

ADVANCING PATIENT-CENTERED COMMUNICATION IN CANCER CARE

A Toolkit for Researchers and Practitioners



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OVERVIEW

Patient-centered communication (PCC) helps provide high-quality, patient-focused medical care. Although PCC has been conceptualized in multiple ways, most agree that clinicians communicating in a patient-centered way

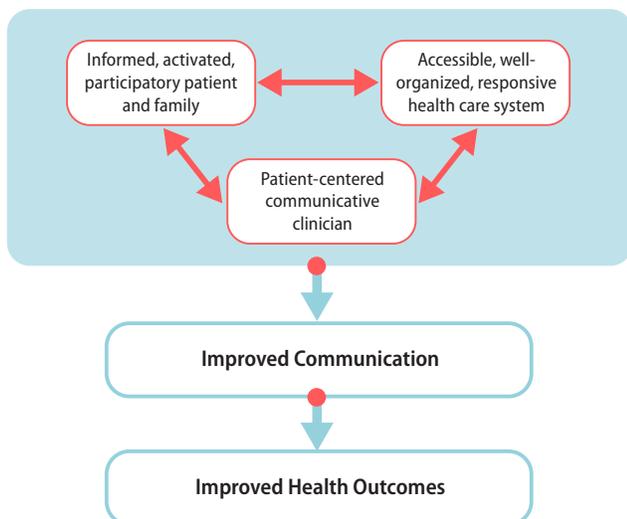
- ♦ show care and respect for the patient as a person;
- ♦ solicit the patient’s perspective and preferences;
- ♦ try to understand how the patient’s health is affecting their everyday life and well-being;
- ♦ involve patients in their care; and
- ♦ make evidence-based decisions that are consistent with patient values and feasible to implement.

Achieving PCC in diverse cancer care settings depends on

- ♦ the extent to which important elements of PCC can be measured and assessed; and
- ♦ researchers’ and clinicians’ efforts to identify the “pathways” through which accomplishing PCC in medical encounters can improve patient outcomes, such as
 - patient satisfaction with care,
 - commitment to treatment plans, and
 - improved health and well-being (biomedical, psychological, and quality of life).

Figure 1. Patient-Centered Care

Clinicians, patients, relationships (clinical and social), and health services are all integral to patient-centered care. The interactions among these elements are complex and deficits in any one area can significantly decrease the quality of patient care.



CONCEPTUAL MODEL

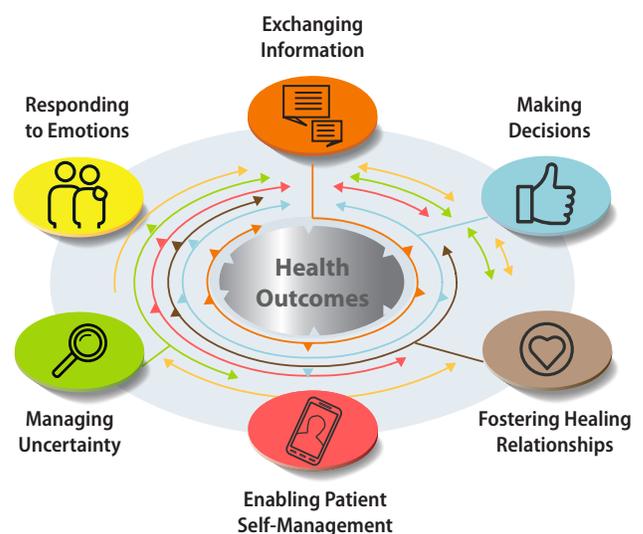
The approach to PCC described here is based on the National Cancer Institute’s 6 function model of PCC in cancer care. Rather than assessing a clinician’s communication style *with patients*—such as friendly, informative or supportive—the model focuses on the *work* that communication must do well to achieve PCC.

The 6 key functions of PCC include:

1. Information exchange
2. Fostering healing relationships
3. Managing uncertainty
4. Making decisions
5. Managing emotions
6. Enabling self-management.

These 6 functions are not independent of one another. For example, information exchange is a critical part of effective decision-making and can help cancer patients manage emotions, which helps foster healing relationships. Although these functions are interconnected, they also relate to distinct communication domains requiring effective clinician-patient communication to achieve high-quality cancer care.

Figure 2. Patient-Care Communication Model



PCC ACROSS THE CANCER CARE CONTINUUM

One way to understand the utility of the NCI model of PCC is to show how the different communication functions apply to different stages in the cancer control continuum.



Early Detection	Diagnosis	Treatment	Survivorship	End of Life
Providing individualized, linguistically accessible information about screening	Addressing the patient's anxiety, fear, emotional response to a cancer diagnosis	Eliciting patient's experiences of treatment, symptoms, and side effects	Helping patient understand and manage uncertainty about recurrence	Eliciting the patient's report of symptoms
Decision-making about screening when risks/benefits are unclear or when multiple options exist	Communicating bad news clearly and compassionately	Sharing information about treatment effectiveness	Eliciting discussion of the patient's concerns and symptoms	Communicating prognosis while maintaining hope
Addressing the patient's concerns and worries about possible cancer diagnosis	Helping patients recall important information	Engaging patient (and family) in decision making about ongoing curative and palliative treatment	Communicating bad news clearly and compassionately	Making decisions about treatment, life support, and hospice care
Helping patient navigate the healthcare system to follow-up on abnormal results	Eliciting preferences for role in decision-making	Eliciting and responding to emotions of patient and family	Engaging patient (and family) in making treatment decisions if recurrence or progression occurs	Helping patients and families navigate transition to hospice or other end-of-life care
	Helping patients understand probabilistic information		Communicating prognosis while maintaining hope	Eliciting and responding to emotions of patient and family
	Communicating prognosis while maintaining hope		Eliciting and responding to emotions of patient and family	
	Making decisions about treatment and advance care planning			

For example, *prevention* and *screening* rely heavily on communication focused on **information exchange**, especially as it applies to an individual's understanding of cancer risks, behaviors that minimize risk, and the importance of routine screening for early detection.

Diagnosis, including sharing bad news, requires clinician communication that help a patient **manage difficult emotions** and **fosters healing relationships** so that the patient and their family understand they are supported, cared for, and will not be abandoned.

During the *treatment stage*, a patient may have options for how to treat their cancer. Consequently, effective **decision-making** is essential as the clinician and patient work together to create a treatment plan supported by the evidence and

consistent with the patient's preferences and values. During treatment, **enabling patient self-management** is also critically important because a patient and their loved ones need to know how to manage side effects of the disease and treatment—such as pain, fatigue, and nausea—as the patient returns to everyday activities outside the clinic.

During the *survivorship stage*, **managing uncertainty** is especially important because the patient may wait, often for weeks and months, to see if treatment leads to cure or remission; and, if so, whether there will be a recurrence. This is not to say that within each stage the other communication functions are less important. As mentioned above, all of the functions are interconnected in practice, but communicating successfully in certain domains will be particularly important.

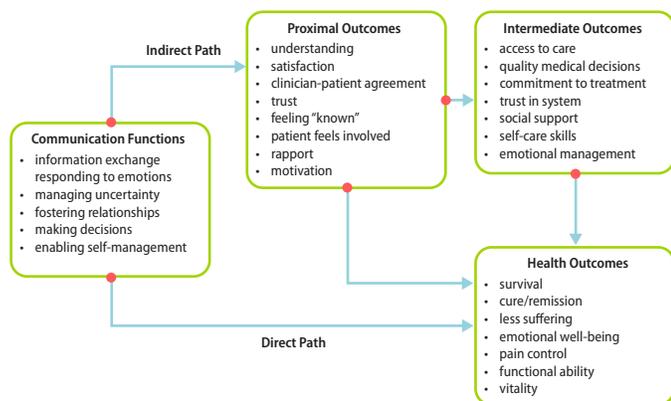


Patient stories

HOW PCC INFLUENCES CANCER CARE OUTCOMES

Conventional wisdom holds that PCC is important in cancer care and contributes to higher quality of care and improved health outcomes. But in what way and based on what evidence? To answer these questions, it is helpful to use a model that describes the potential “pathways” through which PCC can lead to better cancer care and improvement among multiple cancer care outcomes, such as pain control, psychological well-being, remission, and improved physical function.¹ (Figure 3)

Figure 3. Direct and Indirect Pathways from Communication to Health Outcomes



Although clinician-patient communication can directly affect health outcomes, more often than not effective communication will have an indirect effect on health outcomes via its effect on factors closely linked to better health and well-being:

- ♦ Greater patient satisfaction with the support and information received from the healthcare providers
- ♦ Stronger patient commitment to the treatment plan
- ♦ Better self-care and caregiving skills for managing symptoms and side effects of treatment
- ♦ Coping with difficult feelings

Consider some examples from investigations that identified pathways through which PCC contributed to better cancer care and outcomes.

Physicians who more actively involved cancer patients in the decision-making process (decision-making) had patients who reported more confidence in managing the disease and had a greater sense of personal control, which in turn predicted better emotional well-being.²

In a study³ of patients with advanced cancer who were having problems with pain, patients who openly expressed their problems with pain and preferences for pain management (information exchange) were more likely to have their physicians make adjustments in their pain medications. Patients receiving a change in pain management were more likely to report better pain control several weeks after the consultation than patients staying on the same regimen.

An investigation that analyzed videotapes of surgeons’ consultations with breast cancer patients⁴ reported that patients’ expressed greater satisfaction with their care when they were more engaged in stating treatment preferences (decision-making) and when their surgeons provided more good and hopeful news (information exchange, managing emotions). Greater patient satisfaction, in turn, predicted more hopefulness about their treatment following the consultation.

In a longitudinal study of breast cancer patients undergoing radiotherapy,⁵ patients who reported being more engaged in seeking and sharing information (information exchange) and patients that perceived better relational communication with their doctors (fostering healing relationships) reported better coping and less anxiety, which then predicted higher quality of life.

In short, PCC matters. To use a journey analogy, PCC is the key that starts care moving down the road to better cancer care and well-being.

BREAKDOWNS IN PATIENT-PROVIDER COMMUNICATION

Patients’ and family members’ experiences of cancer and cancer care are highly influenced by how their providers communicate with them. Patients value sensitive, caring clinicians who

- ♦ provide information that they need, when they need it, in a way that they can understand;
- ♦ listen and respond to their questions and concerns; and
- ♦ make an effort to understand what the patient experiences.⁶

Communication Breakdowns and the Role of PCC

Potential Communication Breakdowns and the Role of Patient-Centered Communication

Example of Communication Breakdown	How Can PCC Help?
Patient is upset that clinician did not provide information about treatment side effects in advance, including how side effects might affect day-to-day life	 <p>Function: Exchanging Information When discussing the treatment plan, provide information about potential side effects, including</p> <ul style="list-style-type: none"> ◆ how likely patients are to experience side effects, ◆ why side effects occur, ◆ how side effects may impact day-to-day life, and ◆ ways to mitigate or manage side effects.
Patient is uncertain about the step in their care and how things will unfold during treatment	 <p>Function: Managing Uncertainty</p> <ul style="list-style-type: none"> ◆ Provide clear and complete information about planned steps in care and what to expect at different points in care. ◆ Be explicit about any uncertainties related to treatment, such as why, when, and how plans might change. ◆ Reassure patients you will discuss possible changes in their care right away.
Patient feels that clinician treats them like a number or “a guinea pig” and does not know or care about them as an individual	 <p>Function: Fostering Healing Relationships</p> <ul style="list-style-type: none"> ◆ Ask patients about themselves, such as family, interests, or occupation. ◆ Find out what is important to the patient.
Patient is overwhelmed with the cancer care plan and what they need to do	 <p>Function: Enabling Patient Self-Management</p> <ul style="list-style-type: none"> ◆ Acknowledge that cancer care is complex and validate the patient’s feeling of being overwhelmed. ◆ Reassure patients you will help them navigate their care. ◆ Help patients identify strategies to manage their care. ◆ Help patients identify sources of support, such as family and patient navigator.
Patient feels that clinician does not try to understand or appreciate their opinion when making decisions	 <p>Function: Making Decisions</p> <ul style="list-style-type: none"> ◆ Ask patients what is most important to them in making decisions, including what outcomes are most important. ◆ Discuss factors for patients to consider with each option. ◆ Ask for patients’ opinions on the treatment options.
Patient feels like clinician is not aware of or sensitive to their distress and fears	 <p>Function: Recognizing and Responding to Emotions</p> <ul style="list-style-type: none"> ◆ Ask patients how they are feeling emotionally. ◆ Be attentive to nonverbal emotional cues. ◆ Acknowledge and validate patients’ emotions.

The importance of PCC is perhaps most apparent in its absence, when communication breaks down or simply does not occur. One study of patients who had recently undergone cancer treatment found approximately 1 in 4 believed something had gone wrong in their care.⁷ These patients revealed that a majority of problematic events involved communication breakdowns.

Related to information exchange, patients reported

- ◆ not receiving information they needed when they needed it (for instance, about treatment options),
- ◆ receiving inaccurate information (for instance, a wrong diagnosis), or
- ◆ having their reports of symptoms ignored.

Patients also reported problems with relational communication, perceiving cold and uncaring communication from their providers.

Importantly, patients felt these communication breakdowns caused harm—most commonly emotional harm and damage to the provider-patient relationship, but in some cases also physical harm, life disruption, or financial harm. Perhaps most striking was the finding that communication breakdowns were sometimes as harmful from the patients’ perspective as breakdowns in medical care.

A subsequent survey of cancer survivors⁸ found that approximately 1 in 5 identified a specific communication breakdown during their cancer care. Of these, approximately half involved problems with information exchange, and

approximately one quarter involved problems with fostering the relationship. Less frequently reported but also noted were deficits in helping patients with difficult emotions and decision-making. These breakdowns caused patients distress and negatively impacted their overall care experience.

This research and related studies suggest that patients often do not proactively speak up about breakdowns in care, including about communication breakdowns.^{6,9} This makes it all the more important to use strategies to actively reach patients to solicit their perspective on and experiences with communication over the course of cancer care.

Assessment is the first step in identifying whether or where improvements are needed and in preventing the harms that can result when communication falls short.

For more information about communication breakdowns and the role of PCC, see the following:

- ◆ **Patients’ and family members’ views on patient-centered communication during cancer care.** Mazor KM, Beard RL, Alexander GL, Arora NK, Firneno C, Gaglio B, Greene SM, Lemay CA, Robinson BE, Roblin DW, Walsh K. *Psycho-Oncology*. 2013;22(11):2487-2495. doi: 10.1002/pon.3317.
- ◆ **Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response.** Mazor KM, Roblin DW, Greene SM, Lemay CA, Firneno CL, Calvi J, Prouty CD, Horner K, Gallagher TH. *J Clin Oncol*. 2012;30(15):1784-1790. doi: 10.1200/JCO.2011.38.1384.

- ◆ **Encouraging patients to speak up about problems in cancer care.** Mazor KM, Kamineni A, Roblin DW, Anau J, Robinson BE, Dunlap BS, Firneno C, Gallagher TH. *J Patient Saf*. 2018; doi: 10.1097/PTS.0000000000000510.
- ◆ **Cancer survivors’ experiences with breakdowns in patient-centered communication.** Street Jr RL, Spears E, Madrid S, Mazor KM. 2019. *Psycho-Oncology*. 2019;28(2):423-429. doi: 10.1002/pon.4963.

HOW PCC CAN BE MEASURED AND OBSERVED

Reliable and valid measures of PCC are essential for conducting communication research. Communication can be measured using a variety of methods, including:

- ◆ Patient self-report
- ◆ Clinician self-report
- ◆ Observational methods.

RTI International and the University of North Carolina at Chapel Hill developed a patient report measure, the Patient-Centered Communication in Cancer Care (PCC-Ca), which is based on the National Cancer Institute (NCI) conceptual model of PCC.

Methods for Assessment of Patient-Centered Communication

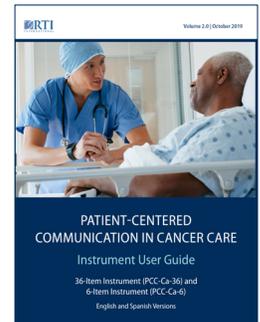
Method	Strengths	Weaknesses	Sample Measures
Patient report (Surveys, diaries)	<ul style="list-style-type: none"> ◆ Measured from the perspective of the patient ◆ Can capture both communication behavior—such as whether a communication happened or the frequency—and patient evaluation of the communication 	<ul style="list-style-type: none"> ◆ Potential recall and reporting biases ◆ Judgment of observers may not correlate with judgments of patients 	<ul style="list-style-type: none"> ◆ Patient Centered Communication in Cancer Care (PCC-CA) ◆ Patient Assessment of cancer Communication Experiences (PACE)¹⁰
Clinician report (Surveys)	<ul style="list-style-type: none"> ◆ Can capture both communication behavior—such as whether a communication happened or the frequency—and clinician evaluation of the communication 	<ul style="list-style-type: none"> ◆ Potential recall and reporting biases ◆ May not correlate with patient report 	<ul style="list-style-type: none"> ◆ Patient report of clinician’s patient-centered communication instrument¹¹
Observational Methods (Direct observation, audio or video recordings, standardized patients [actors])	<ul style="list-style-type: none"> ◆ Real-time measure ◆ Direct view of communication behavior 	<ul style="list-style-type: none"> ◆ Methodology can be intrusive ◆ Complex coding systems ◆ May not correlate with patient perceptions 	<ul style="list-style-type: none"> ◆ Roter Interactive Analysis System (RIAS)¹² ◆ Active Patient Participation Coding Scheme¹³ ◆ Relational Communication Scale¹⁴

The purpose of this measure is to assess PCC in 6 core domains:

1. Exchanging information
2. Making decisions
3. Fostering healing relationships
4. Enabling patient self-management
5. Managing uncertainty
6. Responding to emotions

Researchers and practitioners can use the PCC-Ca for surveillance, quality monitoring, assessment, and intervention evaluation.

This instrument is available in both a long form (36 items) and a short form (6 items) and is easy to score. The [User Guide](#) is publicly available in both English and Spanish.



Development of the PCC-Ca

The PCC-Ca was developed and evaluated by a multidisciplinary team that included communication experts, survey methodologists, clinicians, and patients. The process aimed to develop survey questions that reliably and validly capture the 6 core functions of PCC. This included the involvement of a patient advocacy group, [Fight Colorectal Cancer](#), and a multidisciplinary panel of stakeholders throughout the measurement development process to ensure the survey questions



- ♦ captured aspects of PCC important to patients; and
- ♦ that the questions meet the needs of potential end users, including researchers, healthcare organizations, and health professionals.

For a full description of the development of the PCC-Ca, see the following:

- ♦ **Engaging patient advocates and other stakeholders to design measures of patient-centered communication in cancer care.** Treiman K, McCormack L, Olmsted M, Roach N, Reeve BB, Martens CE, Moultrie RR, Sanoff H. *Patient*. 2017;10(1):93-103. doi: 10.1007/s40271-016-0188-6
- ♦ **Psychometric evaluation and design of patient-centered communication measures for cancer care settings.** Reeve BB, Thissen DM, Bann CM, Mack N, Treiman K, Sanoff HK, Roach N, Magnus BE, He J, Wagner LK, Moultrie R, Jackson KD, Mann C, McCormack LA. *Patient Educ Couns*. 2017;100(7):1322-1328. doi: 10.1016/j.pec.2017.02.011.

The steps in developing the PCC-Ca include the following:

1. **Literature review and formative research** with colorectal cancer patients and clinicians to identify measurement domains
2. **Review of existing survey items** to determine any that could be used or adapted
3. **Develop new survey items** following recommendations for survey item development¹⁵
4. **Cognitive interviews with patients** to evaluate patients' ability to understand and provide valid answers to the PCC questions.
5. **Pilot test the instrument** to establish the reliability and validity of the PCC-Ca. The pilot test involved 501 adult colorectal cancer patients.
6. **Psychometric evaluation of the PCC items to design the final versions of the PCC-Ca-36 and PCC-Ca-6 measures.** The psychometric evaluation used a single-time-point assessment of the psychometric properties, including reliability (internal consistency) and construct validity.

Conversations with Researchers

Hear from PCC researchers in this video, [A Conversation with the Researchers](#). Three experts in patient-centered communication and measurement development discuss their research and share guidance for using the PCC-Ca for surveillance, quality monitoring, assessment, and intervention evaluation.

MEASURING PCC IN CLINICAL SETTINGS

Opportunities

- ◆ **To inform quality improvement initiatives** aimed at improving patient-centered care and communication.
- ◆ **To diagnose potential problem areas in PCC** identified through other means. The findings from patient surveys—such as Press Ganey and Consumer Assessment of Healthcare Providers and Systems (CAHPS)—can identify groups of patients with lower satisfaction levels or clinical teams that receive poorer ratings. Medical records also can

identify issues in quality of care that may be attributed, in part, to shortcomings in patient-clinician communication, such as poor compliance and overuse or underuse of services.

- ◆ **To evaluate interventions** designed to improve patient-clinician communication. PCC assessment can be conducted pre and post interventions.
- ◆ **To provide feedback to clinicians** and clinical teams on patient perceptions of patient-clinician communication.

Addressing Challenges to PCC Assessment in Clinical Settings

Clinicians and healthcare leaders value the importance of PCC and PCC assessment to identify areas for improvement. Patients want to provide feedback both to improve their own care experience and to “pay it forward” to improve the experience of future cancer patients.⁶ However, challenges exist to implementing PCC assessment in cancer care settings.

Potential Challenges and Solutions to Assessing PCC in Clinical Settings

Potential Challenge	Approaches
Patient burden	<ul style="list-style-type: none"> ◆ Use a brief assessment, such as the 6-item version of the PCC-Ca ◆ Clinical sites determine the optimal frequency of PCC assessment, considering other assessments patients are requested to complete so as not to overburden patients ◆ Ensure patients can complete the assessment efficiently either at the clinical site following the clinical encounter or from home
Patient doubts about whether and how results will be used	<ul style="list-style-type: none"> ◆ Explain purpose of assessment is to improve quality of patient-provider communication and specify how results will be shared and used
Patient concerns (such as regarding confidentiality, preserving their relationship with their doctors)	<ul style="list-style-type: none"> ◆ Assure patients that their responses are confidential ◆ Providers or teams will receive summary feedback and will not know how any individual responded
Logistics of implementation	<ul style="list-style-type: none"> ◆ Identify options for fitting the PCC assessment into the clinic workflow so as not to slow things down for the patient or clinical staff ◆ Patients can complete the assessment on a tablet in waiting room or the clinic can send the assessment as a routine appointment follow-up (for example, via a patient portal or text message with link to survey) for patients to complete at home
Healthcare leadership questions and concerns (for example, regarding value, feasibility, and burden)	<ul style="list-style-type: none"> ◆ Share evidence regarding association between PCC and patient satisfaction and other patient outcomes ◆ Plan for how assessment findings will be used as part of quality improvement ◆ Seek input from healthcare leadership on how to share communication assessment results with clinicians and teams ◆ Have a clear plan for follow-up action (such as training and coaching)
Clinicians' questions and concerns (for example, regarding how results will be used)	<ul style="list-style-type: none"> ◆ Seek input from clinicians and teams on preferences for receiving assessment results ◆ Provide opportunities for training, coaching, with hands-on communication practice

PATIENT-CENTERED COMMUNICATION GUIDELINES AND TRAINING RESOURCES

Training Resources		
Resource	Source	Description
<u>OncoTalk</u>	National Cancer Institute	This is a multiple-day training geared toward oncologists and facilitated through conversations with actor-patients.
<u>VitalTalk</u>	Vital Talk	VitalTalk workshops train clinicians to communicate about values and goals, preparing them with constructive tools for creating care plans that match their patients' values.
<u>Communication Skills Pathfinder</u>	Ariadne Labs, the Center to Advance Palliative Care, and VitalTalk	Specifically geared to all clinicians who care for patients living with serious illness, the Communication Skills Pathfinder web portal was developed by a collaboration of three leading healthcare organizations: Ariadne Labs; the Center to Advance Palliative Care, and VitalTalk. The portal aims to connect all clinicians to easily accessible, proven communication skills training.
<u>American Society of Clinical Oncology Quality Training Program</u>	American Society of Clinical Oncology (ASCO)	This 6-month program includes 5 days of in-person learning across three sessions and hands-on learning at the participants' practices. To ensure a well-rounded experience, sessions include seminars, case examples, and small-group exercises.
<u>Academy of Communication in Healthcare Communication Skills Training</u>	Academy of Communication in Healthcare Communication (ACH)	The content and delivery methods of this communication skills training program is tailored to the specific needs of individual healthcare professionals and the organizations they serve.
<u>Communicate Comfort</u>	Elaine Wittenberg, PhD; Joy Goldsmith, PhD, and Sandra Ragan, PhD	The Family Caregiver Communication Tool (online or downloadable) and a variety of COMFORT™ SM Communication courses are tailored to specific audiences.

Guidelines for Patient-Provider Communication		
Resource	Source	Description
<u>Supportive Care and Treatment-Related Issues: Patient-Clinician Communication</u>	American Society of Clinical Oncology (ASCO)	Guidance is provided regarding core communication skills and tasks that apply across the cancer care continuum. Recommendations address specific topics, such as discussion of goals of care and prognosis, treatment selection, end-of-life care, facilitating family involvement in care, and clinician training in communication skills.
<u>National Comprehensive Cancer Network Guidelines</u>	National Comprehensive Cancer Network (NCCN)	This is a suite of guidelines designed to improve the quality of cancer care.

Other Useful Resources			
Resource	Type of Resource	Source	Description
<u>Communication Rx: Transforming Healthcare Through Relationship-Centered Communication</u>	Book	Academy of Communication in Healthcare (ACH)	This is a step-by-step guide that enables the reader to: <ul style="list-style-type: none"> ◆ Provide more accurate diagnoses and effective treatments—and improve patient outcomes ◆ Boost patient adherence and lower hospital readmission rates ◆ Make fewer errors and reduce malpractice risks ◆ Increase patient satisfaction and build teamwork among providers ◆ Further develop your communication skill set—and help others do the same
<u>Smith's Patient-Centered Interviewing, Fourth Edition</u>	Book	Academy of Communication in Healthcare (ACH)	Smith's Patient-Centered Interviewing covers patient-centered and clinician-centered interviewing skills, such as: <ul style="list-style-type: none"> ◆ Patient education ◆ Motivating for behavior change ◆ Sharing bad news ◆ Managing different personality styles ◆ Increasing personal awareness in mindful practice ◆ Nonverbal communication ◆ Using computers in the exam room ◆ Reporting and presenting evaluations
<u>Handbook of Communication in Oncology and Palliative Care 1st Edition</u>	Book	David Kissane, Barry Bultz, Phyllis Butow, and Ilora Finlay	This handbook provided practical and evidence-based guidelines to achieve effective, patient-centered communication in the areas of cancer and palliative care.
<u>Teaching and Learning Communication Skills in Medicine, Second Edition</u>	Book	Suzanne Kurtz, Jonathan Silverman, Juliet Draper	This book and its companion, <i>Skills for Communicating with Patients</i> (2nd ed.), provide a comprehensive approach to improving communication in medicine.
<u>Communication in Cancer Care (PDQ)—Health Professional Version</u>	Evidence-based information	National Cancer Institute (NCI)	This information summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about communicating with cancer patients and their family.
<u>Various on-demand webinars hosted by Academy of Communication in Healthcare</u>	Webinars	Academy of Communication in Healthcare (ACH)	These are prerecorded webinars on a variety of communication topics.
<u>Collection of communication-related articles hosted by Oncology Nursing Society</u>	Articles	Oncology Nursing Society; Various authors	These articles address a variety of communication-related topics.



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