-4675, 2020. [[PUBMED Abstract](#)]
 7. Cloyes KG, Hull W, Davis A: Palliative and End-of-Life Care for Lesbian, Gay, Bisexual, and Transgender (LGBT) Cancer Patients and Their Caregivers. *Semin Oncol Nurs* 34 (1): 60-71, 2018. [[PUBMED Abstract](#)]
 8. Sutter ME, Simmons VN, Sutton SK, et al.: Oncologists' experiences caring for LGBTQ patients with cancer: Qualitative analysis of items on a national survey. *Patient Educ Couns* 104 (4): 871-876, 2021. [[PUBMED Abstract](#)]
 9. Jean-Pierre P, Fiscella K, Griggs J, et al.: Race/ethnicity-based concerns over understanding cancer diagnosis and treatment plan. *J Natl Med Assoc* 102 (3): 184-9, 2010. [[PUBMED Abstract](#)]
 10. Asare M, Peppone LJ, Roscoe JA, et al.: Racial Differences in Information Needs During and After Cancer Treatment: a Nationwide, Longitudinal Survey by the University of Rochester Cancer Center National Cancer Institute Community Oncology Research Program. *J Cancer Educ* 33 (1): 95-101, 2018. [[PUBMED Abstract](#)]
 11. Moreno PI, Ramirez AG, San Miguel-Majors SL, et al.: Unmet supportive care needs in Hispanic/Latino cancer survivors: prevalence and associations with patient-provider communication, satisfaction with cancer care, and symptom burden. *Support Care Cancer* 27 (4): 1383-1394, 2019. [[PUBMED Abstract](#)]
 12. Manfredi C, Kaiser K, Matthews AK, et al.: Are racial

differences in patient-physician cancer communication and information explained by background, predisposing, and enabling factors? *J Health Commun* 15 (3): 272-92, 2010. [[PUBMED Abstract](#)]

13. Gordon HS, Street RL, Sharf BF, et al.: Racial differences in trust and lung cancer patients' perceptions of physician communication. *J Clin Oncol* 24 (6): 904-9, 2006. [[PUBMED Abstract](#)]
14. Do YK, Carpenter WR, Spain P, et al.: Race, healthcare access and physician trust among prostate cancer patients. *Cancer Causes Control* 21 (1): 31-40, 2010. [[PUBMED Abstract](#)]
15. Pollak KI, Alexander SC, Grambow SC, et al.: Oncologist patient-centered communication with patients with advanced cancer: exploring whether race or socioeconomic status matter. *Palliat Med* 24 (1): 96-8, 2010. [[PUBMED Abstract](#)]
16. DiMartino LD, Birken SA, Mayer DK: The Relationship Between Cancer Survivors' Socioeconomic Status and Reports of Follow-up Care Discussions with Providers. *J Cancer Educ* 32 (4): 749-755, 2017. [[PUBMED Abstract](#)]
17. Koay K, Schofield P, Jefford M: Importance of health literacy in oncology. *Asia Pac J Clin Oncol* 8 (1): 14-23, 2012. [[PUBMED Abstract](#)]
18. Helitzer D, Hollis C, Cotner J, et al.: Health literacy demands of written health information materials: an assessment of cervical cancer prevention materials. *Cancer Control* 16 (1): 70-8, 2009. [[PUBMED Abstract](#)]
19. Chesser AK, Keene Woods N, Smothers K, et al.: Health Literacy and Older Adults: A Systematic Review. *Gerontol Geriatr Med* 2: 2333721416630492, 2016 Jan-Dec. [[PUBMED Abstract](#)]
20. Khankari K, Eder M, Osborn CY, et al.: Improving colorectal cancer screening among the medically underserved: a pilot study within a federally qualified health center. *J Gen Intern*

Med 22 (10): 1410-4, 2007. [\[PUBMED Abstract\]](#)

21. Communicating with patients who have limited literacy skills. Report of the National Work Group on Literacy and Health. *J Fam Pract* 46 (2): 168-76, 1998. [\[PUBMED Abstract\]](#)
22. Holmes-Rovner M, Stableford S, Fagerlin A, et al.: Evidence-based patient choice: a prostate cancer decision aid in plain language. *BMC Med Inform Decis Mak* 5: 16, 2005. [\[PUBMED Abstract\]](#)
23. Han HR, Lee H, Kim MT, et al.: Tailored lay health worker intervention improves breast cancer screening outcomes in non-adherent Korean-American women. *Health Educ Res* 24 (2): 318-29, 2009. [\[PUBMED Abstract\]](#)
24. Palmer NR, Weaver KE, Hauser SP, et al.: Disparities in barriers to follow-up care between African American and White breast cancer survivors. *Support Care Cancer* 23 (11): 3201-9, 2015. [\[PUBMED Abstract\]](#)
25. Arora NK, Reeve BB, Hays RD, et al.: Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. *J Clin Oncol* 29 (10): 1280-9, 2011. [\[PUBMED Abstract\]](#)
26. Nickell A, Burke NJ, Cohen E, et al.: Educating low-SES and LEP survivors about breast cancer research: pilot test of the Health Research Engagement Intervention. *J Cancer Educ* 29 (4): 746-52, 2014. [\[PUBMED Abstract\]](#)
27. Anderson LM, Scrimshaw SC, Fullilove MT, et al.: Culturally competent healthcare systems. A systematic review. *Am J Prev Med* 24 (3 Suppl): 68-79, 2003. [\[PUBMED Abstract\]](#)
28. Butow PN, Goldstein D, Bell ML, et al.: Interpretation in consultations with immigrant patients with cancer: how accurate is it? *J Clin Oncol* 29 (20): 2801-7, 2011. [\[PUBMED Abstract\]](#)
29. Misra-Hebert AD: Physician cultural competence: cross-cultural communication improves care. *Cleve Clin J Med* 70 (4): 289, 293, 296-8 passim, 2003. [\[PUBMED Abstract\]](#)

30. Juckett G, Unger K: Appropriate use of medical interpreters. *Am Fam Physician* 90 (7): 476-80, 2014. [[PUBMED Abstract](#)]
31. Harris J, Bowen DJ, Badr H, et al.: Family communication during the cancer experience. *J Health Commun* 14 (Suppl 1): 76-84, 2009. [[PUBMED Abstract](#)]
32. Mills ME, Sullivan K: The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *J Clin Nurs* 8 (6): 631-42, 1999. [[PUBMED Abstract](#)]
33. Nussbaum JF, Baringer O, Kundrat A: Health, communication, and aging: cancer and older adults. *Health Commun* 15 (2): 185-92, 2003. [[PUBMED Abstract](#)]
34. Zhang AY, Siminoff LA: Silence and cancer: why do families and patients fail to communicate? *Health Commun* 15 (4): 415-29, 2003. [[PUBMED Abstract](#)]
35. Byrne A, Ellershaw J, Holcombe C, et al.: Patients' experience of cancer: evidence of the role of 'fighting' in collusive clinical communication. *Patient Educ Couns* 48 (1): 15-21, 2002. [[PUBMED Abstract](#)]
36. Manne S, Sherman M, Ross S, et al.: Couples' support-related communication, psychological distress, and relationship satisfaction among women with early stage breast cancer. *J Consult Clin Psychol* 72 (4): 660-70, 2004. [[PUBMED Abstract](#)]
37. Zaider TI, Kissane DW, Schofield E, et al.: Cancer-related communication during sessions of family therapy at the end of life. *Psychooncology* 29 (2): 373-380, 2020. [[PUBMED Abstract](#)]
38. Kim Y, Wellisch DK, Spillers RL, et al.: Psychological distress of female cancer caregivers: effects of type of cancer and caregivers' spirituality. *Support Care Cancer* 15 (12): 1367-74, 2007. [[PUBMED Abstract](#)]
39. Whitford HS, Olver IN, Peterson MJ: Spirituality as a core domain in the assessment of quality of life in oncology. *Psychooncology* 17 (11): 1121-8, 2008. [[PUBMED Abstract](#)]

Education and Training in Cancer Communication

Status of Education and Training in Cancer Communication

The American College of Graduate Medical Education recognizes interpersonal and communication skills as one of six core competencies.[1] While the importance of educating cancer doctors in communication is recognized, training in communication during oncology fellowship may be lacking. A 2003 survey of U.S. medical, radiation, and surgical oncology programs revealed that only one-third of programs reported offering communication skills training. Lack of faculty time and expertise were identified as the major barriers.[2] Similarly, in a survey by the American Society of Clinical Oncology, few attending oncologists reported receiving mentoring or specific training in communication skills, such as discussing prognosis.[3] Furthermore, while communication is taught to fellows, the quality of that teaching may be inferior. In a national survey of hematology-oncology fellows, 55% reported explicit education on end-of-life communication. However, fellows reported less observation and feedback on a communication skill than on a bone marrow biopsy.[4]

The lack of training is concerning, given how frequently oncologists engage in difficult communication tasks. In one study, oncologists reported delivering bad news an average of 35 times a month.[5] A Delphi panel of medical oncologists endorsed nearly 80% of items related to communication and decision making and advance care planning as within the scope of an oncologist's work, suggesting that most oncologists put a high value on communication as a critical component of their work.[6]

In addition to training for oncologists and fellows, efforts have been made to train nurses. Nurses play a vital role in supporting patients through the crisis of cancer, often advocating for them

and acting as intermediaries for their requests or concerns. Research suggests that communication skills training programs for nurses are well received.[7]

There have been several small studies of communication training programs for nurses, which demonstrated mixed results. They include the following:

- A communication skills training developed for physicians was adapted and given to 247 inpatient nurses. It included a 45-minute didactic on end-of-life (EOL) care, followed by 90 minutes of experiential learning, including a role-play with a simulated patient. Nurses' confidence in discussing death, dying, and EOL goals of care increased after the training, and over 90% reported satisfaction with the module.[8]
- A small study taught nurses in Japan to use the SPIKES (Setting, Perception, Invitation, Knowledge, Empathy, Summary) protocol[9] with patients newly diagnosed with cancer. The study demonstrated that patients seen by trained nurses had decreased psychological distress, enhanced adaptive coping, and increased patient satisfaction with the nurse. Although the study was randomized, it enrolled a mere four nurses in each arm.[10,11] See [Communication Tools and Techniques](#) below.

While communication skills training is generally well received, improves self-rated confidence, and increases communication skills, it is unclear whether the skills are transferred to clinical practice. One study addressed this question by randomly assigning nurses who attended a 3-day communication skills workshop to 4 weeks of clinical supervision or a control group. Only those with the 4 weeks of supervision demonstrated a transfer of skills into clinical practice, and the effect was limited. [12]

In total, these studies suggest the ability of intensive and experiential training programs to improve skills acquisition and self-rated confidence. Few studies assess the effect of

communication skills training on patient-oriented outcomes. These findings raise important questions about the value of communication training programs, many of which are labor intensive.

Methods of Communication Skills Training

In recent years, increasing rigor has been applied to the design and assessment of communication skills education. Over the past two decades, more than 40 randomized controlled trials of communication skills training have been conducted in the United States,[13,14] the United Kingdom,[15] Europe,[16] Australia,[17] and Japan.[11] Methods for evaluating the success of the education varies. Some studies looked at self-assessment before and after training; others assessed the acquisition of behaviors or skills, such as learner response to emotion, using audio or video recordings of encounters in simulated interviews or patient encounters. Few of these studies linked communication training to patient outcomes, such as satisfaction, anxiety, or distress.

Participants: Training programs have targeted various learners, including oncology fellows, practicing oncologists, nurses, and other advanced practice providers. Program sizes have varied widely, with as few as 8 learners [11] and as many as 160 learners.[15]

Design: Most communication skills training programs involve intensive small-group sessions that require participants to practice skills in a role-play, using a standardized or simulated patient. One study suggested that role-plays with higher emotional content were more effective, perhaps because such encounters were more challenging for learners and demonstrated more differences in the untrained versus trained groups.[18] Communication skills training programs vary in length, from half-day to 3.5-day workshops to 105 hours of training.[16] A few include consolidation sessions.[12] Increasingly, the use of electronic and computerized methods of teaching is being explored,[19] with CD-ROMs given to

participants.[20]

Assessment/outcomes: Varied assessment methods are used and depend in part on the study design and the targeted outcome(s) of the work. There are frequently pre- and post-assessments in the intervention and control groups, so the change in learning between the two groups can be compared. Common strategies for evaluation of communication skills training include:

- Self-assessment of skills and confidence.
- Observed skills via direct observation or recordings (audio or video) of encounters, such as:
 - Questions asked.
 - Decreased interruptions.
 - Use of empathy or emotional words.
- Satisfaction (of learners, patients, families).
- Patient outcomes (recognition of distress, level of patient anxiety).[21]

Examples of communication skills trainings: Several standardized training curricula have been developed and become more widely used over time. A few selected examples are mentioned in the table below.

Table 2. Communication Skills Training

Training Curricula	Design	Evidence
Vitaltalk	Provides instruction on communication areas, including developing a relationship, giving bad news, discussing goals of care and	A few small studies indicate participant satisfaction with the training and perceived improvements in

	resuscitation preferences.	communication, but high-quality evidence on communication outcomes is limited.[14,22,23]
Comskil	Provides training on topics, including delivering serious news, discussing prognosis and treatment, maintaining team communication, and responding to patient and family anger. Primarily provided through Memorial Sloan Kettering Cancer Center.	A few small studies indicate participant satisfaction with the training and perceived improvements in communication, but high-quality evidence on communication outcomes is limited.[24-27]
SICG	Provides a structured, question-based framework to help clinicians “assess illness understanding and patient information preferences; share prognosis according to patient preferences; explore patient values, goals, and care preferences; and make a recommendation based on patient priorities.”[28]	The SICG was recently developed, and data on efficacy and outcomes is limited. Available data suggests the following:
		- The SICG improves rates and quality of EMR documentation of serious illness discussions. [28,29]
		- 79% of 118 patients described the discussion using the SICG as worthwhile and reported no change or improvement in

		their sense of peacefulness, hopefulness, or anxiety.[30]
		- Use of the SICG was associated with increased provider satisfaction.[30]
SICG = Serious Illness Conversation Guide; EMR = electronic medical record.		

In summary, communication is a skill that can be taught. Key aspects of communication skills training include opportunities for learners to practice skills and receive feedback. Optimal duration is not known, and no studies compared shorter versus longer workshops to see whether there is a dose-response curve. The need for consolidation or booster lessons after the initial workshop is unclear, with some studies demonstrating substantially better outcomes and uptake of behaviors with additional lessons or consolidation workshops.[16,31]

Communication Tools and Techniques

Some of the training referenced above focuses on specific tools to facilitate recollection and application or transfer of skills into clinical encounters. Evidence linking these tools to provider- or patient-related outcomes is extremely sparse, but as they are commonly used in practice, they have been included here. Three examples of such tools are discussed below:

- Ask-Tell-Ask
- NURSE
- SPIKES

Ask-Tell-Ask

Ask-Tell-Ask is a three-step strategy for facilitating open communication between clinicians and patients. It has also been

successfully applied/used in settings to elicit learner goals and give feedback.[32-34] By starting with a question rather than immediately giving information, clinicians give the patient some element of control.

- The first "Ask" can elicit a patient's understanding, goals, or values or obtain permission to give information. Following are two examples:
 - "Can you tell me what you know so far about your cancer?"
 - "Would it be OK if we start by talking about the findings on your recent scan?"
- The first "Ask" is followed by a "Tell" that focuses on giving the main message briefly and without jargon. For example:
 - "The scan tells us the treatment is not working as well as we'd hoped."
- The second "Ask" ensures that the patient has fully heard and absorbed the information and is ready to move on. Following are two examples:
 - "It's a lot to take in. What are the key things you will share with your family?"
 - "Are you ready to discuss next steps for treatment?"

This approach discourages clinicians from launching into long and detailed medical explanations. Instead, it encourages giving information in small chunks, frequently checking to ensure the patient is understanding and absorbing all that is being said.

NURSE: Tools for responding to emotion

Communication is challenging for cancer providers because it often involves conveying serious news, such as a diagnosis of cancer or a poor prognosis, which changes patients' expectations about the future. Patients typically have a strong emotional response to such news. While emotions are high, the ability to hear and comprehend cognitive information is

impaired. By addressing emotions empathically, clinicians may help patients absorb the information and make decisions.

NURSE is a mnemonic device for five ways to respond to emotion:[33,35]

- Name: "It sounds as if you are very worried."
- Understand: "I cannot imagine how it feels to hear this."
- Respect: "You are asking the right questions and being a strong advocate."
- Support: "I will be here to care for you no matter what happens."
- Explore: "Tell me more about how you are feeling."

SPIKES: A six-step approach to delivering bad news

SPIKES is a specific framework for talking to patients about bad news, such as a cancer recurrence or a treatment failure. It incorporates some of the principles of Ask-Tell-Ask and NURSE in its steps:[9]

- Setting: Arrange for privacy and minimize interruptions.
- Perception: Find out what the patient understands is happening medically.
- Invitation: Discover how much information the patient wants.
- Knowledge: Give information to the patient in small bites without jargon.
- Empathy: Address the patient's emotions with empathy.
- Summary: Sum up the clinical information and make a plan for the next step.

References

1. Swing SR: The ACGME outcome project: retrospective and prospective. Med Teach 29 (7): 648-54, 2007. [\[PUBMED Abstract\]](#)
2. Hoffman M, Ferri J, Sison C, et al.: Teaching communication

- skills: an AACE survey of oncology training programs. *J Cancer Educ* 19 (4): 220-4, 2004. [[PUBMED Abstract](#)]
3. Hilden JM, Emanuel EJ, Fairclough DL, et al.: Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol* 19 (1): 205-12, 2001. [[PUBMED Abstract](#)]
 4. Buss MK, Lessen DS, Sullivan AM, et al.: Hematology/oncology fellows' training in palliative care: results of a national survey. *Cancer* 117 (18): 4304-11, 2011. [[PUBMED Abstract](#)]
 5. Baile WF, Kudelka AP, Beale EA, et al.: Communication skills training in oncology. Description and preliminary outcomes of workshops on breaking bad news and managing patient reactions to illness. *Cancer* 86 (5): 887-97, 1999. [[PUBMED Abstract](#)]
 6. Bickel KE, McNiff K, Buss MK, et al.: Defining High-Quality Palliative Care in Oncology Practice: An American Society of Clinical Oncology/American Academy of Hospice and Palliative Medicine Guidance Statement. *J Oncol Pract* 12 (9): e828-38, 2016. [[PUBMED Abstract](#)]
 7. Kennedy Sheldon L: Communication in oncology care: the effectiveness of skills training workshops for healthcare providers. *Clin J Oncol Nurs* 9 (3): 305-12, 2005. [[PUBMED Abstract](#)]
 8. Coyle N, Manna R, Shen M, et al.: Discussing Death, Dying, and End-of-Life Goals of Care: A Communication Skills Training Module for Oncology Nurses. *Clin J Oncol Nurs* 19 (6): 697-702, 2015. [[PUBMED Abstract](#)]
 9. Baile WF, Buckman R, Lenzi R, et al.: SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 5 (4): 302-11, 2000. [[PUBMED Abstract](#)]
 10. Fukui S, Ogawa K, Ohtsuka M, et al.: A randomized study assessing the efficacy of communication skill training on

patients' psychologic distress and coping: nurses' communication with patients just after being diagnosed with cancer. *Cancer* 113 (6): 1462-70, 2008. [[PUBMED Abstract](#)]

11. Fukui S, Ogawa K, Yamagishi A: Effectiveness of communication skills training of nurses on the quality of life and satisfaction with healthcare professionals among newly diagnosed cancer patients: a preliminary study. *Psychooncology* 20 (12): 1285-91, 2011. [[PUBMED Abstract](#)]
12. Heaven C, Clegg J, Maguire P: Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. *Patient Educ Couns* 60 (3): 313-25, 2006. [[PUBMED Abstract](#)]
13. Back AL, Arnold RM, Tulsky JA, et al.: Teaching communication skills to medical oncology fellows. *J Clin Oncol* 21 (12): 2433-6, 2003. [[PUBMED Abstract](#)]
14. Back AL, Arnold RM, Baile WF, et al.: Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Arch Intern Med* 167 (5): 453-60, 2007. [[PUBMED Abstract](#)]
15. Fallowfield L, Jenkins V, Farewell V, et al.: Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *Lancet* 359 (9307): 650-6, 2002. [[PUBMED Abstract](#)]
16. Razavi D, Merckaert I, Marchal S, et al.: How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of posttraining consolidation workshops. *J Clin Oncol* 21 (16): 3141-9, 2003. [[PUBMED Abstract](#)]
17. Butow PN, Kazemi JN, Beeney LJ, et al.: When the diagnosis is cancer: patient communication experiences and preferences. *Cancer* 77 (12): 2630-7, 1996. [[PUBMED Abstract](#)]
18. Razavi D, Delvaux N, Marchal S, et al.: Testing health care professionals' communication skills: the usefulness of

highly emotional standardized role-playing sessions with simulators. *Psychooncology* 9 (4): 293-302, 2000 Jul-Aug. [\[PUBMED Abstract\]](#)

19. Tulskey JA, Arnold RM, Alexander SC, et al.: Enhancing communication between oncologists and patients with a computer-based training program: a randomized trial. *Ann Intern Med* 155 (9): 593-601, 2011. [\[PUBMED Abstract\]](#)
20. Meropol NJ, Egleston BL, Buzaglo JS, et al.: A Web-based communication aid for patients with cancer: the CONNECT Study. *Cancer* 119 (7): 1437-45, 2013. [\[PUBMED Abstract\]](#)
21. Fujimori M, Shirai Y, Asai M, et al.: Effect of communication skills training program for oncologists based on patient preferences for communication when receiving bad news: a randomized controlled trial. *J Clin Oncol* 32 (20): 2166-72, 2014. [\[PUBMED Abstract\]](#)
22. Urban RR, Fay EE, Podgurski L, et al.: Pilot study of a condensed communication skills workshop for gynecologic oncology fellows. *Gynecol Oncol Rep* 30: 100492, 2019. [\[PUBMED Abstract\]](#)
23. Onishi E, Nakagawa S, Uemura T, et al.: Physicians' Perceptions and Suggestions for the Adaptation of a US-Based Serious Illness Communication Training in a Non-US Culture: A Qualitative Study. *J Pain Symptom Manage* 62 (2): 400-409.e3, 2021. [\[PUBMED Abstract\]](#)
24. Brown R, Bylund CL, Eddington J, et al.: Discussing prognosis in an oncology setting: initial evaluation of a communication skills training module. *Psychooncology* 19 (4): 408-14, 2010. [\[PUBMED Abstract\]](#)
25. Gueguen JA, Bylund CL, Brown RF, et al.: Conducting family meetings in palliative care: themes, techniques, and preliminary evaluation of a communication skills module. *Palliat Support Care* 7 (2): 171-9, 2009. [\[PUBMED Abstract\]](#)
26. Bylund CL, Brown R, Gueguen JA, et al.: The implementation and assessment of a comprehensive communication skills training curriculum for oncologists. *Psychooncology* 19 (6):

583-93, 2010. [\[PUBMED Abstract\]](#)

27. Bylund CL, Brown RF, Bialer PA, et al.: Developing and implementing an advanced communication training program in oncology at a comprehensive cancer center. *J Cancer Educ* 26 (4): 604-11, 2011. [\[PUBMED Abstract\]](#)
28. Paladino J, Bernacki R, Neville BA, et al.: Evaluating an Intervention to Improve Communication Between Oncology Clinicians and Patients With Life-Limiting Cancer: A Cluster Randomized Clinical Trial of the Serious Illness Care Program. *JAMA Oncol* 5 (6): 801-809, 2019. [\[PUBMED Abstract\]](#)
29. Lally K, Tuya Fulton A, Ducharme C, et al.: Using Nurse Care Managers Trained in the Serious Illness Conversation Guide to Increase Goals-of-Care Conversations in an Accountable Care Organization. *J Palliat Med* 23 (1): 112-115, 2020. [\[PUBMED Abstract\]](#)
30. Paladino J, Koritsanszky L, Nisotel L, et al.: Patient and clinician experience of a serious illness conversation guide in oncology: A descriptive analysis. *Cancer Med* 9 (13): 4550-4560, 2020. [\[PUBMED Abstract\]](#)
31. Delvaux N, Merckaert I, Marchal S, et al.: Physicians' communication with a cancer patient and a relative: a randomized study assessing the efficacy of consolidation workshops. *Cancer* 103 (11): 2397-411, 2005. [\[PUBMED Abstract\]](#)
32. French JC, Colbert CY, Pien LC, et al.: Targeted Feedback in the Milestones Era: Utilization of the Ask-Tell-Ask Feedback Model to Promote Reflection and Self-Assessment. *J Surg Educ* 72 (6): e274-9, 2015 Nov-Dec. [\[PUBMED Abstract\]](#)
33. Back AL, Arnold RM, Baile WF, et al.: Approaching difficult communication tasks in oncology. *CA Cancer J Clin* 55 (3): 164-77, 2005 May-Jun. [\[PUBMED Abstract\]](#)
34. Gaster B, Edwards K, Trinidad SB, et al.: Patient-centered discussions about prostate cancer screening: a real-world approach. *Ann Intern Med* 153 (10): 661-5, 2010. [\[PUBMED](#)

35. Smith RC: Patient-Centered Interviewing: An Evidence-Based Method. 2nd ed. Lippincott Williams & Wilkins, 2002.

eHealth as a Communication Tool in Cancer Care

Another communication method that is increasingly used in cancer care is eHealth. The proliferation of mobile digital devices, software applications, and websites on the Internet has the potential to transform the ways in which people with cancer and their families seek and receive care for good or ill.

This section uses the term **eHealth** as an umbrella term for a wide variety of computer-based supports for patients and informal caregivers. It enumerates the goals and risks of eHealth-based interventions and summarizes the lessons learned to date. Studies of specific interventions are summarized after the introductory sections.

Definition of eHealth

A wide variety of interventions may be included in a summary of eHealth and cancer communication. For clarity and brevity, however, no evaluations will be made of video or multimedia interventions available primarily via CD-ROM or DVD; websites, unless specifically designed as part of a studied intervention; or resources available on the Internet independent of the provider-patient relationship.[1] In addition, programs designed to educate health care providers that take advantage of computers and related technology will not be summarized. Several recent systematic reviews with broader inclusion criteria provide additional information.[2-4]

Goals of eHealth

The goals of eHealth include the following:

- Enhancing communication among patients, clinicians, and family members, for example, to ensure that information is clear.
- Enhancing shared decision making.
- Optimizing management of patients' and informal caregivers' physical and psychological symptoms.
- Improving the communication of patient-reported concerns to the health care team.
- Changing health-related behaviors.
- Providing social support.
- Enhancing clinical trial enrollment.

Potential Negative Effects of eHealth

The potentially negative effects of eHealth include the following:

- **Access to unreliable or contradictory information about diagnosis, prognosis, treatment goals, and side effects or anticipated complications that can increase patient distress.** Data suggest that there are not significant harms to patients accessing information online.^[5] This finding may reflect the number of reputable websites maintained by disease-specific advocacy groups and professional societies.
- **Erosion of trust in providers.** There was an initial concern that online information may cause patients to second-guess or lose confidence in providers. At present, the limited data do not support this concern, as levels of trust remain high.^[6,7]
- **Increased demand on clinicians' time.** Clinicians help patients interpret information found online or respond to patients who expect timely responses to e-communications via email, text, or patient portals.
- **Creation of a digital divide or disparity.** One group of investigators conducted surveys and focus groups to describe patient and caregiver perspectives on information related to symptom management and decision support.^[8]

The preference was for face-to-face communication, although most recognized the potential value of eHealth in supporting decisions. Of note, however, 38% of participants rarely used computers.

- **Computers in the examination room.**

Summary of eHealth

The majority of the experience to date is based on pilot studies designed to evaluate acceptability and measure preliminary effect sizes. Observations based on these studies include the following:

- Most interventions were developed without an underlying theoretical framework. When a framework was cited, coping was the most frequently cited.[9] The goal was largely to enhance coping by giving patients additional resources such as information, greater access to clinicians, or education to improve their communication competence.
- The increased connectedness fostered by websites and mobile applications are driven by factors such as convenience, ease of use, and greater consumer choice and may not translate well into health care interactions.
- The tested communication technologies have varied widely. A systematic review related to end-of-life communication identified 11 technologies: video, prototype website, telephone, videoconferencing, email prompts, telemonitoring, Internet search strategies, compact disc, fax, mobile devices, and text messaging.[2]
- Digital or web-based strategies potentially provide cost-effective dissemination of standardized and (presumably) experimentally validated interventions. However, the use of care coordinators during the interactions may limit the scalability of the intervention.[10,11]
- The types of information or interactions and how patients and family caregivers access the resources and the desired format of the resources will require elucidation.[12]

- A related challenge is the difficulty of formally evaluating rapidly advancing and overlapping eHealth technologies. For example, websites, automatic texting, or mobile applications may possess advantages or disadvantages, but conducting trials to isolate the effect of a particular technology is time consuming and unlikely to provide a single best solution.
- Patient preferences and changes in preferences with generational shifts will likely require developers to modify the content and format of resources and the technology to access the resources. Differences in digital competence and comfort based on age, ethnicity, and socioeconomic factors will require clinicians to maintain channels of communication in both digital and nondigital environments.[13]
- Digital or web-based strategies often require significant self-directed effort on the part of the patient.[14] The willingness of patients to interact with multiple platforms over time is a potential limit to the efficacy of such interventions.

References

1. Bouma G, Admiraal JM, de Vries EG, et al.: Internet-based support programs to alleviate psychosocial and physical symptoms in cancer patients: a literature analysis. *Crit Rev Oncol Hematol* 95 (1): 26-37, 2015. [\[PUBMED Abstract\]](#)
2. Ostherr K, Killoran P, Shegog R, et al.: Death in the Digital Age: A Systematic Review of Information and Communication Technologies in End-of-Life Care. *J Palliat Med* 19 (4): 408-20, 2016. [\[PUBMED Abstract\]](#)
3. Allsop MJ, Taylor S, Mulvey MR, et al.: Information and communication technology for managing pain in palliative care: a review of the literature. *BMJ Support Palliat Care* 5 (5): 481-9, 2015. [\[PUBMED Abstract\]](#)
4. Wasilewski MB, Stinson JN, Cameron JI: Web-based health interventions for family caregivers of elderly individuals: A Scoping Review. *Int J Med Inform* 103: 109-138, 2017. [\[PUBMED Abstract\]](#)
5. Crocco AG, Villasis-Keever M, Jadad AR: Analysis of cases of

harm associated with use of health information on the internet. *JAMA* 287 (21): 2869-71, 2002. [[PUBMED Abstract](#)]

6. Hesse BW, Nelson DE, Kreps GL, et al.: Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Arch Intern Med* 165 (22): 2618-24, 2005 Dec 12-26. [[PUBMED Abstract](#)]
7. Hesse BW, Moser RP, Rutten LJ: Surveys of physicians and electronic health information. *N Engl J Med* 362 (9): 859-60, 2010. [[PUBMED Abstract](#)]
8. Cooley ME, Nayak MM, Abrahm JL, et al.: Patient and caregiver perspectives on decision support for symptom and quality of life management during cancer treatment: Implications for eHealth. *Psychooncology* 26 (8): 1105-1112, 2017. [[PUBMED Abstract](#)]
9. Lazarus RS, Folkman S: *Stress, Appraisal, and Coping*. Springer Publishing Co, 1984.
10. Steel JL, Geller DA, Kim KH, et al.: Web-based collaborative care intervention to manage cancer-related symptoms in the palliative care setting. *Cancer* 122 (8): 1270-82, 2016. [[PUBMED Abstract](#)]
11. Donovan HS, Ward SE, Sereika SM, et al.: Web-based symptom management for women with recurrent ovarian cancer: a pilot randomized controlled trial of the WRITE Symptoms intervention. *J Pain Symptom Manage* 47 (2): 218-30, 2014. [[PUBMED Abstract](#)]
12. DuBenske LL, Gustafson DH, Namkoong K, et al.: CHESS improves cancer caregivers' burden and mood: results of an eHealth RCT. *Health Psychol* 33 (10): 1261-72, 2014. [[PUBMED Abstract](#)]
13. Hesse BW, Greenberg AJ, Rutten LJ: The role of Internet resources in clinical oncology: promises and challenges. *Nat Rev Clin Oncol* 13 (12): 767-776, 2016. [[PUBMED Abstract](#)]
14. Wootten AC, Abbott JA, Meyer D, et al.: Preliminary results of a randomised controlled trial of an online psychological

intervention to reduce distress in men treated for localised prostate cancer. Eur Urol 68 (3): 471-9, 2015. [[PUBMED Abstract](#)]

Communication Challenges in Oncology

Diagnostic Disclosure and Breaking Bad News

Oncologists break bad news to patients thousands of times in their careers, whether related to a diagnosis of new or recurrent cancer, disease progression, disease- or treatment-related prognosis, or transitions to end-of-life (EOL) care. Disclosing a new cancer diagnosis is a frequent and significant communication challenge for oncologists.

This process is made difficult by the following factors:[[1-4](#)]

- 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.

While much has been written about breaking bad news, there is limited level I evidence to support the use of a specific method for disclosing difficult news to cancer patients. What is clear is that not discussing the diagnosis may engender in patients 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 planning for the future.[5]

In an innovative qualitative study focused on communicating bad news related to cancer recurrence,[6] patients with diagnoses of gastrointestinal cancers during the previous 2 years listened to audio recordings of oncologists using the SPIKES (Setting, Perception, Invitation, Knowledge, Empathy, Summary) approach (with standardized actors) and then identified what they liked and disliked about the communication. 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 guidance using an interactive, 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."

General principles, outlined by the American Society of Clinical Oncology (ASCO),[7] offer the oncologist approaches to discussing diagnostic information. The ASCO group consensus was that the oncologist should provide information tailored to the patient's needs, providing hope and reassurance without misleading the patient. This is done by assessing patient and family preferences for information, setting an agenda, providing news in appropriately targeted language for the health literacy level of the patient and family, responding to emotion, and providing a structure for follow-up care that limits patients' experience of abandonment.

Patients with new diagnoses of cancer preferred their physicians to give them the diagnosis in person rather than by phone and in

private settings. In addition, they wanted their physicians to spend adequate time (>10 minutes) and to be prepared to describe treatment options.[8,9] These factors were associated with higher patient satisfaction ratings, as were patient-associated factors, such as feeling empowered to ask questions during the encounter, and physician-associated behavior and communication, such as using lay language and eliciting patients' concerns about their health, which demonstrated caring and confidence.[9]

A study of 351 patients with 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 about an initial cancer diagnosis or recurrence. [10] 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, 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.

Oncologists continue to struggle with a lack of consistency and equality in patient communication at the time of diagnosis. This experience has been demonstrated in a study of 405 women with newly diagnosed breast cancer, which found that White and more affluent patients had more interpersonal relationship-building moments within their initial diagnostic consultation.

Oncologists may benefit from self-reflection and communication skills training to increase their awareness of unconscious bias.

[11]

Discussing Prognosis

Preference for information about prognosis

Patients with life-limiting illnesses desire information about prognosis,[12] believe that such information may be provided without compromising hope,[13] and prefer that oncologists inquire about their preferences for such information.[14]

Younger patient age, female sex, and a shorter life expectancy as perceived by the patient correlate with increased information needs.[15]

A consistent finding over the last two decades is that patients with advanced cancer are typically overly optimistic about their life expectancies or the potential for cure with cancer-directed therapies.

- In a study of 1,193 patients in the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium, a significant majority of patients with advanced lung or colorectal cancer did not understand that treatment was not curative. Sixty-nine percent of patients did not understand that chemotherapy was unlikely to cure their cancers.[16] Patients who were not White, were diagnosed with colorectal cancer, or reported satisfaction with physician communication were more likely to report inaccurate understanding of treatment intent.
- Similarly, 64% of patients with incurable lung cancer who received radiation therapy did not understand that it was not likely to cure their cancers. Older and non-White patients were more likely to misunderstand; surrogates of patients were more likely to understand.[17]

There are many potential barriers to a more accurate understanding of prognosis, including poor communication by

oncology clinicians. However, patients also interpret information for reasons unrelated to the quality of communication. The perspectives of patients with advanced cancer who enroll in phase I clinical trials or surrogate decision makers for patients in intensive care units (ICUs) provide some insights into why advanced cancer patients might misinterpret prognostic information.

- Patients' optimistic expectations of benefit from phase I trials were associated with a better quality of life, stronger religious faith, optimism, poorer numeracy (ability to understand a statistical estimate of treatment outcome), and monetary risk seeking. They were unrelated to age, gender, educational level, or functional status.[18]
- In a study of 163 patients enrolled in a phase I trial, most were aware of hospice (81%) or palliative care (84%), but few considered either choice seriously (hospice, 10%; palliative care, 7%). Seventy-five percent of patients reported the most important influence was awareness that their cancer was growing; 63% of them stated the knowledge that the phase I drug killed cancer cells was the most important factor in their decision to enroll.[19]
- In a study of 80 surrogate decision makers recruited from the families of ICU patients, most were fairly accurate in their interpretations of quantitative information and less ambiguous qualitative estimates by ICU physicians. However, several potentially relevant sources of prognostic misunderstanding included the need to express optimism, the belief that the patients' fortitude would lead to better-than-predicted outcomes, and a disbelief that physicians can predict accurately.[20]

One group of investigators analyzed the prognostic estimates of 917 adults with metastatic colorectal or lung cancer who were enrolled in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments and their physicians.[21] There were three notable findings:

- Patients were more optimistic than physicians.
- Physician estimates were more calibrated with the observed survival than were the patient estimates.
- Patients who were more optimistic than their oncologists were more likely to prefer life-extending treatments.

The poor concordance between patients and oncology clinicians has been observed in a diverse range of patients, including patients with acute myeloid leukemia [22] and those considering allogeneic stem cell transplantation.[23] For additional information about patient prognostic understanding, see the [Patients' Interpretations of Prognostic Information](#) section in *Planning the Transition to End-of-Life Care in Advanced Cancer*.

Oncologist self-reported practices in prognostic communication

There is evidence that physicians' attitudes toward prognostic communication influence patients' prognostic awareness. In an analysis of physician surveys from the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium,[24] investigators reported that patients with metastatic lung or colorectal cancer were more likely to have an accurate prognostic awareness if their most important doctor reported discussing prognosis earlier rather than waiting for deterioration (18.5% vs. 7.6%; odds ratio, 3.23; 95% confidence interval, 1.39–7.52; $P = .006$). Thus, understanding the factors that influence oncologists' attitudes is relevant to improving prognostic communication. Two additional surveys of American oncologists and communication about prognosis have been published. One study analyzed the survey responses of 729 oncologists (64% response rate).[25] Almost all (98%) indicated they would disclose a terminal prognosis, but 48% indicated they would do so only when the patient's preference for disclosure of prognosis was known. Fewer than half (43%) of the oncologists always provided an estimate of time until death. Three-quarters of them indicated they had not received formal training in communication of terminal prognoses; 96% thought training

should be mandatory.

Another study reported that 65% of physicians surveyed discussed prognosis immediately with asymptomatic patients who had advanced cancer and anticipated life expectancies of 4 to 6 months.[26] However, fewer physicians would immediately discuss resuscitation preference (44%), hospice (26%), or preferred site of death (21%), with most physicians waiting for patient symptoms to appear or until there were no more treatments to offer. Younger physicians, surgeons, and oncologists were more likely than noncancer specialists to discuss prognosis.

For more information, see [Planning the Transition to End-of-Life Care in Advanced Cancer](#).

Discussing Consent for Cancer-Directed Therapy

Decision making in the setting of a cancer diagnosis presents its unique set of challenges. The choices can range from curative to palliative treatment, from surgery to radiation to chemotherapy, all with a broad potential side effect profile that could be either short- or long-term. There is increasing research into how providers approach treatment conversations with patients and how to actively involve them and to make sure their preferences are an important part of treatment decision making.

The ASCO published a consensus guideline for patient-clinician communication. In addition to guidance regarding core communication skills and tasks that apply across the continuum of cancer care, recommendations address specific topics, such as discussion of goals of care and prognosis, treatment selection, EOL care, facilitating family involvement in care, and clinician training in communication skills. Recommendations are accompanied by suggested strategies for implementation.

[Additional information](#) is available.[7]

When considering how to approach discussions about cancer-

directed therapy with a patient, a provider should take into account the patient's preferred approach to decision making. In a meta-analysis, 26% of patients preferred active roles, 49% preferred collaborative roles, and 25% preferred passive roles in treatment decision making.[27] Forty percent of patients in the study had discordance between their preferred communication role and their experience in the clinic setting. Evaluation of a patient's preferred communication style should be considered at initial intake so that clinicians can use the preferred style during patient encounters for treatment decision making.

Patients with colon and breast cancer were given questionnaires directly after a consultation with their oncologist and then 3 months later. The questionnaires assessed their preferred and perceived decision-making styles, physician empathy, and shared decision making and the impact on patients' decision regret.[28] Greater physician empathy was significantly associated with more shared decision making and less decision regret. If patients participated less than they desired in their visits, they reported more decision regret with their follow-up. This finding emphasizes the need for physician empathy, as well as the need to match patients' preferred and perceived roles in medical decision making to enhance treatment decision making and minimize regret.

Patients who are candidates for palliative treatment alone can face different barriers to shared decision making. Faced with treatment that is not curative, some patients prefer to know less, and others desire significantly more information about treatment side effects, response rate, and prognosis. Clinical factors are the primary indicator for treatment options that an oncologist presents, but if all clinical factors are even, emotion is a strong influence. When chemotherapy near the EOL is being considered, oncologists feel that patients drive the desire for the treatment.[29] Despite that, the majority of patients in another study clearly desired to receive information on tumor response (91%) and survival benefit (74%). Oncologists, though, had difficulty judging the information preferences of individual

patients.[30]

Transitions in Care, Advance Care Planning, and EOL Care

Effective communication between patients, caregivers and providers is central to transitioning from disease-directed to comfort-focused treatment plans. Prognostic disclosure; eliciting patient goals, values and preferences; advance care planning; and EOL care discussions are integral to providing quality cancer care. These topics are discussed in detail in [Planning the Transition to End-of-Life Care in Advanced Cancer](#).

Communication About the Costs of Cancer Care

The cost of cancer care has attracted increased attention with the development of new, more expensive chemotherapies, immunotherapies, and genomic treatment. As reported in 2018, the average monthly price of anticancer drug therapy was \$13,176 (range, \$5,454–\$45,004), with an average increase of 9% from 2006 to 2015.[31] Research on communication and cancer costs is an emerging field, but data are limited. Communication about cancer treatment costs have been limited by the lack of education in medical school about health care systems, quality improvement, and medical economics. This gap impacts the physician's ability to integrate comparative effectiveness into medical decision making.[32] Compounding this deficiency is the variability of health care costs and insurance drug coverage, resulting in a lack of transparency in the cost of cancer care. Although most people in the United States have insurance coverage, their out-of-pocket costs can still be quite significant, resulting in double the personal bankruptcy rates of the general population.[33]

Research shows that the majority of patients want cost-information discussions with their oncologist or another health care provider and that most oncologists believe that a cost discussion is important. However, these conversations are

infrequent.[34,35] In one study, 80% of patients had no negative feelings toward their oncologist after hearing cost information. [36] In contrast, the minority of oncologists feel comfortable discussing costs with patients.[37] One of the concerns related to cancer treatment cost is medication nonadherence. Patients with high or overwhelming financial distress or those who experience a higher financial burden than expected were more likely to skip doses of chemotherapy, take a reduced dose than that prescribed, or not fill a prescription at all because of cost. [34]

In one study, 57% of patients who did have a cost conversation reported lower out-of-pocket costs. Data show that 52% to 59% of patients wanted to discuss out-of-pocket costs with their physician, but most patients did not consider out-of-pocket costs in their decision making and did not believe their physician should, either.[38,39]

Research needs to persist in this area. Clinicians should assess their patients' level of concern about the cost of cancer therapy and be willing to address the needs and questions of those in financial distress or refer them to a financial counselor.

References

1. Baile WF, Buckman R, Lenzi R, et al.: SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 5 (4): 302-11, 2000. [[PUBMED Abstract](#)]
2. Hietanen P, Aro AR, Holli K, et al.: Information and communication in the context of a clinical trial. *Eur J Cancer* 36 (16): 2096-104, 2000. [[PUBMED Abstract](#)]
3. Buckman R: Communications and emotions. *BMJ* 325 (7366): 672, 2002. [[PUBMED Abstract](#)]
4. Baile WF: Training oncology practitioners in communication skills. *J Pediatr Hematol Oncol* 33 (Suppl 2): S115-22, 2011. [[PUBMED Abstract](#)]
5. Arber A, Gallagher A: Breaking bad news revisited: the push

for negotiated disclosure and changing practice implications. *Int J Palliat Nurs* 9 (4): 166-72, 2003. [[PUBMED Abstract](#)]

6. Back AL, Trinidad SB, Hopley EK, et al.: What patients value when oncologists give news of cancer recurrence: commentary on specific moments in audio-recorded conversations. *Oncologist* 16 (3): 342-50, 2011. [[PUBMED Abstract](#)]
7. Gilligan T, Coyle N, Frankel RM, et al.: Patient-Clinician Communication: American Society of Clinical Oncology Consensus Guideline. *J Clin Oncol* 35 (31): 3618-3632, 2017. [[PUBMED Abstract](#)]
8. Figg WD, Smith EK, Price DK, et al.: Disclosing a diagnosis of cancer: where and how does it occur? *J Clin Oncol* 28 (22): 3630-5, 2010. [[PUBMED Abstract](#)]
9. Kuroki LM, Zhao Q, Jeffe DB, et al.: Disclosing a diagnosis of cancer: considerations specific to gynecologic oncology patients. *Obstet Gynecol* 122 (5): 1033-9, 2013. [[PUBMED Abstract](#)]
10. Parker PA, Baile WF, de Moor C, et al.: Breaking bad news about cancer: patients' preferences for communication. *J Clin Oncol* 19 (7): 2049-56, 2001. [[PUBMED Abstract](#)]
11. Siminoff LA, Graham GC, Gordon NH: Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. *Patient Educ Couns* 62 (3): 355-60, 2006. [[PUBMED Abstract](#)]
12. Fried TR, Bradley EH, O'Leary J: Prognosis communication in serious illness: perceptions of older patients, caregivers, and clinicians. *J Am Geriatr Soc* 51 (10): 1398-403, 2003. [[PUBMED Abstract](#)]
13. Hagerty RG, Butow PN, Ellis PM, et al.: Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol* 23 (6): 1278-88, 2005. [[PUBMED Abstract](#)]

14. Hagerty RG, Butow PN, Ellis PM, et al.: Communicating prognosis in cancer care: a systematic review of the literature. *Ann Oncol* 16 (7): 1005-53, 2005. [[PUBMED Abstract](#)]
15. Elkin EB, Kim SH, Casper ES, et al.: Desire for information and involvement in treatment decisions: elderly cancer patients' preferences and their physicians' perceptions. *J Clin Oncol* 25 (33): 5275-80, 2007. [[PUBMED Abstract](#)]
16. Weeks JC, Catalano PJ, Cronin A, et al.: Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med* 367 (17): 1616-25, 2012. [[PUBMED Abstract](#)]
17. Chen AB, Cronin A, Weeks JC, et al.: Expectations about the effectiveness of radiation therapy among patients with incurable lung cancer. *J Clin Oncol* 31 (21): 2730-5, 2013. [[PUBMED Abstract](#)]
18. Weinfurt KP, Castel LD, Li Y, et al.: The correlation between patient characteristics and expectations of benefit from Phase I clinical trials. *Cancer* 98 (1): 166-75, 2003. [[PUBMED Abstract](#)]
19. Agrawal M, Grady C, Fairclough DL, et al.: Patients' decision-making process regarding participation in phase I oncology research. *J Clin Oncol* 24 (27): 4479-84, 2006. [[PUBMED Abstract](#)]
20. Zier LS, Sottile PD, Hong SY, et al.: Surrogate decision makers' interpretation of prognostic information: a mixed-methods study. *Ann Intern Med* 156 (5): 360-6, 2012. [[PUBMED Abstract](#)]
21. Weeks JC, Cook EF, O'Day SJ, et al.: Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* 279 (21): 1709-14, 1998. [[PUBMED Abstract](#)]
22. Sekeres MA, Stone RM, Zahrieh D, et al.: Decision-making and quality of life in older adults with acute myeloid leukemia or advanced myelodysplastic syndrome.

- Leukemia 18 (4): 809-16, 2004. [\[PUBMED Abstract\]](#)
23. Lee SJ, Fairclough D, Antin JH, et al.: Discrepancies between patient and physician estimates for the success of stem cell transplantation. JAMA 285 (8): 1034-8, 2001. [\[PUBMED Abstract\]](#)
 24. Liu PH, Landrum MB, Weeks JC, et al.: Physicians' propensity to discuss prognosis is associated with patients' awareness of prognosis for metastatic cancers. J Palliat Med 17 (6): 673-82, 2014. [\[PUBMED Abstract\]](#)
 25. Daugherty CK, Hlubocky FJ: What are terminally ill cancer patients told about their expected deaths? A study of cancer physicians' self-reports of prognosis disclosure. J Clin Oncol 26 (36): 5988-93, 2008. [\[PUBMED Abstract\]](#)
 26. Keating NL, Landrum MB, Rogers SO, et al.: Physician factors associated with discussions about end-of-life care. Cancer 116 (4): 998-1006, 2010. [\[PUBMED Abstract\]](#)
 27. Singh JA, Sloan JA, Atherton PJ, et al.: Preferred roles in treatment decision making among patients with cancer: a pooled analysis of studies using the Control Preferences Scale. Am J Manag Care 16 (9): 688-96, 2010. [\[PUBMED Abstract\]](#)
 28. Nicolai J, Buchholz A, Seefried N, et al.: When do cancer patients regret their treatment decision? A path analysis of the influence of clinicians' communication styles and the match of decision-making styles on decision regret. Patient Educ Couns 99 (5): 739-46, 2016. [\[PUBMED Abstract\]](#)
 29. Bluhm M, Connell CM, De Vries RG, et al.: Paradox of Prescribing Late Chemotherapy: Oncologists Explain. J Oncol Pract 12 (12): e1006-e1015, 2016. [\[PUBMED Abstract\]](#)
 30. Oostendorp LJ, Ottevanger PB, van de Wouw AJ, et al.: Patients' Preferences for Information About the Benefits and Risks of Second-Line Palliative Chemotherapy and Their Oncologist's Awareness of These Preferences. J Cancer Educ 31 (3): 443-8, 2016. [\[PUBMED Abstract\]](#)
 31. Saluja R, Arciero VS, Cheng S, et al.: Examining Trends in

Cost and Clinical Benefit of Novel Anticancer Drugs Over Time. *J Oncol Pract* 14 (5): e280-e294, 2018. [[PUBMED Abstract](#)]

32. Patel MS, Davis MM, Lypson ML: Advancing medical education by teaching health policy. *N Engl J Med* 364 (8): 695-7, 2011. [[PUBMED Abstract](#)]
33. Ramsey S, Blough D, Kirchhoff A, et al.: Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Aff (Millwood)* 32 (6): 1143-52, 2013. [[PUBMED Abstract](#)]
34. Bestvina CM, Zullig LL, Rushing C, et al.: Patient-oncologist cost communication, financial distress, and medication adherence. *J Oncol Pract* 10 (3): 162-7, 2014. [[PUBMED Abstract](#)]
35. Henrikson NB, Tuzzio L, Loggers ET, et al.: Patient and oncologist discussions about cancer care costs. *Support Care Cancer* 22 (4): 961-7, 2014. [[PUBMED Abstract](#)]
36. Kelly RJ, Forde PM, Elnahal SM, et al.: Patients and Physicians Can Discuss Costs of Cancer Treatment in the Clinic. *J Oncol Pract* 11 (4): 308-12, 2015. [[PUBMED Abstract](#)]
37. Shih YT, Chien CR: A review of cost communication in oncology: Patient attitude, provider acceptance, and outcome assessment. *Cancer* 123 (6): 928-939, 2017. [[PUBMED Abstract](#)]
38. Zafar SY, Chino F, Ubel PA, et al.: The utility of cost discussions between patients with cancer and oncologists. *Am J Manag Care* 21 (9): 607-15, 2015. [[PUBMED Abstract](#)]
39. Bullock AJ, Hofstatter EW, Yushak ML, et al.: Understanding patients' attitudes toward communication about the cost of cancer care. *J Oncol Pract* 8 (4): e50-8, 2012. [[PUBMED Abstract](#)]

Communication in Pediatric Oncology

In recent years, high-quality communication has been identified as both a standard of care and a top research priority in the fields of pediatric oncology and pediatric palliative care.[1,2]

Prognostic Communication With Parents

Over the past decade, clinical research has helped provide insight into improving prognostic communication in pediatric oncology. Many parents find news about their child's prognosis upsetting, but they want to hear as much information as possible.[3,4] When information is upsetting, they tend to want more detail.[3] Instead of extinguishing hope, honest prognostic communication promotes it by facilitating informed decision making, even when the prognosis is poor.[5-7]

One study confirmed these findings in a longitudinal, prospective, questionnaire-based cohort study. In a survey of 156 parents of children with cancer who were treated at two academic pediatric hospitals, the vast majority wanted to hear about prognosis in as much detail as possible, and 85% considered a numeric estimate to be important. This desire for detailed information did not change with time. At the time of diagnosis and at 4 months and 12 months later, 87%, 85%, and 84% of parents, respectively, preferred to hear about prognosis in as much detail as possible. Furthermore, parents were more likely to be satisfied with prognostic disclosure if it had been discussed at diagnosis and then again before the 4-month point.[8] However, the same study population also reported receiving high-quality physician communication and had a trusting relationship with their child's oncologist, despite reporting overly optimistic prognostic estimates.[9]

A study also evaluated the impact of race and ethnicity in prognostic communication among 357 parents of children with cancer and their physicians.[10] Again, regardless of race, parents wanted as much detail as possible about the child's prognosis. Physicians in this study incorrectly estimated the needs of minority patients.

Communication Regarding Clinical Trials

Participating in cancer clinical trials requires parents to weigh the potential benefit of longer survival against the potential risk of unknown or increased toxicities. Most children in the United States with newly diagnosed cancer participate in a clinical research trial. A multisite study of the informed consent communication process for randomized controlled trials for childhood leukemia revealed that 50% of the 137 parents enrolled did not understand the randomization process.[11]

In general, children aged 7 to 18 years must provide their assent before enrolling in a trial. However, a study of 37 children with cancer who were enrolled in a clinical trial revealed that 51% did not know or recall that their treatment involved research. In addition, although all expressed a desire to be involved in decision making, 49% did not recall having a role in the decision to enroll in the trial.[12] A study looking at parents' and adolescents' inclinations toward a study involving intensified or reduced therapy revealed divergent inclinations, highlighting the need for communication with both parents and adolescents during the informed consent process.[13]

Phase I clinical trials in particular require clear communication between provider and parent or patient, given that these trials offer minimal prospect of direct benefit to the child. In one study, 85 informed-consent conferences for phase I research between June 2008 and May 2011 were directly observed, and 60 parents were subsequently interviewed. Results showed that only 32% of parents demonstrated a substantial understanding of the scientific purpose of phase I cancer trials.[14] On the basis of these results, attempts to develop tools to improve communication have been published.[15]

Prognostic Communication With Children

Studies show that children wish to be informed about their illness and plans for treatment.[16] Although children's information needs may be age dependent, most children 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. [17] A study published in 2018 explored the development of an understanding of death in a group of 136 children aged 4 to 11 years.[18] It found that children understood key aspects of death as young as age 4 or 5 years, with the understanding of irreversibility and the cessation of mental and physical processes also emerging during early childhood.

In a cross-sectional study of 131 caregivers of children who died of cancer, two-thirds of caregivers reported talking to their child about death or dying.[19] When asked how staff could best support caregivers to have these conversations, most caregivers suggested offering resources on how to have these conversations with a child. Few caregivers wanted clinicians to talk to the child themselves or be in the room while the caregiver talked to the child.

Communication With Adolescents

Navigating communication with adolescents with serious, potentially progressive illness can be challenging. There are ethical issues of autonomy, as well as a general lack of evidence regarding the exact timing and extent of information sharing. [20] Studies indicate that although most adolescents with long-term illness want to participate in medical decision making, when and how much they want to be involved are variable. [21,22] A single-institution longitudinal study on prognostic communication for adolescents and young adults found that 85% found prognostic information was very important/extremely important at the time of diagnosis. This number increased to 96% of patients 4 months after diagnosis. While most adolescents and young adults were satisfied with the amount of prognostic information they received, a sizable minority (19%–21%) desired additional information.[23][[Level of evidence: II](#)] A study of teens with advanced cancer suggested not only that they are capable of participating in complex decision making, but

also that nearly all understand the consequences of their end-of-life (EOL) decisions and care about how they affect surviving friends and family.[24] Finally, a study of bereaved caregivers of adolescents and young adults cited delayed or absent communication about prognosis as a barrier to optimal EOL care.[25]

Communication With Siblings

Siblings of children with cancer experience psychosocial distress during cancer therapy and after bereavement. In a study of 174 siblings of children who died of cancer, the siblings reported poor knowledge and experienced a lack of communication about the death of their brother or sister. Siblings who reported a lack of communication surrounding the death of their brother or sister reported higher levels of anxiety 2 to 9 years after the loss. [26] Of these 174 bereaved siblings, 108 participated in a survey in which 56% suggested that providers communicate better medical information. Other suggestions included giving parents more guidance on how to communicate with siblings and incorporate them into the care of the patient with cancer.[27] Similarly, a cross-sectional, survey-based study of bereaved siblings reported dissatisfaction with communication as a factor in higher distress scores.[28]

Communication With a Child Whose Parent Has Cancer

A child whose parent has a diagnosis of advanced cancer experiences high levels of distress. A study of 28 families indicated that children wanted honest information from a variety of sources, including health professionals, and access to confidential conversations to avoid upsetting the ill parent.[29] In another study, 279 fathers widowed by cancer completed a survey about their own depression and bereavement symptoms, their wife's illness, and EOL parental communication priorities. The study supports the importance of parental communication with children about death. Parents with terminal cancer identified illness-related communication with children as a

source of concern, and many reported that they lacked the necessary confidence or information to effectively communicate with their children.[30]

References

1. Field MJ, Behrman RE, eds.: When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families. Institute of Medicine, National Academies Press, 2003. [Also available online](#). Last accessed January 20, 2022.
2. Epstein RM, Street RL Jr: Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, 2007. NIH Pub. No. 07-6225. [Also available online](#). Last accessed June 22, 2023.
3. Mack JW, Wolfe J, Grier HE, et al.: Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *J Clin Oncol* 24 (33): 5265-70, 2006. [[PUBMED Abstract](#)]
4. Mack JW, Wolfe J, Cook EF, et al.: Hope and prognostic disclosure. *J Clin Oncol* 25 (35): 5636-42, 2007. [[PUBMED Abstract](#)]
5. Smith TJ, Dow LA, Virago E, et al.: Giving honest information to patients with advanced cancer maintains hope. *Oncology (Williston Park)* 24 (6): 521-5, 2010. [[PUBMED Abstract](#)]
6. Hagerty RG, Butow PN, Ellis PM, et al.: Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol* 23 (6): 1278-88, 2005. [[PUBMED Abstract](#)]
7. Nyborn JA, Olcese M, Nickerson T, et al.: "Don't Try to Cover the Sky with Your Hands": Parents' Experiences with Prognosis Communication About Their Children with Advanced Cancer. *J Palliat Med* 19 (6): 626-31, 2016. [[PUBMED Abstract](#)]
8. Sisk BA, Kang TI, Mack JW: Prognostic disclosures over time: Parental preferences and physician practices. *Cancer* 123

(20): 4031-4038, 2017. [\[PUBMED Abstract\]](#)

9. Sisk BA, Kang TI, Mack JW: How Parents of Children With Cancer Learn About Their Children's Prognosis. *Pediatrics* 141 (1): , 2018. [\[PUBMED Abstract\]](#)
10. Ilowite MF, Cronin AM, Kang TI, et al.: Disparities in prognosis communication among parents of children with cancer: The impact of race and ethnicity. *Cancer* 123 (20): 3995-4003, 2017. [\[PUBMED Abstract\]](#)
11. Kodish E, Eder M, Noll RB, et al.: Communication of randomization in childhood leukemia trials. *JAMA* 291 (4): 470-5, 2004. [\[PUBMED Abstract\]](#)
12. Unguru Y, Sill AM, Kamani N: The experiences of children enrolled in pediatric oncology research: implications for assent. *Pediatrics* 125 (4): e876-83, 2010. [\[PUBMED Abstract\]](#)
13. Tulstrup M, Larsen HB, Castor A, et al.: Parents' and Adolescents' Preferences for Intensified or Reduced Treatment in Randomized Lymphoblastic Leukemia Trials. *Pediatr Blood Cancer* 63 (5): 865-71, 2016. [\[PUBMED Abstract\]](#)
14. Cousino MK, Zyzanski SJ, Yamokoski AD, et al.: Communicating and understanding the purpose of pediatric phase I cancer trials. *J Clin Oncol* 30 (35): 4367-72, 2012. [\[PUBMED Abstract\]](#)
15. Johnson LM, Leek AC, Drotar D, et al.: Practical communication guidance to improve phase 1 informed consent conversations and decision-making in pediatric oncology. *Cancer* 121 (14): 2439-48, 2015. [\[PUBMED Abstract\]](#)
16. Wangmo T, De Clercq E, Ruhe KM, et al.: Better to know than to imagine: Including children in their health care. *AJOB Empir Bioeth* 8 (1): 11-20, 2017 Jan-Mar. [\[PUBMED Abstract\]](#)
17. Beale EA, Baile WF, Aaron J: Silence is not golden: communicating with children dying from cancer. *J Clin*

Oncol 23 (15): 3629-31, 2005. [\[PUBMED Abstract\]](#)

18. Panagiotaki G, Hopkins M, Nobes G, et al.: Children's and adults' understanding of death: Cognitive, parental, and experiential influences. *J Exp Child Psychol* 166: 96-115, 2018. [\[PUBMED Abstract\]](#)
19. Kenney AE, Bedoya SZ, Gerhardt CA, et al.: End of life communication among caregivers of children with cancer: A qualitative approach to understanding support desired by families. *Palliat Support Care* 19 (6): 715-722, 2021. [\[PUBMED Abstract\]](#)
20. Rosenberg AR, Wolfe J, Wiener L, et al.: Ethics, Emotions, and the Skills of Talking About Progressing Disease With Terminally Ill Adolescents: A Review. *JAMA Pediatr* 170 (12): 1216-1223, 2016. [\[PUBMED Abstract\]](#)
21. Lyon ME, McCabe MA, Patel KM, et al.: What do adolescents want? An exploratory study regarding end-of-life decision-making. *J Adolesc Health* 35 (6): 529.e1-6, 2004. [\[PUBMED Abstract\]](#)
22. Pao M, Mahoney MR: "Will You Remember Me?": Talking with Adolescents About Death and Dying. *Child Adolesc Psychiatr Clin N Am* 27 (4): 511-526, 2018. [\[PUBMED Abstract\]](#)
23. Sisk BA, Fasciano K, Block SD, et al.: Longitudinal prognostic communication needs of adolescents and young adults with cancer. *Cancer* 126 (2): 400-407, 2020. [\[PUBMED Abstract\]](#)
24. Hinds PS, Drew D, Oakes LL, et al.: End-of-life care preferences of pediatric patients with cancer. *J Clin Oncol* 23 (36): 9146-54, 2005. [\[PUBMED Abstract\]](#)
25. Mack JW, Currie ER, Martello V, et al.: Barriers to Optimal End-of-Life Care for Adolescents and Young Adults With Cancer: Bereaved Caregiver Perspectives. *J Natl Compr Canc Netw* 19 (5): 528-533, 2021. [\[PUBMED Abstract\]](#)
26. Lövgren M, Jalmsell L, Eilegård Wallin A, et al.: Siblings' experiences of their brother's or sister's cancer death: a

nationwide follow-up 2-9 years later. *Psychooncology* 25 (4): 435-40, 2016. [[PUBMED Abstract](#)]

27. Lövgren M, Bylund-Grenklo T, Jalmsell L, et al.: Bereaved Siblings' Advice to Health Care Professionals Working With Children With Cancer and Their Families. *J Pediatr Oncol Nurs* 33 (4): 297-305, 2016. [[PUBMED Abstract](#)]
28. Rosenberg AR, Postier A, Osenga K, et al.: Long-term psychosocial outcomes among bereaved siblings of children with cancer. *J Pain Symptom Manage* 49 (1): 55-65, 2015. [[PUBMED Abstract](#)]
29. Kennedy VL, Lloyd-Williams M: Information and communication when a parent has advanced cancer. *J Affect Disord* 114 (1-3): 149-55, 2009. [[PUBMED Abstract](#)]
30. Park EM, Deal AM, Yopp JM, et al.: End-of-life parental communication priorities among bereaved fathers due to cancer. *Patient Educ Couns* 100 (5): 1019-1023, 2017. [[PUBMED Abstract](#)]

Latest Updates to This Summary (06/22/2023)

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.

Communication in Pediatric Oncology

Added [text](#) about a cross-sectional study of 131 caregivers of children who died of cancer, in which two-thirds of caregivers reported talking to their child about death or dying. Most caregivers suggested offering resources on how to have these conversations with a child. Few caregivers wanted clinicians to talk to the child themselves or be in the room while the caregiver talked to the child (cited Kenney et al. as reference 19).

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- Larry D. Cripe, MD (Indiana University School of Medicine)
- Natalie Jacobowski, MD (Nationwide Children's Hospital)
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