National Cancer Institute

PATIENT-CENTERED COMMUNICATION IN CANCER CARE

Promoting Healing and Reducing Suffering

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Reducing Suffering

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National Cancer Institute

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Foreword

There is growing recognition throughout the medical and scientific research community that an interdisciplinary approach to cancer prevention and control should incorporate patient-centered communication to maximize the benefit of current medical discoveries in diagnosis and treatment—particularly in the emerging era of personalized medicine. Although patient-clinician communication research traditionally has focused on outcomes such as patient satisfaction, comprehension, and adjustment, we need to strengthen our understanding of how these impact health behaviors and disease outcomes. As emphasized in the recent NCI-designated cancer center directors' report, *Accelerating Success against Cancer*, "Patient-provider communications play a critical role in determining who will engage in health-enhancing lifestyles that reduce cancer risk. They impact the likelihood that a person at risk for cancer will seek and engage in appropriate screening, and they also determine whether appropriate pharmaco-therapies are used, and used appropriately to effectively blend with critical behavioral and lifestyle changes."

Highlighting the need to integrate social, psychological, and communication research with biomedical research, *NCI's Strategic Plan for Leading the Nation* calls for research assessing the delivery and impact of patient-centered communication across the cancer care continuum, as well as innovative measurement approaches and study designs to help monitor and track the success of communication efforts over the course of the patient, family, and health care provider experience.

Since its creation in 1997, the Division of Cancer Control at the NCI has played an important leadership role in this essential area of research. Originally under the leadership of Dr. Barbara Rimer (now at the University of North Carolina, Chapel Hill), we funded a major research initiative, the Centers of Excellence in Cancer Communication Research, and a new surveillance tool, the Health Information National Trends Survey. As we celebrate the 10-year anniversary of the division and identify research priorities for the future, we continue to emphasize research on communication that is customized to patients' needs. To further our goals in this direction, we commissioned the following monograph, *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*.

Authors Ronald Epstein and Richard Street, Jr, propose a conceptual framework and describe the state of the science in patient-centered communication, noting several gaps in the research and the need to improve and diversify study designs and methods. Their thoughtful analysis challenges the research community to undertake more ambitious studies of communication processes that address the temporal and contextual complexities of cancer care over the course of treatment and survivorship. This will require the development and use of more sophisticated measurement and analysis techniques, and NCI remains committed to supporting this essential work.

Understanding how to optimize the communication process between patients/family and the health care delivery team is essential to our goal of reducing the burden of cancer. We look forward to continued collaboration with researchers and practitioners to improve patient-centered cancer communication strategies and hope that this monograph will help to inform your own work in communication science.

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Preface

When faced with a cancer diagnosis, patients often experience significant emotional distress and feelings of uncertainty about their future. They have to deal with complex medical information and make difficult, life-altering, treatment decisions. Patients with cancer and their family members hope to receive care within a health care system that would provide them with an environment of unfailing support and focus on meeting their needs as best as possible.

To facilitate the delivery of such "patient-centered" care and to enhance the National Cancer Institute's (NCI) mission of reducing suffering due to cancer, the Outcomes Research Branch and the Health Communication and Informatics Research Branch of the Division of Cancer Control and Population Sciences at NCI, have identified the assessment, monitoring, and improvement of the delivery of patient-centered communication between patients/family and health care delivery teams across the cancer care continuum as a key research priority.

Our prior work in the area of patient-clinician communication led us to identify the need for a comprehensive conceptual framework that would define core elements of patient-centered communication that could then be operationalized into standardized metrics for collecting data in diverse cancer care delivery settings. We also recognized the relative lack of understanding in the current literature on potential mechanisms by which patient-centered communication is likely to result in optimal patient health outcomes. To address these issues and to lay the foundation for future innovative research in this area, we commissioned this monograph, *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*.

The authors of the monograph, Ronald M. Epstein, MD, and Richard L. Street, Jr, PhD, have created a valuable piece of scholarship that has resulted from a critical synthesis of existing literature, the authors' personal research experience of more than 25 years, as well as discussions with a number of internationally recognized experts in the area of communication, oncology, health care delivery, quality of care assessment, and patient advocacy who participated in a symposium on patient-centered communication in cancer care that was organized by NCI during the course of the monograph project.

Readers of the monograph should note that its focus is on optimizing communication processes between patients/family and health care delivery teams and not just the patient-physician dyad. Consequently, the authors' conception of the term "patient-clinician communication" in this monograph is very broad, with the term "clinician" referring to all professionals who provide care to patients within the cancer context, not just physicians, and the term "patient" being used as a proxy for both the patient and their family members who are involved in their care.

This monograph is a critical first step in our efforts to plan future NCI-funding opportunities that will facilitate innovative research studies in the area of patient-centered communication and patient outcomes. We hope researchers, practitioners, and policy makers will find it as beneficial in their respective work.

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A Patient-Centered Approach to Cancer Communication Research

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Although cancer communication has much in common with communication in other health contexts, several unique elements of cancer care make cancer communication research important. Among the distinct features of cancer care that affect communication are that few other illnesses are both life-threatening and potentially curable, that care involves numerous clinicians and multiple treatment modalities (such as oral and intravenous medications, radiation, and surgery); that there is often a long period of uncertainty after treatment, and that the patient's health care team often changes over time. In particular, communication in the cancer care setting must help patients:

- Receive bad news

- Handle the emotional impact of a life-threatening illness

- Understand and remember complex information

- Communicate with multiple health professionals

- Understand statistics related to prognosis

- Deal with uncertainty while maintaining hope

- Build trust that will sustain long-term clinical relationships

- Make decisions about treatment, possibly including participation in clinical trials

- Adopt health-promoting behaviors

As acknowledged by the American Society of Clinical Oncology[1] and Institute of Medicine (IOM) reports,[2-4] communication is a key clinical skill. Unfortunately, few guidelines exist to help clinicians and health care systems communicate effectively with patients who have cancer.

This monograph addresses communication between patients and clinicians that embraces three core attributes of "patient-centered" care: consideration of patients' needs, perspectives, and individual experiences; provision of opportunities to patients to participate in their care; and enhancement of the patient-clinician relationship.[5] In a 2001 IOM report, patient-centeredness is noted to be a quality that relates not only to individual clinicians but also to the health care system (Figure 1.1).[4] That is, patient-centered care depends collectively on clinicians, patients, relationships (clinical and social), and health services. The interactions among these elements are complex, and the shortcomings of any one element can significantly decrease the quality of care a patient receives.

Figure 1.1 Clinicians, patients, relationships (clinical and social), and health services are all integral to patient-centered care. The interactions among these elements are complex[5] and deficits in any one area can significantly decrease the quality of patient care.
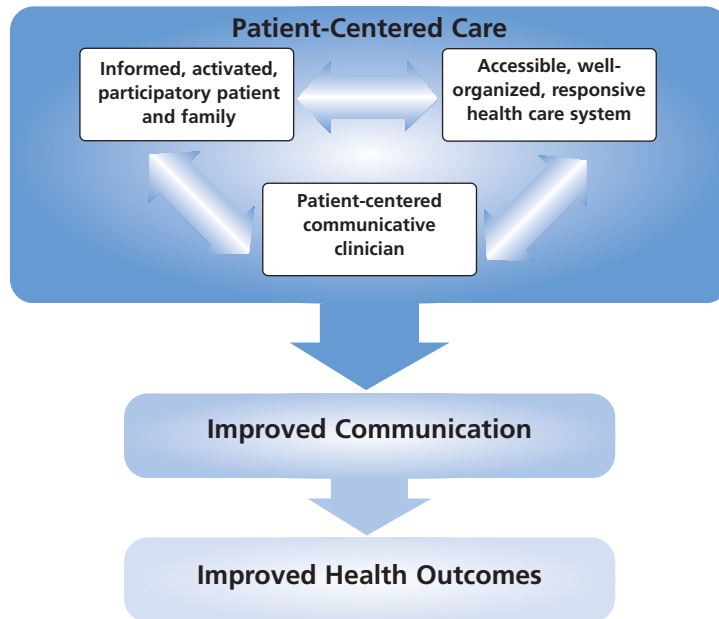
We define patient-centered communication in terms of processes and outcomes of the patient-clinician interaction:[5]

- Eliciting, understanding, and validating the patient's perspective (e.g., concerns, feelings, expectations)

- Understanding the patient within his or her own psychological and social context

- Reaching a shared understanding of the patient's problem and its treatment

- Helping a patient share power by offering him or her meaningful involvement in choices relating to his or her health

Patient-centered communication also builds a stronger patient-clinician relationship characterized by mutual trust, respect, and commitment. However, the outcomes of patient-clinician communication must extend beyond the interaction; ideally, communication must also contribute to enhancing the patient's well-being and to reducing suffering after the patient leaves the consultation. For example, a patient-clinician encounter that meets the four criteria noted here may do little to enhance the patient's well-being if a medical error occurred, if treatment was unacceptably delayed, if access to needed services was not available, or if subsequent family decisions undermined the intentions and decisions reached in the consultation. A model of patient-centered communication in cancer care not only must describe the process of effective communication between clinicians and patients but also must identify, account for, and/or control for contextual factors mediating and moderating the link between communication and health outcomes.

1.1 Process of Communication. I: Capacity for Effective Patient-Clinician Communication

For communication to contribute to healing and reduced suffering, clinicians, patients, and their families must have the capacity to engage in communication behaviors that contribute to the objectives of patient-centered care. As individuals, clinicians and patients will communicate competently when each is motivated; has sufficient knowledge, understanding, and self-awareness of what is required to communicate effectively; and has suitable perceptual and linguistic skills to produce effective communication behaviors and adapt them appropriately.[6,7]

1.1.1 Role of motivation

Simply put, competent communicators want to be so. Although it is reasonable to believe that clinicians typically have a strong motivation to provide high-quality health care, several factors can interfere with this desire. As with many types of skills, an individual's effort often wanes when experiencing fatigue, a factor that may contribute to medical errors. Some clinicians may set priority for their own needs over those of

patients; for example, rushing through a consultation to get back on schedule or avoiding a discussion about uncomfortable or emotionally laden topics. The commitment to patient-centered communication appears to be stronger for clinicians who value caring and sharing in the patient-clinician relationship[8,9] and approach communication as not simply the transfer of information but also as the formation of relationships.[10,11]

Patients, too, must be motivated to talk openly and honestly about their concerns, fears, expectations, and preferences. Some patients may deliberately avoid topics they find embarrassing or uncomfortable to discuss (such as sexual activity), that they think the clinician would disapprove of (such as disagreement with the clinician's recommendation), or that they believe are not pertinent to the interaction or the clinician's role (such as family relationships).[12]

1.1.2 Role of knowledge

Effective communication in health care settings requires that the clinician and patient have sufficient understanding of one another's perspectives, the health condition, and the purpose of the interaction. They also should share conversational norms and an understanding of each other's role in the interaction. With respect to knowledge, a significant challenge for clinicians is having an accurate understanding of the patient's perspective, including his or her concerns, feel-

ings, preferences, beliefs, and values. With such an understanding, clinicians are better positioned to personalize treatment recommendations, use language the patient understands, provide clear explanations, and validate or address the patient's emotional state.[12,13] Some research indicates that problems of misunderstanding may contribute to bias, especially when the race or ethnicity of the clinician and patient differs.[14,15]

Although such knowledge can be learned through direct experience or vicariously through observation or experiential training, research indicates that clinicians often misjudge patients' perspectives, including their preferences,[16,17] likelihood to follow treatment, satisfaction with care[18] understandings and beliefs about health,[19-21] or emotional states.[22]

With respect to patients, perhaps the greatest knowledge barriers are related to *health literacy*. This includes having an accurate understanding of health in general, as well as of disease states, the care process, and health-related terminology.[23] For example, with some understanding of health concepts and terminology, patients are better able to understand and talk about various topics that arise in cancer consultations.[24] This, in turn, increases the likelihood that patients can contribute to decision-making to the degree they wish and more capably provide informed consent.[23,25,26] Thus, patient education interventions aimed at increasing patient involvement not only should

encourage patients to be more active communicators (i.e., the motivational aspect of capacity) but should also provide patients with cognitive resources (e.g., concepts, terminology) related to their health concerns.[26]

1.1.3 Role of skill: clinicians

The capacity to produce patient-centered communication also depends on two types of skills: behavioral and perceptual. Several clinician behaviors can be considered "patient-centered," given research that shows them to frequently correlate with patient satisfaction, adherence, and improved health outcomes (Table 1.1).[27-30]

Some behaviors, especially those in the nonverbal domain, are directly a function of one's *motivational state and orientation* toward the patient. For example, a clinician who cares about the patient and is genuinely interested in what the patient has to say will naturally have eye contact, be nonverbally attentive, and talk about topics raised by the patient. Other behaviors may require more cognitive effort, especially if they are not part of the clinician's communication style, such as avoiding interrupting the patient early in the consultation. Still other behaviors may be quite novel for clinicians—such as explaining disease processes in everyday language—and considerable training and practice may be necessary before these behaviors can be carried out effectively.

From a communication perspective, the most effective clinicians

Table 1.1 Examples of Patient-Centered Clinician Behaviors

Nonverbal Behaviors
- Maintaining eye contact
- Forward lean to indicate attentiveness
- Nodding to indicate understanding
- Absence of distracting movements (e.g., fidgeting)

Verbal Behaviors
- Avoiding interruptions
- Establishing purpose of the visit
- Encouraging patient participation
- Soliciting the patient's beliefs, values, and preferences
- Eliciting and validating the patient's emotions
- Asking about family and social context
- Providing sufficient information
- Providing clear, jargon-free explanations
- Checking for patient understanding
- Offering reassurance
- Offering encouragement and support

are those who have a *patient-centered communication "style"* that they use across their consultations and in multiple contexts.[30] For example, research shows that some clinicians routinely provide more information; engage in partnership building; use supportive communication, including reassurance and encouragement; and are more willing than other clinicians to talk about psychosocial topics.[31-33] A clinician's style of communicating emerges from a variety of sources, including socialization (e.g., as related to gender[33,34] or culture[35]); repeated experience with certain kinds of patients, such as children or individuals older than 65 years; medical training;[35-37] and philosophy of care.[8]

Clinicians also must have observational skills and an appropriate level of *self-awareness*. Few studies have focused on clinicians' mindfulness and self-monitoring, but the lack of these skills may lead to unexamined biases, careless errors in clinical practice,[38,39] and confusion between the emotional needs of the patient and those of the clinician.[40,41] Patient-centered clinicians presumably would be more successful when monitoring the dynamics of the interaction, including their role in the encounter, the patient's role, and the way in which the encounter is unfolding. These clinicians also are aware of differences between the patient's and their own explanatory model of the patient's health and will explore the patient's model in order to identify potentially problematic incongruities.[21,42] Because they have a more general orientation to the patient's perspective, as well as an awareness of their own feelings, patient-centered clinicians should be able to accurately assess the patient's needs and be less likely to act on the basis of perceptual bias and stereotyping. Perceptual and self-awareness skills that recognize and prevent bias are particularly important in light of research indicating that physicians perceive some patients less favorably than others[43,44] and that these attitudes may affect the quality of care patients receive.[43,44]

The principles of self-monitoring, self-calibration, and self-awareness during clinical practice have been formalized in discussions of *mindful practice*—practice characterized by the capacity for attentiveness to one's own internal processes, curiosity in the face of disconfirming data, informed flexibility, and presence.[45-47] Some training programs for cancer clinicians have incorporated self-awareness activities.[48-52] However, few empirical studies have explored how self-awareness enhances clinical practice.

Admittedly, there may be some situations—such as a medical emergency or a self-destructive patient—that call for clinicians to use a communication style in which they strictly control the content of the interaction, focus on biomedical issues, interrupt, use closed-ended questions, and make decisions for patients. However, as a general rule, "clinician-centered" communication does little to enhance care or bring the patient's perspective into the encounter.

1.1.4 Role of skill: patients

To achieve patient-centered care, patients with cancer must communicate in a way that reveals their needs, preferences, expectations,

concerns, and perspectives. Particularly important are active communication behaviors such as asking questions, expressing concerns, being assertive in stating opinions and preferences, introducing topics for discussion, and telling their "health stories" (Table 1.2).[53]

These behaviors are "active" forms of communication because they interject the patient's perspective into the interaction and have the potential to influence the clinician's behavior and decision-making.[32,33,54-56] By contrast, a patient who remains passive during the interaction does little to convey his or her needs, fears, expectations, beliefs, and preferences. Health outcomes may be at risk in these situations, and the encounter will not satisfy the patient's need to feel known, understood, or heard or satisfy the clinician's moral obligation to address the patient's underlying concerns in order to maximize healing.

Patients vary in their abilities to be active communicators. Although we are aware of no studies that have examined the communication of a particular patient across interactions with different clinicians, research indicates that patients' communicative styles are associated with social, cultural, and personality factors. For example, the degree to which patients with cancer are active participants in consultations has been linked to their level of education[24,57,58] and ethnicity.[59] In other clinical settings, more active patient participation is associated with orientations to the patient-clinician relation-

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Table 1.2 Examples of Active Patient Communication Behaviors

Asking questions

Communicating assertively
- Offering opinions
- Stating preferences
- Interrupting, if necessary
- Sharing beliefs about health
- Introducing topics for discussion

Expressing concerns and feelings
- Expressing emotions
- Disclosing fears and worries
- Noting frustration

Telling one's health "story" in the context of everyday life

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ships (e.g., shared control vs. physician control),[60] gender,[61] and personality.[62]

1.1.5 Implications for improving patient-clinician communication

Future research should focus on the most effective and efficient ways to expand clinician and patient capacity for patient-centered communication, particularly in the skill domain. Because personality and socialization are relatively stable attributes of individuals after age 30,[63] skill-building in communication style and observation is particularly important early in a clinician's

medical training, before these behaviors become more habitual and intractable with age and repeated performance. More research needs to be done on the pedagogical methods that can help clinicians acquire and efficiently deploy patient-centered behaviors, develop the perceptual acuity to assess the patient's situation accurately, maintain a sense of self-awareness, and monitor the course of the encounter. To be effective, the instruction will need to use multiple techniques, such as role-playing, group discussion, testimonials, patient or expert feedback, self-assessment, and practice.[64-66] Given that misunderstanding and subconscious bias are particularly problematic when the clinician and patient are from different cultural backgrounds, research is especially needed to develop models for cultural competency training involving patient-centered care. An individual patient, on the other hand, has fewer encounters with clinicians than an individual clinician will have with patients. Thus, patients' communication behaviors are conceivably more modifiable. Patient "activation" interventions are most successful when patients[65-68]

- Believe in the legitimacy of their participation in care

- Have some information about their health condition and treatment options

- Learn specific communication strategies and behaviors to use in their interactions with clinicians

- Receive the intervention in a timely fashion so that they have an opportunity to implement the suggestions

Culturally appropriate resources are important for patient interventions as well, as research has shown that patients in minority groups and with lower socioeconomic backgrounds are often less participatory than their counterparts[24,59] and that some patient education interventions are less effective for such individuals.[69,70] Clinician and patient interventions are reviewed in greater detail in Appendix E.

1.2 Process of Communication. II: Aligning Patient and Clinician Perspectives

Although the behaviors listed in Tables 1.1 and 1.2 often characterize patient-centered communication at the level of the *individual* communicator, effective (or ineffective) communication is fundamentally an outcome of the *interaction* between the clinician and the patient and family members. Thus, patient-centered communication occurs when both parties communicate in a way to reveal, understand, and, ideally, align their respective perspectives on the patient's health. We use the term "alignment" to capture the fact that effective communication is a process that requires cooperation, coordination, discovery, negotiation, and reconciliation in order to achieve mutual understanding, an accurate diagnosis, shared goals, an appropriate treatment plan, and a stronger patient-clinician relationship.

Three issues are most relevant to the alignment process: communication is a process of mutual influence, clinicians and patients need to have common goals for the encounter, and clinicians must make appropriate adaptations to meet the patient's needs. Although individual behaviors have been the subject of communication research, the process of alignment rarely has been studied.

1.2.1 Communication as a process of mutual influence

As with all communication encounters, the clinical consultation is jointly constructed by the participants as they weave together communicative actions to create the conversation. How one participant communicates will affect the communication of the other.[71] The fact that interpersonal communication is a process of mutual influence has important implications for patient-centered communication. If a patient believes that his or her perspective is not being addressed, he or she can use active communication tactics such as asking questions, interrupting, and expressing worries that may elicit more interest and inquiry from the clinician. For example, by asking a question, stating an opinion, or expressing concerns, the patient explicitly provides information that the clinician can use to meet the patient's needs more effectively. This approach also serves to introduce conversational content the clinician is expected to address. Indeed, clinicians often are more informative, accommodative, and supportive with patients who

are forthcoming with questions, concerns, opinions, and preferences.[32,33,54,56,60] Similarly, if a patient with cancer is passive, a clinician could use partnering and other facilitative behavior such as asking for the patient's opinion or concerns, or offering encouragement. Such behaviors generally elicit greater patient involvement because the clinician's communication both legitimizes and specifically asks for the patient's views.[24,59,60,71,72] In short, many of the behaviors listed in Table 1.1 can elicit those in Table 1.2, and vice versa.

1.2.2 Aligning communication goals

Within any clinical encounter, both the clinician and patient have goals for the interaction. These goals are related to each person's expectations, preferences, and perceived purposes of the consultation. Sometimes these goals may be quite specific and explicit, such as deciding on cancer treatment, or discussing the side effects of radiation. Other goals may be more general and vague; for example, a patient may want to avoid discussing sexual dysfunction as a side effect of prostate cancer treatment, or a clinician may hope that the patient does not get "emotional."

Communication goals can be problematic in consultations for several reasons. First, clinicians and patients often assume that the other shares the same goals, an assumption that may be erroneous because clinicians and patients may have different expectations, preferences,

and needs during the encounter. A large body of research demonstrates that concordance between patients' and physicians' goals is generally poor unless these goals are made explicit, preferably early in the interview.[17,73-76] Patient and clinician concordance on shared understanding of goals and expectations is important, as research links the lack of concordance to lower patient satisfaction and adherence.[18,76] Also, not all patients may have the same goals. For example, some patients want to talk to their clinicians about family and work relationships; others think these topics are not pertinent to the consultation.[77] Physicians may assume that a patient wants diagnostic testing for reassurance, but the patient may not necessarily want more tests.[78] Without verifying that the clinician and patient share the same goals, the consultation may unfold with the clinician accomplishing his or her agenda, believing it is the patient's agenda as well. The patient may appear to be listening cooperatively, while in reality he or she may be frustrated by the course of the consultation but does little to communicate that frustration to the clinician.

In a particular series of consultations, an individual patient may seek many different things:

- Care for routine surveillance

- Test results

- Discussion of treatment options

- Evaluation of the effectiveness of treatment

- Relief of symptoms

- Causal explanation about the disease or symptoms

- Dispelling of fears (the patient's or the family's) that serious disease is present

- Consideration of decisions about current and future care

- Administrative purposes (work excuse, prescription refill)

In addition, a patient may simply want to be understood. On the other hand, clinicians make choices about what to discuss. As mentioned previously, they may avoid some topics in an attempt to stay on schedule. They also may consider some issues, such as making sure that the patient understands the treatment options, more appropriate than others, such as discussing the patient's family problems.

On an individual level, a clinician or patient may have multiple, sometimes conflicting goals. As an example, a patient with cancer may want to talk about his or her feelings of losing hope, yet want to be perceived as strong and a fighter; a clinician may want to be supportive but feels a need to scold a self-destructive patient. Moreover, these goals and preferences may change during the course of the consultation (e.g., a patient initially wants to make a treatment decision but then wants the clinician to decide; a patient does not want chemotherapy but decides to schedule it after hearing the clinician's reasoning). Patients with multiple and conflicting goals may

communicate with some degree of inconsistency or vagueness, thus highlighting the need for the clinician and the patient to make explicit the goals relevant to the consultation. More research is needed to understand the impact of incongruity and malleability of clinician and patient goals on the communication in the consultation, the decisions reached, and the subsequent follow through.

1.2.3 Adapting to meet the patient's needs

While communication is characterized by mutual influence, these influences are often below the level of awareness. One key defining element of effective patient-centered communication is the clinician's ability to monitor and *consciously* adapt communication to meet the patient's needs. The observational and perceptual skills described earlier provide guidance for how clinicians can appropriately adapt their communication. An obvious, but important, form of adaptation is presenting information in a way the patient understands. For example, when discussing diagnostic information, an observant clinician will detect subtle, nonverbal cues of patient confusion and either rephrase or restate the information. Also, periodically checking for patient understanding will help the clinician determine whether communicative adaptations are needed. A clinician may approach the discussion of cancer treatment options in a cognitive, rational way but notice that the patient is emotionally distraught. In this circum-

stance, a patient-centered clinician would validate and explore the patient's emotions before continuing the discussion of treatment options and may decide to spend more time at that particular visit offering reassurance or support.

A second area important for alignment is discovering the way in which patients want to be involved in decision-making. Clinicians are not particularly good judges of patients' preferences for involvement in decision-making in the cancer setting.[16,17,73] Thus, it is important to identify these preferences and make appropriate adaptations. An oncologist who routinely solicits and encourages patient involvement in decision-making may take more responsibility if he or she senses that the patient wants this. This clinician may still actively encourage the patient to talk about his or her concerns, however. Conversely, clinicians who have limited perceptiveness or a fixed communication style will have less adaptability and will find they interact with some patients effectively but have considerable difficulty with others.

Lastly, communication errors and misinterpretations are quite common in conversation and even more likely in cancer settings, where cognitive complexity and emotional intensity are particularly common. Thus, conversation repair is a normal and expected form of communication adaptation. Conversation repair is needed when there is a difference between how the clinician and the patient define or interpret words or concepts. For

example, a clinician may describe a potential side effect of a medication as "rare," considering it to mean a 5% chance of occurrence; however, most patients would consider "rare" to indicate a probability of 24% (standard deviation, 30%).[79] Similarly, in discussions of advance directives and resuscitation, the question of "doing everything" often arises;[80] yet, families and patients may not have the same understanding as the clinician about the extent of "everything." These kinds of miscommunications are even more likely when clinicians and patients are not of the same race, ethnicity, or socioeconomic status.[14,15,81] On discovering these misinterpretations, clinicians can adapt their communication by simply rephrasing the information or perhaps engaging in a detailed discussion to unravel the miscommunication about therapeutic goals or actions.[9,82-84] The key skills for clinicians are to recognize these miscommunications and make appropriate conversational repair.

1.2.4 Implications for improving patient-clinician communication

Clinicians vary their communication with different types of patients. Studies have shown that clinicians often talk more about relationships and feelings with female patients[85] and give more information to better educated patients,[33,35] and white patients.[86] In addition, clinicians sometimes talk in more simplistic terms to older patients[86] and vary the tone and length of their consultations depending on the nature of the

patient's illness.[87,88] An important direction for future research is to evaluate whether these adaptations are appropriate responses to the patient's needs or inappropriate responses that are driven by clinician bias or prejudicial attitudes.

Lastly, little is known about how patients monitor, adapt, and respond to specific situations. Apter's reversal theory[89] suggests that in situations of low emotional distress, patients make communicative adaptations to meet their information needs, emotional needs, or treatment preferences. For example, a patient who has accepted the fact of a cancer diagnosis might bring concerns about the side effects of chemotherapy to the clinician and discuss different management options with few emotional overtones. This patient might be able to interject his or her perspective when given the explicit opportunity in response to a question or a clinician's partnering behavior. More assertive patients may introduce a new topic of discussion even without the clinician's invitation. However, in situations characterized by high levels of physical discomfort, anxiety, cognitive complexity, and/or ambiguity, the same patient may become overwhelmed because the cognitive and emotional burden exceeds his or her capacity to adapt to the requirements of the situation.[90] In those cases, clinicians may need to adopt a different communication style than would ordinarily work well for that patient.

Similarly, clinicians can become overwhelmed, and as a result, distance themselves from the patient and fail to elicit and respond to the patient's needs. Of particular concern are communicative adjustments clinicians make in response to ambiguous symptoms or poor prognoses. Recent findings suggest that when patients present symptoms that do not conform to typical disease patterns ("medically unexplained symptoms"), physicians tend toward premature closure, explore those concerns less thoroughly, and offer less validation and empathy.[91] When encountering a patient with an incurable cancer, a sympathetic clinician may attempt to reduce his or her own anxiety or the patient's anxiety by inflating estimates of a favorable prognosis.[92] The clinician's task, then, is to restore sufficient comfort and order so that the patient can participate to the degree that he or she is capable.

1.3 Communication and Outcomes of Care

Patient-clinician communication may contribute directly or indirectly to a number of outcomes, a partial list of which is presented in Table 1.3. From a patient-centered care perspective, patient-clinician communication should contribute positively to at least one of three sets of outcomes; the first two, quality of the encounter and intermediate outcomes (e.g., adherence, self-care efficacy), may contribute to the third, health outcomes (improved survival, subjective well-being, and functioning).

1.3.1 Quality of the encounter

Judgments of effective patient-clinician communication and quality of care can come from multiple perspectives—the patient, the clinician, and third parties. These perceptions are not necessarily congruent and often are highly subjective. For example, an oncologist may believe that his or her performance was effective because he or she provided the patient with extensive treatment information and was optimistic about the prognosis. However, the patient may have been dissatisfied because the oncologist dominated the conver-

Table 1.3 Outcomes of Effective Communication

Communication outcomes
- Strong patient/family-clinician relationships (trust, rapport, respect, involvement of family and caregivers)
- Effective information exchange (recall of information, feeling known and understood)
- Validation of emotions (e.g., empathy)
- Acknowledgment, understanding, and tolerance of uncertainty
- Patient participation in decision-making
- Coordination of care

Intermediate outcomes
- Strong therapeutic alliances
- Patient knowledge and understanding
- Emotional self-management
- High-quality medical decisions (informed by clinical evidence, concordant with patient values, and mutually endorsed)
- Family/social support and advocacy
- Patient self-efficacy, empowerment, and enablement

- Improved adherence, health habits, and self-care
- Access to care and effective use of the health care system

Health outcomes
- Survival and disease-free survival
  - Prevention and early detection of cancer
  - Accurate diagnosis and completion of evidence-based treatment
  - Maintenance of remission
- Health-related quality of life
  - Functioning: cognitive, physical, mental, social, and role
  - Well-being: physical, emotional
  - Health perceptions

Societal outcomes
- Cost-effective utilization of health services
- Reduction in disparities in health and health care
- Ethical practice (e.g., informed consent)

sational floor and did not let the patient fully discuss his or her fears. Both clinician and patient may believe they had engaged in collaborative decision- making even though there may be no behavioral evidence of such when a video recording of the encounter is evaluated.[93] Lastly, the clinician and patient may believe they had a high-quality encounter although a chart audit finds evidence of inadequate care. Although a patient-centered care perspective might emphasize the patient's judgment of quality, our contention for cancer care is that the perspectives of all stakeholders—patients, clinicians, relevant third parties (e.g., family members, clinic administrators)—must be recognized and, when discrepant, aligned.

From the patient's perspective, effective cancer communication should promote overall satisfaction with care as well as satisfaction with the clinician's technical skills, the clinician's communication, and the decision reached. Other indicators of high-quality care from the *patient's* viewpoint might be considered proximal outcomes of communication, such as the following:

- Feeling understood by his or her clinician

- Actively participating in the interaction

- Gaining an improved understanding of the diagnosis and treatment options

- Obtaining help in coping with uncertainty

- Establishing trust in his or her clinicians and the health care system

These outcomes are tied directly to the quality of patient-clinician communication, both past and current. In other words, positive or negative experiences in the past may influence how the patient perceives the quality of the current encounter.

Although much less studied, the *clinician's* perceptions of effective communication are also important. These outcomes include the following:

- Satisfaction with the encounter

- Sufficient understanding of the patient's perspective (beliefs, values, concerns, preferences) to guide further medical care

- Sense of having provided high-quality health care (e.g., the patient is satisfied, is committed to a treatment plan, and leaves the interaction with a sense of purpose, hope, and optimism)

- Rapport with the patient (trust, cooperation)

While the patient's judgment of quality of care may be related to intermediate patient outcomes such as self-care skills and adherence to a treatment plan, the clinician's judgment of quality relate to job satisfaction and a lower level of burnout,[94] both of which may affect the quality of future interactions with patients,[95] attitudes toward patients (including bias), patient adherence,[96] and even quality of care delivered.[97,98]

Quality of the encounter also can be assessed from the viewpoint of other *stakeholders.* Family members' perceptions of quality of care are important because their views may reinforce or contradict the patient's judgments. When a family member's views differ from those of the patient, family relationships may be strained, perhaps lowering the patient's quality of life or becoming a barrier to the patient's commitment to treatment. Administrators and insurers have a perspective on the patient-clinician encounter (e.g., guideline adherence, evidence of medical errors), especially as it relates to assessing quality of care, efficient and appropriate use of resources, and reducing risk of litigation. These perspectives are often not aligned, yet there is little research on how the alignment might be improved. More studies are needed to compare the patient's, family's, clinician's, and other stakeholders' assessments of quality of care, and, importantly, to evaluate the communication factors that affect their respective judgments and the degree of congruence among them.

1.3.2 Communication and intermediate outcomes

For patient-clinician communication to contribute to healing and reduced suffering in cancer care, it must activate mechanisms that directly affect health. In this monograph, we propose that most of the health benefits of effective patient-clinician communication are from its role in accomplishing intermediate outcomes (Table 1.3). These

intermediate outcomes include appropriate medical decisions and patients with a stronger sense of agency, self-care skills, and commitment to treatment. For example, a patient-clinician encounter that produces greater patient understanding of the benefits of tamoxifen should lead, in turn, to better adherence to a therapy that has proven effectiveness in preventing breast cancer recurrence. If a patient with prostate cancer leaves a consultation with an accurate understanding of the risks and benefits of brachytherapy and feels involved and satisfied with a decision to undergo this treatment, he may be better prepared to cope with the potential side effects and thus have better emotional well-being. If, during a consultation, a patient with colon cancer learns sufficient self-care skills for managing a colostomy, he or she may be better able to cope with the day-to-day management of fecal discharge in a way that did not interfere with social functioning. These potential pathways that link communication to improved health are discussed in more detail in Chapter 3.

Clinician and patient perceptions of effective communication can contribute to, but do not guarantee, actual improvement in patient's health or health behavior. Kinmonth et al.[99] found that patients more satisfied with their diabetes care (an indicator of quality of care) actually gained more weight following the visit (an indicator of poorer diabetes management) than did less satisfied patients. Perhaps satisfied patients were less vigilant of their own self-

care responsibilities. In most cases, active patient participation is a positive feature of patient-clinician interactions, but some negative consequences may emerge. For example, when patients made explicit requests for antidepressant medications they saw advertised on television, physician prescribing increased not only for patients with major depression but also for patients with questionable clinical indications.[54]

1.3.3 Communication and health outcomes

The two primary outcomes of effective communication should be improved survival and improved quality of life, particularly health-related quality of life.

Even though, theoretically, better communication can lead to better treatment choices, the evidence is scant for direct links between specific patient-clinician communications and measurable changes in survival or the biological course of disease. However, there is growing evidence that communication can directly affect the patient's emotional well-being and psychological symptoms. For example, adults with cancer have reported more hope,[100,101] and children with cancer have experienced less anxiety and depression[102] when physicians were open about the diagnosis and prognosis. According to Schofield et al.,[103] communication that may lower anxiety included preparing the patient for diagnosis, giving the patient clear information, providing written information, discussing

questions and feelings, and being reassuring. Additionally, empathy reduces patient anxiety and emotional distress.[104,105] However, the relationship between patient-clinician communication and patient's emotional states can be quite complex. For example, patients with cancer are often very anxious about common physical symptoms (i.e., the fear these symptoms might be related to the cancer) and the clinicians' use of reassurance can reduce this anxiety. In some cases, however, providing reassurance may worsen outcomes if it appears to avoid the focus of the patient's anxiety or is offered before the patient can express his or her concerns.[106]

Little is known about how the *patient's* communication during a consultation affects emotional well-being. Some studies indicate that a patient's participation in decision-making may result in greater levels of anxiety,[107] perhaps due to a greater sense of responsibility for treatment outcome. On the other hand, patient involvement may lead to greater satisfaction, which, in turn, is associated with less emotional distress.[105,107,108]

In short, much more research is needed on how patient-clinician communication and clinician-family communication affect health outcomes directly and through various mediators. We will address some of these issues in Chapters 3 and 6.

1.4 Understanding the Importance of Context

As with all forms of communication, patient/family-clinician interactions are situated within multiple layers of context, including the following:

- Disease factors (e.g., type of cancer, stage of disease)

- Family and social environment

- Cultural context

- Media environments (e.g., coverage of health topics, access to information through the Internet)

- Health care system

- Societal factors (e.g., laws, socioeconomic status)

Obviously, an attempt to account simultaneously for all elements of context that potentially affect all aspects of communication and cancer outcomes would be futile. Hence, in this monograph, we adopted the following as a way to make the role of context manageable.

First, context is important for cancer communication because it is a source of potentially powerful mediators and moderators of patient-centered communication processes and outcomes (discussed in Chapter 3).

Second, we hold that the *primary* context for the processes of patient-centered communication is the interpersonal context—the actual encounter among clinicians, patients, and families. In other words, what unfolds in these encounters is a function of the participants' goals, perceptions, and communication capabilities, as well as the communicative actions of the other participant(s) in the encounter.[71] The type of health care system; media coverage of a cancer issue; cultural aspects, such as the degree of fatalism and spirituality; and insurance coverage can influence whether clinician and patient even have a consultation at all. However, once the patient and clinician interact, these contextual factors influence communication through their effect on the interactants' goals, perceptions, and behaviors. For example, a clinician and patient may discuss experimental treatment as one option only if the patient lives in a location where phase 3 clinical trials are being conducted. Family members may pressure a patient toward unconventional therapies which, in turn, may affect how the patient discusses treatment options with the clinician.

Third, as will be discussed in Chapter 3, context is a source of moderators that reinforce or constrain the various pathways linking communication to improved health. Examples of such effects include a patient's stronger intent to follow through on a treatment decision when family members support such a decision; a patient's decision to stop chemotherapy because of news stories of miraculous recoveries from herbal treatments; or a patient's decreased sense of personal control because of a spiritual belief that his or her fate rests in God's hands.

Lastly, the communication issues of importance and the relevance of certain outcomes depend heavily on whether the patient is at a particular phase of the cancer care continuum: prevention, screening, diagnosis, treatment, survivorship, or end of life. In Chapter 4, we will examine cancer communication processes and outcomes within each of these phases.

1.5 Conclusion

This chapter provides an overview of patient-centered communication with a specific focus on how effective communication depends not only on clinicians' and patients' individual capacity for competent communication but also on their abilities to adapt behavior and align their perspectives to accomplish shared goals. We identified several levels of outcomes that can be linked to effective communication, ranging from quality of care within the encounter itself to health improvement long after the consultation is over. However, it is also important to recognize that patient-clinician communication is embedded within multiple layers of context that can moderate and mediate the relationships between communication processes and outcomes. Future research must lead to an understanding of the ecology of cancer communication to provide insight into how best to design interventions to improve cancer care.

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A Framework for Patient-Centered Communication in Cancer Care

2

Our goal in this and the next three chapters is to develop a framework that can guide future research in patient-clinician communication in cancer settings. The framework should have several qualities; it should be

- Simple enough to be generally understood and useful

- Complex enough to account for clinical reality

- Designed to involve all relevant players, including different types of patients, families, clinicians, and health care systems

- Applicable to the relationship between clinical communication and relevant patient health outcomes

Furthermore, the framework should contain measurable communication behaviors and meaningful links between the players, functions, and desired health outcomes.

Our framework for patient-centered communication processes and outcomes in cancer care is organized around six core functions of patient-clinician communication (Figure 2.1):

- Fostering healing relationships

- Exchanging information

- Responding to emotions

- Managing uncertainty

- Making decisions

- Enabling patient self-management

These functions, however, are neither independent nor hierarchical. Rather, they overlap and interact to produce communication that can affect important health outcomes. Consider the situation of a woman with breast cancer who has been advised to take tamoxifen for five years after initial treatment. Several factors are necessary to maximize the likelihood that she will follow through with this recommendation. She should trust her clinical team, have information about side effects, know ways to manage her fears and anxiety, understand the uncertainties implicit in any treatment recommendation, have participated in the decision to take tamoxifen, and remember to take the medication. Interactions among these functions can be complex and recursive. For example, clinicians who provide high-quality information may be more trusted, which, in turn, may reduce patient anxiety. Conversely, patients who are excessively anxious may have difficulty assimilating information, which, in turn, may affect trust.

Far more is known about some of these functions than others. There are hundreds of articles and several reviews of patients' information

Figure 2.1 The six core functions of patient-clinician communication overlap and interact to produce communication that can affect important health outcomes.
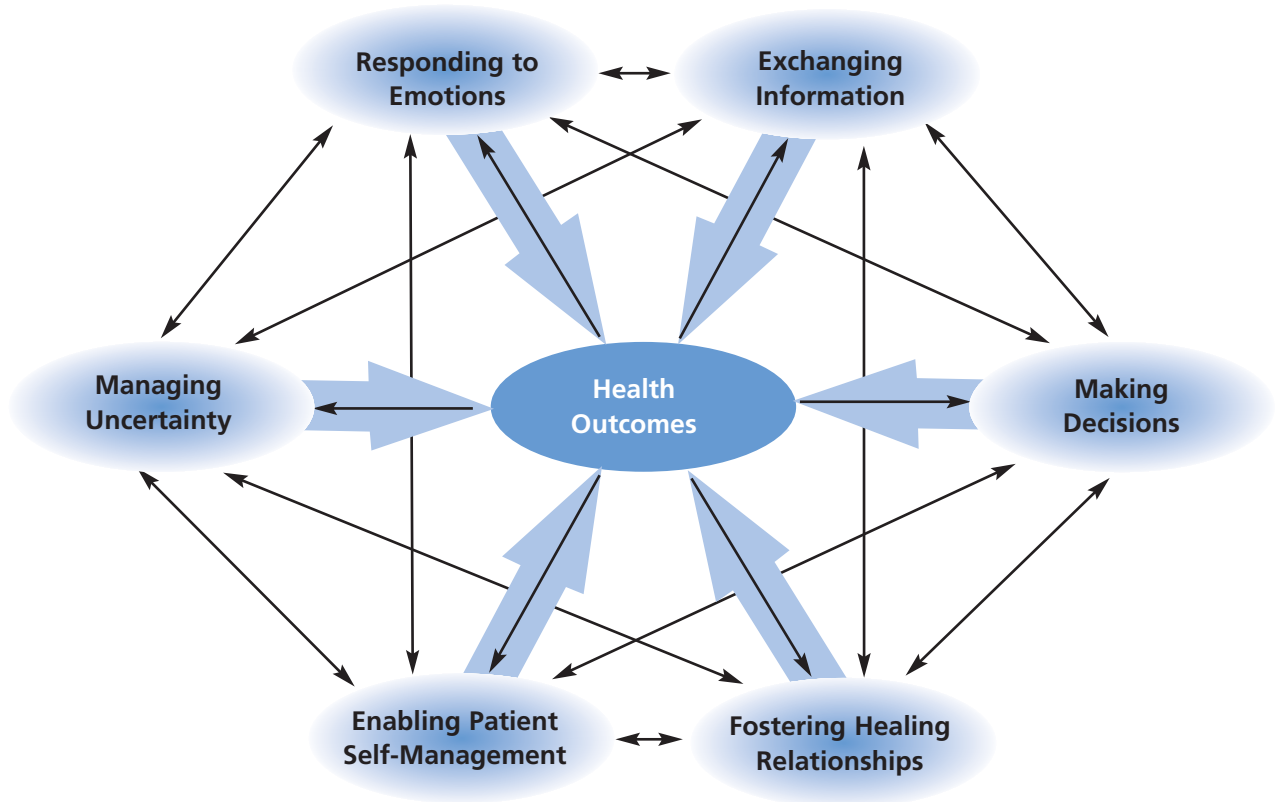
needs and sources and on patients' preferred roles in decision-making. There are also published articles about responding to patients' emotions and the patient-clinician relationship in general. The literature on uncertainty and enablement is sparse, but the absence of prior studies should not diminish the importance of the role of these factors in effective communication. Research to date pertaining to these communication functions is summarized briefly here, with more extensive literature reviews and references in Appendices A through D.

In this chapter, we describe the six functions and associated communication behaviors for both clinicians and patients. In the next chapter, we discuss various "pathways" through which these functions affect outcomes of care and factors that moderate the relationships between communication and outcomes. In Chapter 4, we discuss each of the functions and pathways within the context of each phase of the cancer care continuum. As previously noted, we use the words "clinician" and "patient" to refer to all relevant members of the health care team and patients' family units, respectively.

2.1 Fostering the Patient-Clinician Relationship

Patient-centered cancer care requires patient/family-clinician relationships that are characterized by trust and rapport. Furthermore, all parties should have a mutual understanding of each other's roles and responsibilities. Relationships are stronger when clinicians work to maximize the likelihood that patients and families will participate actively in clinical encounters. This may involve addressing issues that can create disparities in care, such as those related to race, ethnicity, language, and literacy. Fostering effective relationships

between clinicians and patients also requires *clinician* self-awareness and is related to clinician well-being. Appendix A contains a detailed literature review of relationship factors in cancer communication.

Healing relationships are more than sources of information and expertise; they also provide emotional support, guidance, and understanding.[1-3] These relationships can help patients adjust better to their illnesses,[3-6] perhaps partially by increasing social support, by providing early recognition of symptoms and emotional responsiveness, and by attenuating the effects of uncertainty. When interviewed, patients with cancer and their families say that they value clinicians' enduring characteristics—caring; trust; continuity; and feeling known, acknowledged, and connected—more than specific communication techniques.[4,7-11] Patients' perceptions of their physicians' overall interpersonal style can be quite nuanced,[12] yet patients' questionnaire ratings about their health care experiences tend to reflect an underlying global sense of the physician rather than specific behaviors.[13] In the following discussion, we focus on several factors that contribute to strong relationships, including trust, respect, and mutual understanding about roles and responsibilities, as well as the clinician-related factors of self-awareness and well-being.

The patient's and family's *trust* in the clinician is a perception that the clinician will be present, com-

mitted to the patient's best interests, and technically competent. Patients with cancer have reported greater trust in their physicians following consultations in which they perceived the physician to be informative, they were allowed to participate in the decision-making process, and they believed that the physician was sensitive to their concerns.[14,15] However, the relationship between trust and the patient's communication can be complex. On the one hand, a patient may be more open and willing to discuss personal and sensitive topics with clinicians they trust.[16] On the other hand, patients who are trusting may feel less of a need to seek information and be involved in decisions, instead leaving these matters to the clinician.[7] A trusting relationship can both depend on and facilitate communication. Less is known about clinicians' trust of patients, but trust arguably must be mutual to have a committed and functional relationship in cancer care.

Rapport is a perception of connection with another individual based on respect, acceptance, empathy, and a mutual commitment to the relationship.[17] Rapport is accomplished both verbally, by expressing interest in another's views, discussing shared goals and interests, and responding to emotions, as well as nonverbally, through directly facing another, using facial expressions of attentiveness, and speaking in an appropriate tone of voice.[18] A sign of rapport is reciprocity of positive affect and

mutual engagement. For example, a clinician's question may signal interest and concern, which, in turn, helps the patient elaborate on sensitive issues.[19] Rapport enhances the strength of relationships and leads to more satisfactory interactions.

One of the most important tasks in cancer care is for the clinician, patient, and family to establish and negotiate, if necessary, their respective *roles in the relationship*. Patients and clinicians have expectations for each other's role and behavior in the encounter.[20-22] Sometimes the roles are clear and mutually agreed upon at the outset of the interaction, as would be the case when both clinician and patient prefer greater clinician control of the consultation and decision-making. Sometimes the expected roles are discrepant and must be reconciled, such as when both clinician and patient want more control over the decision-making process. As mentioned in Chapter 1, the alignment process is often successful when clinician and patient cooperate and coordinate their communication to establish mutually agreed upon norms for their relationship.

Regardless of their preferences for the clinician's communication style, patients and their families generally want to be involved in the process of care, be informed of all the treatment options, feel listened to, and feel that their physicians know them as people, not simply diseases.[23-25] In order to be involved and to feel understood, patients must be able to effectively

and actively communicate their needs, concerns, and perspectives. Many of the features of patient communication that facilitate involvement were discussed in Chapter 1, such as an assertive communication style, linguistic skills (e.g., health literacy), and belief in the legitimacy of patient participation.[26,27] Correspondingly, clinicians can facilitate patient involvement in the relationship by engaging in the following:[28-30]

- Partnership building and encouragement
- Joint agenda setting
- Active listening
- Taking measures to ensure patient understanding
- Nonverbal behaviors conveying empathy and warmth

Some researchers have examined congruence between what patients with cancer prefer regarding their involvement in medical decisions and what physicians perceive patients' preferences to be.[31,32] However, few studies have been carried out in the cancer setting to compare the preferences of clinicians and their own patients about each other's roles in the decision-making process. More research needs to be conducted on these issues, as discrepancies between the expectations of a clinician and patient for their relationship may lead to frustration and misunderstanding. Clarification, open discussion, and accommodation can repair misunderstanding,[33] but often, misunderstandings remain unaddressed.

Often the discordance between clinicians' and patients' expectations is subtle, especially when the clinician is not carefully monitoring the interaction and the patient does not actively state his or her own views and expectations. These factors may explain why clinicians are not very accurate judges of patients' preferences, a situation further complicated by differences in race, language, ethnicity, or educational level.[34] Alignment of clinicians' and patients' expectations likely occurs when clinicians are more aware of and attentive to patients' needs and when patients express their beliefs about the relationship openly. When patients and physicians are aligned in their preferences for control in the relationship, patients report greater endorsement of the physician, satisfaction with care, and intent to adhere to treatment.[21,35]

To date, little research has examined the effect of clinician well-being and self-awareness on communication and healing relationships and the effect of the patient-clinician relationship on clinician satisfaction, attitudes, and behavior. As noted in Chapter 1, communication requires clinicians' ongoing capacity for attentiveness and self monitoring[36,37] in order to identify patients' perspectives and distinguish them from their own.[38] Clinicians' ability to be attentive is also related to their own well-being. Clinicians who report burnout or job dissatisfaction also report lower quality of clinical care and demonstrate decreased capacity for empathy.[39-48] With

these factors in mind, self-awareness, sharing of feelings and responsibilities, self-care, development of a personal philosophy, and limit-setting have been incorporated into some clinician training programs.[40,46,49-54] Because many clinicians find relationships with patients to be a major source of meaning in their work,[55] stronger patient-clinician relationships will likely contribute to higher job satisfaction and less burnout, and, in turn, higher quality of care.

2.2 Exchanging Information

Patients with cancer and their families seek information about the cause, diagnosis, treatment, prognosis, and psychosocial aspects of the illness. Attending to information needs is important not only to help the patient gain knowledge about his or her illness, but also to develop a strong patient-clinician relationship, to assist patients with decision-making, and to reduce patients' uncertainty.[56-58] Providing patients with information tends to increase satisfaction,[59] facilitate participation in the consultation, decrease anxiety, and increase ability to cope.[60] Patients with cancer and their families often use their information resources not only to understand the disease but also to find hope.[61-63] A review of selected literature on information exchange in cancer settings is presented in Appendix B.

Important changes have occurred in the process of information exchange over the past four decades. Historically, the clini-

cian's role has been to provide disease-related information and recommendations, and the patient's role has been to share symptoms and concerns. However, increased attention has been given to patients' opinions, needs, beliefs, values, and preferences. In addition, patients bring disease-related information to the consultation, often from discussions with other health professionals, lay informants, family members, media sources, and, especially, the Internet. Thus, there is a need to rethink research on patient-clinician information exchange, which has largely taken the *deficit* model. With a focus on insufficient information, the deficit model emphasizes that patients with cancer want as much information as possible[64,65] and do not receive enough information from clinicians.[66] However, we embrace a *process* model of information exchange that focuses on the reciprocal efforts of both clinician and patient to manage information and achieve, even negotiate, a shared understanding of the medical and personal issues underlying the patient's health condition. The wide availability of health information on the Internet can cause patients to become frustrated by information "overload" and their inability to clearly understand their health status and appropriate course of treatment.[67] Clinicians must help patients filter and understand clinical information, a *sine qua non* for informed or participatory decision-making.[58,68,69] Moreover, information content varies accord-

ing to the phase on the cancer care continuum:

- Prevention: discussing risks and benefits of screening with asymptomatic patients

- Diagnosis or recurrence: sharing bad news and explaining test results

- Treatment: Interpreting results of clinical trials for making decisions

These information-sharing tasks are challenging. Related issues that are critically important to effective information management include uncovering the patient's information needs and understanding what the patient knows and believes about health, including the meaning the patient ascribes to the illness.

2.2.1 Patients' information needs

The information needs of patients with cancer differ among patients, change over time,[68,69] vary depending on the type and stage of cancer, and persist throughout the cancer care continuum.[70] Most patients report that they want to know as much information as possible about their type of cancer and the treatment options[71,72] but often are overwhelmed by the sheer amount of information provided by clinicians, the mass media, and the Internet.[67] However, some patients do not want information and use avoidance as a coping mechanism.[73] At the same time, the family also may be requesting information. The difficulty in effectively managing

information is further compounded by the fact that clinicians often feel uncomfortable providing information about sexuality and inquiring about psychosocial and emotional needs.[62,71,74-78] Clinicians do not always appreciate the complexity of patients' and families' concerns[79,80] and thus may not get to the "heart" of the matter. The absence of perceptual skills (Chapter 1) to detect the patient's expressed needs may explain in part why many patients and family members remain dissatisfied with the timing and amount of information they are given by clinicians.[62,66,75,76,78,81]

As discussed in Chapter 1, asking patients about their information needs, providing clear explanations, avoiding medical jargon, and checking for understanding are patient-centered communication behaviors that facilitate effective information management.[81-83] Ideally, when patients perceive they are not getting sufficient or clear information, they should ask questions or express their views or concerns, actions that typically elicit more information from clinicians. Correspondingly, clinicians should realize that patients want information and should find ways of eliciting their information needs. Asking about information needs is especially important for patients with cognitive deficits or limited health literacy, as such patients may want information but be less assertive and take more time with their physicians in getting it.[84] Health care systems can also help address the patient's

information needs by providing the following:

- Audio recordings of clinical consultations to help patients with cancer recall and assimilate information[85]

- Multimedia resources that help explain complex features of disease and treatment options[29]

- Educational resources that provide instructions for patients and their family members on how to use the Internet to get the most useful information[86]

2.2.2 Understanding what patients know and believe about health

Clinicians, patients, and families often have very different illness representations,[87] otherwise known as explanatory models,[88] or "lay" or "common sense" models of health and illness.[89-91] Illness representations consist of ideas and expectations about causality, time course, treatment, and prognosis and shape how patients respond to illness. These representations are the ways in which patients make sense of and react to their experiences of the illness. However, there are often unexplored differences between clinicians' and patients' illness representations, which can lead to misunderstandings and may lower quality of care. For example, a patient who believes that pain is an inevitable feature of cancer may not report new painful symptoms, thus delaying diagnosis of a potentially treatable recurrence. Because commu-

nication- related disparities in health care may stem from culturally mediated misunderstandings, clinicians should make particular efforts to understand patients' illness representations during cross-cultural health care encounters. Illness representations are learned from a variety of sources, including mass media, the Internet, family, friends, and coworkers.[92]

One of the factors contributing to differences in patient and clinician understanding of health information is that existential aspects of illness shape how patients interpret and use the information they have. Uncovering the meaning of the illness to the patient is an important part of the information-exchange process because patients with cancer often find that information not only helps them to understand the disease but also helps them to find hope,[61-63] to feel known and understood by their caregivers,[10] and to ascribe spiritual and other meanings to illness.[93] This understanding can, in turn, enhance patient's sense of self, peace, and well-being. Although patients most often prefer to get information from their health care providers[92] and trust such information, clinicians should not assume that patients have a similar understanding of clinical information, even when they are well educated, are likely to have greater health literacy, and are familiar with medical terminology.[94] Hence, an important communicative task for the clinician is to uncover the meaning of the illness to the patient through empathy, active listening, and

encouraging patient expression. By so doing, the patient feels understood and the clinician acquires valuable information about the patient's perspective, which the clinician can use to align the respective illness representations and to provide more personalized cancer care.

2.2.3 Communicating clinical information

Communicating clinical evidence is challenging and requires that clinicians have skill in offering explanations the patient understands, in framing information, and in using visual aids.[95] Communicating quantitative information is particularly challenging. Patient understanding of statistics may be limited, and misunderstandings about absolute and relative risk or means and standard deviations, may result in overly concrete interpretations. Graphical displays, especially 100-person diagrams, are increasingly being used to improve patient understanding of statistical data, but the findings of at least one survey suggested that patients preferred words to pictures.[96] Not only does the content of clinical evidence change across the cancer care continuum, but the intended goals of sharing the information vary as well. For example, clinicians may provide statistics on the accuracy of mammography in detecting cancer in order to persuade a patient to have a mammogram. A clinician may present information about the risks and benefits of various prostate cancer treatments in order to have patients articulate their

preferences and values. For example, while most patients would rather know that they have cancer even if treatment is ineffective, others might prefer not to know. Because patients tend to favor estimates that are framed in positive outcomes (a 60% chance of surviving for five years) rather than estimates that are framed in negative outcomes (a 40% chance of dying within five years), clinicians should frame the information in both ways to avoid having the information be perceived as overly hopeful or pessimistic.

In short, communicating clinical evidence is more than just "stating the facts." Patients make subjective sense of the information through their own interpretive lens, and these interpretations are influenced by past experiences, their own illness representations and beliefs,[90,97] the experiences of others, their emotional states, and their goals. Patient-centered communication skills that can help clinicians manage clinical information include the following: [61,98]

- Use everyday language as much as possible

- Repeat and summarize

- Ask patients to restate information as a way to ensure they understand

- Encourage patients to ask questions

- Engage in active listening

- Allow adequate time for discussion with the patient

- Be honest

2.2.4 Sharing bad news and prognostic information

Although patients and clinicians in the United States and other English-speaking countries overwhelmingly endorse honest disclosure of a cancer diagnosis,[99] the delivery of bad news continues to be stressful for clinicians and ineffective and/or traumatic for patients and their families.[100] Patients report feeling upset or overwhelmed after they hear the devastating news of a cancer diagnosis; such anxiety makes assimilation and recall of further information difficult. Although no communication intervention can eliminate the life-changing impact of a cancer diagnosis, the effective delivery of bad news can at least help patients become the following:

- Better informed

- More motivated to follow through with further evaluation and treatment

- Less emotionally distressed

- Better able to ask questions and participate in the clinical encounter

- Better prepared to make treatment decisions

- Better able to navigate the health care system

- Clear about the level of uncertainty of the diagnosis

The difficulty in managing bad news may be further compounded by a patient's psychological and emotional factors, cognitive impairment, and low health literacy.[94]

Cultural factors also play a role, especially the interface between mainstream American culture and cultures in which families play a central role in managing health-related information.

Clinicians, too, have considerable difficulty delivering bad news compassionately and clearly. Despite a large body of literature with seemingly sensible recommendations for delivering bad news, and an increasing number of courses for students and residents, clinicians often deliver diagnostic information without prior training or support.[101] Many physicians report having felt overwhelmed and traumatized by their early experiences at delivering bad news.[102] They may know how bad news should be delivered, but they may be unable to carry out the process effectively because of their own discomfort, fear, anxiety,[103,104] and lack of forums to deal with their own feelings. Correspondingly, it is not surprising that the popular press and the medical literature still includes patient reports of cold, impersonal, blunt, evasive, tactless, indirect, jargon-laden, and poorly timed delivery of bad news. Clinicians' actions at times favor their needs to reduce their own anxiety and uncertainty and bring the visit to closure, rather than address such patient needs as the desire to understand and be understood, to gain emotional support and hope, and to be reassured that they are getting the best available treatment.[105]

Uncertainty is implicit in discussions of prognosis. Patients generally state that they want an accu-

rate prognosis but also want to be given hope.[98,106] Generally, the more serious the prognosis, the fewer the number of patients who want an honest assessment of life expectancy.[96,107] Many patients prefer to be asked what information they wish to hear before it is disclosed, as well as when the disclosure should take place.[96] However, physicians' prospective estimates of prognosis are usually more favorable than the actual course of the disease,[108] and many intentionally exaggerate prognosis when communicating with patients and families,[109] probably because of their own discomfort.[110] Correspondingly, patients frequently report not knowing their prognosis[111,112] or they overestimate their prognosis, even when they have been given accurate information.[111,113-119] As with bad news, cultural factors may be paramount. One recent review of interventions designed to help clinicians better inform patients about their prognoses and plan for end-of-life care indicated that most clinicians have not been successful with this task, perhaps because of inadequate attention to communication factors.[120]

2.3 Responding to Emotions

The threat, diagnosis, and treatment of cancer elicit a range of emotions in patients that include fear, sadness, anger, anxiety, and depression. Often, there are corresponding reactions in friends and family members. In clinical encounters, patients and families express these emotions in a variety of ways: fear,[121] humor,[122,123] nerv-

ousness, worry, sadness, or fatalistic thinking.[124,125] Moreover, these emotions are rarely static; rather, they ebb and flow over the course of the cancer experience.

It is particularly important to recognize and respond to patients' emotional states, given that depression, anxiety, and adjustment disorders have major effects on the quality of life of patients with cancer.[126-129] These emotions also can affect response to chemotherapy[130] and the experience of pain.[131] Clinicians can appropriately and directly address patients' emotional distress by using verbal expressions of understanding, legitimation, empathy, and support, which, in turn, can lead to improvements in physical symptoms,[132] alleviate the negative effects of inadequate social support,[133] and foster a perception of being understood.[134] Moreover, by recognizing serious levels of emotional distress, anxiety, or depressive disorders, clinicians can prescribe medications or offer referral for psychotherapy that could directly improve the patient's well-being,[2,6,135] lead to mobilizing social support,[136] and increase the likelihood that cancer treatment is completed. Attention to family members' emotions can prevent caregiver burnout. Further discussion and a literature review on recognizing and responding to emotions in cancer settings can be found in Appendix C.

Given the magnitude of patients' and family members' emotions generated by a cancer diagnosis, clinicians should be able to recognize a patient's emotional state, ask

the appropriate questions to understand it, communicate that understanding to the patient, and respond with empathy or tangible help. Unfortunately, clinicians typically are not adequately cognizant of patients' emotional cues, nor are they effective at uncovering patients' fears and concerns.[121,137] Fewer than one-third of emotionally distressed patients are recognized as such by their physicians.[138,139] In general, clinicians rarely initiate conversations about emotions, and, correspondingly, some patients learn not to bring up these issues at all. Part of the difficulty is that, while some patients express emotions explicitly ("I'm frightened that …"), others are more willing to disclose physical symptoms than psychological problems,[140] and yet others reveal their fears and concerns indirectly[80] or not at all, unless prompted by the clinician.

These direct and indirect cues to emotional distress are often ignored, displaced, or dismissed rather than being met with empathic responses that acknowledge cognitive and affective dimensions of the patient's experience.[141,142] Paradoxically, reassurance can be counterproductive. Although reassurance usually reduces anxiety initially, anxiety may rebound to even higher levels after clinicians' attempts to reassure, especially if the patient feels as if his or her concerns were addressed superficially and if the clinician did not provide an adequate rationale for reassurance.[143-146] Effective responses to emotional expression include the following:

- Legitimation: "It's only natural to feel that…."

- Validation: "Yes, this is a very anxiety-provoking time for you."

- Empathy: "This is making you both worried and sad, is that right?"

- Tangible help: "I think I can help by…."

In contrast, less effective responses are asking leading questions, focusing on the physical aspects of health, and prematurely giving advice and reassurance. The absence of communication skills described in Chapter 1, as well as lack of time, environmental noise, and lack of privacy can be additional barriers to clinicians' validation of and responsiveness to patients' emotions.[147,148] Educational interventions can help clinicians address patients' emotional needs[149,150] and the effects of interventions can be long-lasting.[151]

Before leaving the discussion of responding to patients' emotions, it is important to recognize that clinicians, too, experience a variety of emotions as they treat their patients, especially when confronting patients with life-threatening illnesses and patients for whom treatment is not always effective.[40,43,47,48,152] Clinicians should have self-awareness of their emotions and must acknowledge and manage their emotions effectively; an important aspect of managing emotions is finding the right balance between involvement and distance to provide appropriate

care. Clinicians frequently do not explore their own emotions about patients or their own emotional needs, leading to confusion between the patient's emotional needs and those of the clinician.[36] Unexamined negative emotions, in particular, can create distance between clinicians and patients that may be interpreted by patients as lack of caring.

2.4 Managing Uncertainty

We separate management of uncertainty from information exchange and decision-making because information, emotional support, and mutual understanding between clinicians and patients do not necessarily mean a reduction of uncertainty. Uncertainty is particularly salient in cancer care because the outcomes of cancer usually occur closer to the time of diagnosis (e.g., within five years) and cancer is often curable; in contrast, other major causes of death, such as diabetes, emphysema, and coronary artery disease, have more protracted courses and are usually not eradicated. According to Mishel,[153,154] uncertainty in illness occurs when a person perceives aspects of the illness, treatment, and recovery as inconsistent, random, complex, and unpredictable. Uncertainty can have negative consequences, such as emotional distress, a loss of sense of control, and lower quality of life.[155,156] However, maintenance of uncertainty may have self-protective value for some patients and families by allowing space for hope.[157] Although uncertainty may stem from a lack of

information (Does the patient have cancer?), it can also be created when there is too much information (Which treatment regimen is more appropriate for the patient?) or when the available information may be interpreted in many ways (Is no change in tumor marker level a positive sign?).

Uncertainty is particularly salient in discussions of prognosis, which usually involve the presentation of statistics. Many patients have difficulty understanding statistical estimates and often interpret them as precise predictions. It is sometimes difficult to convey that statistical estimates are no more than a probabilistic structuring of uncertainty. Furthermore, physicians have long been perceived to have an excessive need for certainty[158] and for maintaining an illusion of certainty.[159] Few empirical studies have focused on the effect of sharing uncertainty with patients and families, and no study has been specific to cancer settings. Some vignette studies in primary care settings suggest that expressions of clinician uncertainty in the form of "I don't know" or "Let's see what happens" or the use of vague language may have detrimental effects on patient confidence.[160,161] In other studies,[162] however, expressions of uncertainty in the context of an otherwise patient-centered style correlated with improved patient satisfaction.

Patient-centered communication should not only reduce uncertainty but also help patients with cancer *manage* uncertainty.[68] In many situations, patients appreciate

when the clinician can acknowledge that uncertainty is unavoidable and can frame information in terms of what is known and what is unknown. Cognitive-behavioral techniques for patients facing uncertainty can improve understanding and probabilistic thinking, help maintain a positive outlook on future treatments and developments, and engage patients in vigilant self-monitoring for emerging symptoms. These interventions may improve communication and quality of life. One cognitive-behavioral intervention for patients with breast cancer, for example, improved cognitive reframing, cancer knowledge, communication skills, and coping.[153] Similar interventions for men with prostate cancer led to improved psychological, sexual, and urinary functioning after prostatectomy.[163] A similar intervention led to better quality of life for men who chose "watchful waiting" without treatment.[164] Internet resources may also help patients manage uncertainty, especially when the information and support received is perceived to be trustworthy and of high quality.[165] In addition, health care systems can greatly assist the management of uncertainty by providing patient education resources and access to cognitive interventions.

Although theories about the management of uncertainty have been proposed and psychological interventions based on those theories have been successful, little is known about what can be done as

part of routine clinical care to lower the burden of anxiety related to uncertainty experienced by patients and families. Patients need information, cognitive strategies, and skills to manage emotions in order to handle uncertainty effectively, yet it is not clear whether these resources can be provided during routine clinical care or if specialized psychological interventions are necessary. Clinicians' actions to reduce uncertainty or provide reassurance have the potential to backfire, further raising patient anxiety and distrust.[143-146] These issues are paramount in the survivorship phase and will affect an increasing number of patients, including patients who do not have a guarantee of cure on the immediate horizon or who have oncogenetic mutations. These issues also affect patients for whom the management of long-term sequelae of treatment may introduce new uncertainties.

2.5 Making Decisions

Decision-making is a communicative task that is important in all phases of the cancer care continuum. A high-quality decision is one that is based on the patient's values and understanding of the evidence and rationale for the decision. To achieve a high-quality decision, the patient's needs, values, and preferences should be articulated and taken into account. However, achieving the best decision possible is often difficult for several reasons:

- Clinicians are often unaware of the patient's needs, values, and preferences

- Patients have not necessarily considered all of the options prior to the medical visit

- Patients and clinicians often hold different beliefs about health

- Patients are often not familiar with the clinical reasoning supporting a preferred option

An additional complication in the process is that patients vary greatly with respect to their preferred degree of involvement in decision-making.[32,64,65,166-170] Clinicians are often unaware of patients' preferences for involvement[32,171] and the patient's preferred level of involvement and decision may change during the course of the consultation or from one visit to the next.[172] Most of the literature on decision-making assumes a dyadic patient-clinician relationship, despite the fact that most important decisions in cancer care involve at least one other accompanying family member. A detailed literature review on decision-making in cancer care settings is in Appendix D.

We find the model of treatment decision-making proposed by Charles et al.[173] to be a particularly useful starting point because it helps distinguish active patient participation from control of decision-making. The model presents three types of decision-making that lie along a spectrum:

- *Paternalistic:* clinician decides treatment

- *Shared:* clinician and patient together decide treatment

• *Informed:* patient decides treatment based on information from the clinician and other sources

Although each type of decision-making process differs with respect to the degree of patient or clinician control over the decision, each type proceeds through the same three stages—*information exchange, deliberation, and making the final decision*. Regardless of who is responsible for the final decision, the process is one that is ideally characterized by mutual engagement and participation at both the information-exchange and deliberation stages. Information exchange involves the clinician and the patient seeking and giving their respective viewpoints on the patient's health condition. The clinician discusses clinical findings, options for treatment, the procedures involved, and his or her experience with these conditions. The patient discloses his or her needs, questions, preferences, concerns, and his or her knowledge about health and treatment.

As discussed in Chapter 1 and earlier in the section on information exchange, clinicians and patients may need to help one another be accountable in the information-exchange process. If information presented by a clinician is difficult for the patient to understand or seems counter to what the patient knows, an educated, activated and motivated patient would normally ask questions and offer his or her own perspective.[26] However, patients are often passive and intimidated by the clinical setting.

In those cases, the clinician may need to use partnership-building and other facilitative communication to elicit the patient's perspective.[30,174] Clinicians' use of partnering behaviors will also help uncover the reasons for the patient's treatment preferences, which are often not readily apparent. For example, clinicians often have little understanding of patient's reasons to forego mainstream therapy, and these reasons can be quite varied, including having a close friend/relative who died from cancer when receiving conventional treatments, a need for control, fear of side effects of conventional treatments, poor communication with clinicians, and expected benefits of treatment. As they work toward mutual or shared understanding of the situation during the deliberation stage, clinician, patient, and family identify similarities in their viewpoints and resolve any differences. In short, even if the final decision is made unilaterally, the decision-making process itself should still have been characterized by active engagement by all parties in the information-exchange and deliberation stages.

In most cases, the quality of the decision reached will depend on how well four tasks were accomplished:

• Perspectives of both clinician and patients were voiced and understood

• Differences were reconciled satisfactorily

• Mutual agreement was achieved regarding the best course of action

• Decision was supported by current clinical evidence

Each of the steps in decision-making—information exchange, deliberation, and the final decision—is critical for effective decision-making. For example, some research indicates that the greater the match between the preferences of patients with breast cancer to be involved and their perception of actual involvement, the less decisional regret and greater satisfaction with care.[173,175] Patients' evaluations of care are better predicted by perceptions of having had a shared role in decision-making than by their initial preferred role;[173,176] this may in part be due to their feelings of being involved in the process. Physician support of patient participation can increase the participation of patients with cancer,[29,177] foster a sense of having a choice of treatment, and lead to greater satisfaction with care.[24]

This adaptation of the model by Charles et al.[173] is useful in that it makes an important distinction between patient involvement in the decision-making process, which a number of studies indicate is a positive feature of patient-centered care, and the issue of who assumes responsibility for making the decision. This model would account for findings indicating that most patients want to be involved in decision-making, want to know all of their options for treatment, and want the decision to take into account their needs and values. Yet, many of these patients may choose not to have sole or even partial responsibility for the final

decision, instead deferring that to the clinician. This model also highlights the fact that a 'shared decision' is not inherently a positive outcome of the decision-making process. Instead, the quality of the patient-clinician interaction, and not the patient's role per se in deciding treatment, is arguably the most important factor affecting the quality of decision-making.

Specific communication strategies that could facilitate patient/family-clinician communication about treatment include the following:

- Setting an explicit agenda

- Listening actively

- Checking understanding

- Offering opportunities for involvement

- Endorsing patient participation in discussions and the decision

- Accommodating patients' preferences

- Communicating empathy and warmth both verbally and nonverbally

Health care systems also have a role in supporting decision-making by facilitating access to information and providing decision aids and other resources. Decision aids, in the form of booklets, prompt sheets, video recordings, and interactive Web-based formats, can help patients understand and take an active role in decision-making.[178,179] Decision aids increase patients' knowledge about options, lower decisional conflict, and reduce the proportion of patients remaining

undecided about the treatment, but few studies have addressed the impact of decision aids on patient-clinician communication.

2.6 Enabling Patient Self-Management

A sixth function of communication in cancer care deals with the practicalities of following through with care, helping patients to enhance their ability to solve health-related problems and to take actions to improve their health. This function is somewhat different from information management because it comprises recommendations ('should do' communication), instruction ('how to' communication), and advocacy ('can do' communication). *Enablement* [180-182] refers to patients' perceived ability to self-manage important aspects of their illness, which includes their ability to *find information* about the illness, *cope* with treatment effects, and *seek appropriate care* when needed. Implicit in enablement is the ability to adhere to treatment, navigate the health care system, and garner resources.[181-183] Enablement includes things that clinicians can do *for* patients to remove barriers to self-management, as well as ways clinicians can *help* patients be more autonomous and capable of caring for themselves. The concept of self-management was advanced by Bodenheimer et al. and has been formalized into a chronic care model to be applied in primary care settings.[184,185] Enablement includes both things that clinicians can do *for* patients

to remove barriers to self-management, as well as *helping* patients be more autonomous and capable of caring for themselves.

The concept of self-management has been expanded and applied to chronic disease management in primary care settings.[184,185] The chronic care model emphasizes collaboration in which the patient and the team of health professionals each identifies problems and sets goals. Clinicians provide information but also teach patients how to gain access to and utilize knowledge. Education and information may come directly from the health professional and also from other patients (in group settings), peers, or family members. Each contributes expertise and shares responsibility for problem-solving, the achievement of health outcomes and caregiving. In contrast to a paternalistic approach, professionals help the patient make informed choices. Clinicians understand that their responsibility is to help patients find internal motivation rather than to dictate a course of action. The clinician's role is to teach problem-solving rather than solve all problems for patients—with an explicit goal of enhancing self-efficacy.

Self-management leads to improved health outcomes and reduced hospitalizations for patients with chronic disease.[186] However, the idea that patient-clinician communication can enhance self-management is relatively new to cancer settings. Patient-clinician communication about self-management can focus on any number of issues, but

we believe that three are particularly important in cancer care: advocating and navigating, supporting patient autonomy, and providing guidance, skills, and access to resources.

2.6.1 Advocating for patients and helping to navigate the health care system

Patients often need *advocacy,* or actions taken on their behalf. Advocacy often includes interactions between clinicians and others within as well as outside the health care system. Some examples of advocacy are contacting insurance companies to provide needed care, personally coordinating care with another specialist, and making sure that a terminally ill patient has adequate home care services. Advocacy also includes interactions with the family to support the patient's healing efforts.

Navigation is a special form of advocacy. More so than with care of other illnesses, cancer care typically requires that patients navigate a complex health care system in which they interact with a variety of health professionals performing specialized services at multiple locations. Navigating the health care system is particularly challenging in the trajectory from detection of cancer to initiation of treatment but is also important in accessing services related to survivorship issues and end-of-life care. In some settings, specially trained "navigators" assess patients' needs and, in collaboration with the patient, develop a

plan to address these needs and assist patients in overcoming various barriers to obtaining timely, high-quality care.[187] Although navigator programs are increasingly used, there are limited data regarding their effectiveness or costs. Some ways in which clinicians can contribute to navigation include the following:

- Help patients obtain confirmatory testing for suspected cancer in a timely fashion

- Tell patients how to get to a specialist's office

- Explain clearly about when and with whom to follow up

- Arrange referrals for psychotherapy, support groups, and/or social work

- Coordinate care among specialists for hospitalized patients

- Provide palliative/end-of-life care or direct patients to resources for such care, as appropriate

2.6.2 Supporting patient autonomy

Autonomy requires motivation and self-efficacy. Motivation has been studied in other settings, using self-determination theory to predict and influence patients' motivation for change. Self-determination theory suggests that *autonomy-supportive* clinician behaviors tend to foster patient motivation.[188] In contrast, when clinicians are directive and controlling, motivation tends to

diminish. Autonomy-supportive behaviors include exploring patients' ambivalence about taking action, providing several options for achieving the same goal and giving patients time to consider choices rather than forcing a premature decision. This approach has been applied with success to smoking cessation, weight loss, adherence to treatment, and exercise, topics that are related to cancer prevention and quality of life.[28,189,190] Autonomy-supportive clinician behaviors can also enhance a patient's sense of self-efficacy,[186,191] but, as is the case with motivation, self-efficacy is a prerequisite for enablement but is not synonymous with that concept.

While navigation is a form of advocacy *for* the patient, *activation* is a form of self-advocacy *by* the patient. Patient activation interventions,[192] however, have mostly focused on training patients about how to get their questions answered and how to participate in decision-making. Interventions can help patients with the following:

- Find their way through the health care system

- Obtain access to the best clinicians for their particular condition

- Recognize gaps and lapses in care and bring them to clinicians' attention

- Improve adherence to treatment

- Become educated consumers of health care

2.6.3 Providing guidance, skills, and access to resources

By providing access to resources, clinicians can help patients directly or help patients help themselves. In addition to motivation and confidence (self-efficacy), patients also need the knowledge, skills, and resources to be able to follow through. Clinicians still need to provide recommendations, instruction, advocacy, and support. Even if a patient feels empowered and enabled, situations with regard to the patient's illness change over time. *Recommendations* should be clear, with nontechnical language and simple sentence structure. Recommendations should be accompanied by recall-promoting behaviors such as repetition, summarization, categorization, and asking the patient to repeat complex recommendations so that it is clear that they understand.[193-199] *Instruction* helps patients do things for themselves. Instructions should include clear explanations on ways the patient should manage pain and other symptoms and how to follow through with a mutually agreed upon plan that might include scheduling medications, having an x-ray done, or talking to a social worker. Instruction also can include telling the patient and the family how and when to contact the clinician, how to make sure that the right people are present during family meetings, and what websites will provide relevant information.

Self-management needs vary greatly among patients. All aspects of self-management take the patient and clinician outside the confines of the clinical office or hospital room to involve other settings, people and organizations. In particular, health care systems have an important role in supporting patients' self-management by providing easy access to personnel, experts, programs, and media that can guide and inform self-management. Some supportive resources that have been discussed in the literature include the following:

- Use of lay health educators[200] and interactive media[201] to help patients be more proactive in controlling pain and other cancer-related symptoms

- Training patients how to use the Internet more effectively to access health information[202]

- Sponsoring of community-based programs for the management of cancer-related symptoms[203]

- Assistance for patients regarding the use of complementary and alternative medicine[204]

- Toolkits for learning self-advocacy[205]

Few studies of enablement per se have been carried out in cancer settings, and navigation studies are just now being conducted. It is clear, though, that enabling patients to take a more active role in managing aspects of their own health care should be a focus for future communication research.

2.7 Conclusion

In this chapter, we outlined six functions of communication in cancer settings that likely have an impact on important intermediate and health outcomes. *Fostering healing relationships* emphasizes the importance of mutual trust, rapport, understanding, and commitment, as well as agreement about each others' roles and expectations as both requirements and results of effective communication.

Exchanging information emphasizes the importance of recognizing patients' information needs, integrating clinical information with the patient's illness representations (explanatory models), acknowledging both the content and process of information exchange, recognizing that disease-related information now is more available through the Internet, communicating prognostic information accurately while also providing hope, and overcoming barriers related to low health literacy and poor understanding of statistical information.

Responding to emotions requires clinicians to elicit patients' emotional distress; communicate an understanding of the patient's emotions to him or her; and respond with legitimation, validation, empathy, and support.

Managing uncertainty emphasizes that uncertainty often cannot be eliminated but can be managed by providing information, support, and cognitive strategies to help

patients and families deal more effectively with the anxiety related to uncertainty.

Making decisions involves consideration of both the active involvement of the patient and family in the information exchange and deliberation stages of the decision-making process and the identification of the person responsible for the final decision.

Lastly, *enabling patient self-management* involves advocacy for the patient, including navigating the patient through the health care system; supporting patient autonomy; and providing guidance, skills, and access to resources.

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Pathways from Communication to Health Outcomes: Mediators and Moderators

The relationship between patient-clinician communication and outcomes of care is, from a conceptual standpoint, one of the least developed areas of communication research. Much of the current literature on cancer communication focuses on immediate, proximal outcomes of com- munication, such as whether patients recall clinician recommen- dations, and intermediate out- comes, such as whether patients follow through with treatment (Table 3.1). The outcomes of great- est relevance to patients and their families, however, are health, sur- vival, and quality of life. Survival

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Table 3.1 Pathways from Patient Needs to Communication to Outcomes: Mediators

Communication outcomes (also mediators of relationships between communication and intermediate and primary outcomes)

- Strong patient/family-clinician relationships (trust, rapport, respect, patient participation in the visit, involvement of family and caregivers, patient feels known and understood)
- Effective information exchange (e.g., patient asks questions)
- Validation of emotions (e.g., clinician expresses empathy)
- Appropriate acknowledgment, understanding, and tolerance of uncertainty
- Patient participation in decision-making
- Patient self-management, navigation of health care system, and coordination of care

Intermediate outcomes (also mediators between proximal communication outcomes and primary outcomes)

- Patient knowledge and understanding
- Access to care
- Therapeutic alliances
- Emotional self-management
- Family/social support and advocacy
- High quality of medical decisions (e.g.,

informed, concordant with patient values, and mutually endorsed)
- Patient agency (self-efficacy, empowerment, and enablement) leading to improved treatment adherence, health habits, and self-care

Health outcomes

- Survival and disease-free survival
- Cancer prevention
- Early detection of cancer
- Accurate diagnosis
- Completion of evidence-based treatment
- Maintenance of remission
- Health-related quality of life
- Functioning: cognitive, physical, social, and role
- Well-being: physical, emotional, energy
- Health perceptions
- Other aspects of suffering (meaning, spirituality, etc.)

Societal outcomes

- Cost and utilization of health services
- Disparities in health and health care
- Ethical practice (e.g., informed consent)

(with or without disease) and quality of life are considered primary because they reflect the patient's experience in the world, not just in the clinic. In addition, societal outcomes, such as reduction in health disparities, are important on a population level. Many of the mediators and moderators between communication behavior and these outcomes and between intermediate and primary health outcomes are poorly understood.

Broadly speaking, the relationships between communication and survival (and disease-free survival) are likely to be mediated by patient access to and completion of recommended health care. Markers of disease such as blood tests, radiographic studies, and physical signs are commonly used to judge the effectiveness of treatments and are sometimes used as surrogate markers for survival. Although disease markers and adherence to treatment have been used in communication research in the settings of diabetes, hypertension, and other chronic illnesses,[1] these markers have been used much less frequently in communication research in the cancer setting.

The construct of health-related quality of life (HRQOL) is increasingly being used to measure subjective outcomes of care (Table 3.2). HRQOL refers to the impact of an individual's health on his or her ability to function and on his or her perceived well-being, in physical, mental, and social domains of life. The functioning aspect of HRQOL includes basic activities, such as self-care, cognitive ability, and ability to perform at work, and the extent to which one is able to interact with family and friends. The well-being component of HRQOL relies almost exclusively on the perceptions of the patient and is therefore more subjective than the functioning aspect. Included in the well-being component is the degree to which the person has symptoms (physical well-being); feels happy, sad, depressed, or anxious (emotional well-being); and feels energetic or lethargic. Comprehensive HRQOL measures address multiple domains of function and well-being. Cancer can affect non-HRQOL domains as well, such as earning potential and standard of living, but the impact of communication on these domains is more speculative.[2,3] Elements of HRQOL that have been assessed in communication studies in cancer and non-cancer settings include emotional and social well-being, and in some cases, symptoms and physical functioning.[4,5] Very few cancer communication studies have focused on the effects of communication on societal outcomes such as costs and health care disparities.

In this chapter, we discuss the links between communication, proximal outcomes, intermediate outcomes, and health outcomes, with particular attention to the various pathways through which the communication functions described in Chapter 2 can lead to improved health. The chapter also

Table 3.2 Domains of Health-Related Quality of Life		
Domain		**Examples***
Functioning	Physical	Mobility, bathing, dressing
	Cognitive	Problem-solving, memory
	Social	Interacting with friends and family
	Role	Performing job, housework, hobbies
Symptoms	General	Pain, nausea, fatigue, weakness
	Disease specific	Itching, breathlessness, constipation, urinary frequency
	Emotional	Anxiety, depression, hopefulness (body image)
	Social	Enjoying friends and family
	(Spiritual)	(Personal meaning, transcendence)
General health perception		Self-reported overall health

*Items in parentheses are encountered less frequently.

addresses various moderators of these relationships. In addition, we explore ways in which health care systems can provide resources that facilitate more effective communication and facilitate the links between improved communication and health outcomes.

3.1 The Fundamental Task: Explaining the Link between Communication and Outcomes

In this chapter, we discuss ways in which communication can lead to improved survival and quality of life either directly or through the mediating effects of proximal and intermediate outcomes. However, much of what we present is speculative, because very little is known about the mechanisms by which communication affects health outcomes. It is clear, however, that in some instances patient-clinician communication directly improves well-being. For example, a clinician who is encouraging and reassuring and offers clear, understandable explanations may help an anxious patient in the hospital to have a lower level of anxiety, sleep better, and have an improved appetite immediately after the clinical encounter. However, in most situations a more complex series of mechanisms links communication to health outcomes.[6] Collectively, these links constitute particular pathways to better health through immediate outcomes such as greater mutual understanding, trust, and patient involvement in decision-making and through intermediate outcomes such as changes in patient health

behaviors, self-care skills, social support, and quality of care.

An initial task for researchers is to determine whether patient-clinician communication is actually a reason for a particular observed outcome. A clinician's efforts to inform a patient about the benefits of treatment can increase the likelihood that the patient adheres to a potentially curative treatment regimen through several pathways. Those pathways might be mediated by increased trust and/or increased understanding. To study whether these pathways explain an effect of communication on health outcomes would require measures of the purported mediators: information giving, trust, understanding, and adherence. Although the cancer communication literature includes relatively few examples of studies in which mediation hypotheses have been tested, such hypotheses have been examined in communication studies in other settings.[7] Future studies should include measures of the elements necessary to establish whether a proposed factor is indeed a mediator of patient-clinician communication and health outcomes (Figure 3.1).

Consider one of the few studies in which patient activation interventions have been evaluated in cancer settings. Oliver et al.[8] examined the effects of interventions in which patients were coached to ask questions about the management of cancer-related pain. Patients in the activation group reported less cancer-related pain at follow-up than did patients in the control group. Changes were not mediated by

patient knowledge or adherence, as the two groups did not differ with respect to those measures. Questions remain about the reason for the difference in pain. Was the decrease in pain related to the effects of the intervention on patient-clinician communication? Did the intervention improve the patient's information-gathering skills so that he or she knew how to self-manage pain more effectively? Did the intervention promote a sense of self-efficacy and confidence to use existing knowledge? Did the intervention lead the patient to disclose more information about the pain so the clinician could provide a personalized pain management plan to which the patient could adhere more easily? Without evidence of mediating factors, we can only speculate about why a patient intervention led to improved health.

Before discussing pathways that link patient-centered communication to outcomes, we should acknowledge some controversial philosophical and theoretical issues that are often embedded in the discussion of the relationship between patient-centered communication and outcomes. First, opinions differ regarding whether communication is a means to an end or is simply an end itself. The instrumental viewpoint holds that communication is considered to be important only when it can be linked to changes in intermediate or distal outcomes. Alternatively, the deontological viewpoint holds that communication can be considered to be an important feature of

care that has intrinsic value regardless of other outcomes. Krupat et al.[9] reported that most patients endorse this latter viewpoint.

Second, the same communication behaviors may improve some outcomes but worsen others. Patients' perspectives about the quality of care (e.g., as reflected in satisfaction measures) are particularly problematic because the clinician behaviors that enhance patient satisfaction are sometimes distinct from those that improve health outcomes. Patients who value patient-centered communication and who trust and endorse their physicians may be no more satisfied than patients who do not.[10] In some situations, improved patient satisfaction may even mask deficiencies in other domains of practice. For example, patients who are more satisfied with their care sometimes have poorer intermediate outcomes, such as less healthy behavior, as indicated in a study in which diabetic patients who were more satisfied with their care maintained poorer weight control than did less satisfied patients.[11] Also, some forms of active patient participation, such as question-asking and assertiveness, may produce more friction in the patient-clinician relationship, which, in turn, may decrease patient satisfaction.[12] Yet, active participation in communication may result in better understanding and self-management. We would argue that, in these circumstances, patient activation was not the problem; rather, the patient may have achieved better clarity about his or her own values, and

the lower level of satisfaction reflects the difficulty that the clinician and patient had in aligning their perspectives (see Chapter 1).

In summary, outcomes of effective communication are many and, as noted in Chapter 1, may differ based on patients' and clinicians' values and goals. Moreover, some outcomes, such as satisfaction with care, may work against others, such as healthier behaviors. Communication, outcomes, and some mediators of the two are complex constructs, and each desired outcome will be affected by certain domains of patient-centered communication more than others.[13] Ideally, relevant health outcomes should be defined through dialogue between patient and clinician. In this way, patient preferences can be clarified and the clinician can avoid mistaking a self-defined "good outcome" for what the patient really wants, as well as avoiding confusion of true disagreements in values or intentions with "poor adherence."[14]

3.2 A Conceptual Model of Communication and Outcomes

The pathways linking the effects of communication with outcomes have not been explored in detail, but studies on communication in both cancer and noncancer settings suggest several common mediating pathways (Figure 3.1). By *mediation*, we refer to the steps between two components of a causal pathway that are necessary for proceeding from one level of the pathway to the next. *Proximal* and *interme-*

diate outcomes (Table 3.1) become mediators only when they are proved to be important steps along the pathway from communication to more distal outcomes. *Links*, indicated by the letters B through G in Figure 3.1, are components of larger pathways that start with communication and end with the most distal outcomes. Mediation may involve one, two, or many more steps, but the conceptual model shown here is simplified to illustrate two steps between a communication act and distal health and societal outcomes. Some pathways may terminate at proximal or intermediate outcomes when credible links can be found for initial steps B and C, but evidence is lacking for step D or F (Figure 3.1).

At the top of the conceptual model are patients' and families' health-related communication needs, which include the following:

- Development of a trusting relationship

- Access to disease-related information

- Response to their emotions

- Help with decision-making and management of uncertainty

- Being empowered and capable of self-care

Although some of these needs can be met without involving communication with clinicians (link G), we will focus on the needs that require some form of clinical communication, whether encounter-based, asynchronous, or otherwise.

Figure 3.1 Our conceptual model includes several mediating pathways that link the effects of communication with health outcomes. Links (B through G) are components of larger pathways that start with communication and end with the most distal outcome.
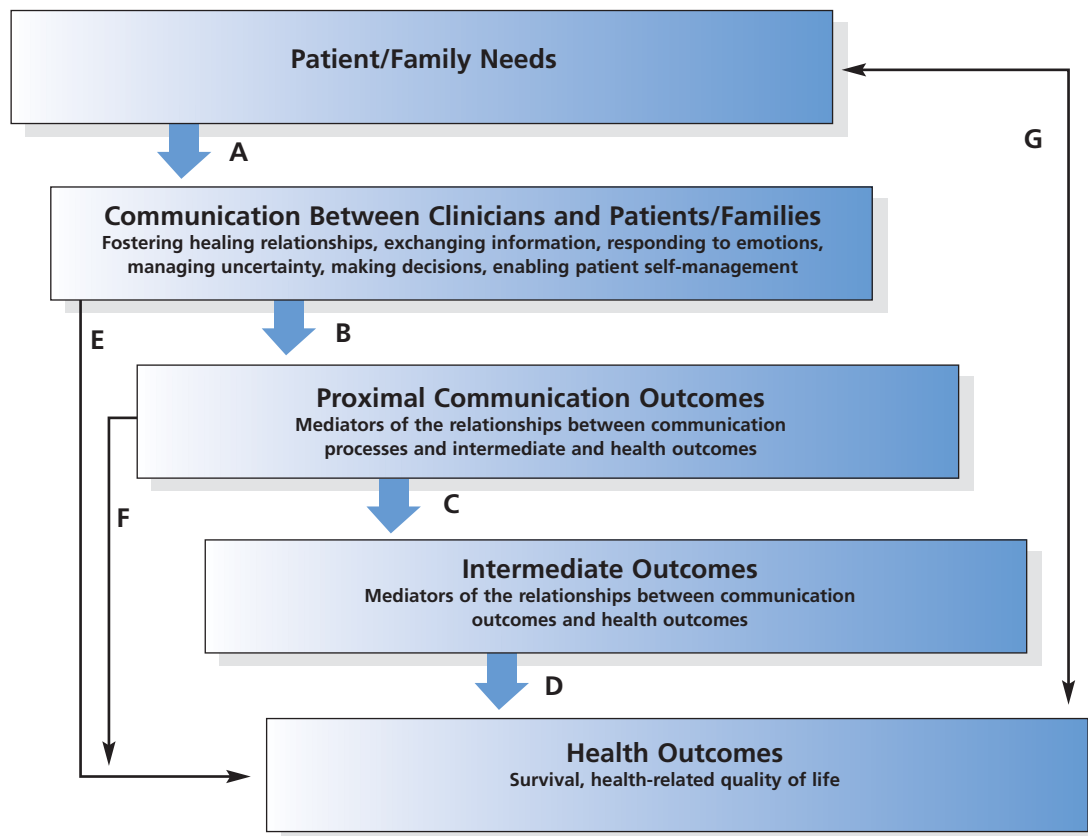
Link E suggests that sometimes communication can have a direct therapeutic effect on patients and families. For example, by providing information that a test result is normal, a clinician may directly reduce anxiety and thus contribute to improved HRQOL. In contrast, links B through F suggest that the pathway between communication and outcomes is mediated by a more complex series of steps. For example, a patient with breast cancer who is reluctant to take tamoxifen may first need to feel empowered to ask questions during a clinical consultation (a communication behavior). In response to the patient's questions, the clinician is more likely to provide information about the overall benefits compared with the risks in a way the patient understands. The clinician's provision of information leads to greater trust (a proximal outcome) and a greater willingness of the patient to follow through with recommended therapy (an intermediate outcome), which, in turn, may affect survival. However, development of the patient's trust in the clinician and the health care system may involve not only the provision of information but also other kinds of communication behaviors, such as empathy and asking for the patient's perspective.[15] Furthermore, the establishment of trust may facilitate future communication about different topics in different contexts; thus, the effects of communication are both recursive (link G, Figure 3.1) and cumulative across time.

The first set of mediators consists of proximal outcomes of communication, depicted by pathways that include link B (Figure 3.1). This step is explicit in the causal pathway because one should not assume that the performance of a communication task—the exchange

of information—will necessarily result in effective communication; that is, the patient becomes more knowledgeable. A patient may not gain knowledge or understanding of the illness if a clinician uses excessive jargon or if the patient forgets, misunderstands, or misinterprets the clinician's statements. Patients also vary in how they interpret emotional messages. A statement intended to convey empathy (e.g., "This must have been difficult for you.") may be comforting to one patient but be experienced as insincere or patronizing by another. The social, psychological, and demographic factors that influence the pathway between communication and proximal outcomes is discussed in greater detail when we describe moderators of the relationships between communication and outcomes.

The second set of mediators comprises at least seven pathways that form important steps between communication and health outcomes, providing improvements in the following:

- Access to care

- Patient knowledge and shared understanding

- Therapeutic alliances (i.e., patient and clinician commitment to the relationship)

- Emotional self-management

- Family/social support and advocacy

- Quality of medical decisions (e.g., informed, clinically sound, concordant with patient values, and mutually endorsed)

- Patient agency (self-efficacy, empowerment, and enablement)

These pathways link effective communication to improved quality of care, adherence, health habits, and self-care, which, in turn, can contribute to healing and reduced suffering.

We do not imply that these are the only mediators of these relationships. We propose these pathways as a conceptual starting point and will describe them in greater detail. It must be emphasized that the relationships between intermediate outcomes and health outcomes comprise a vast body of literature encompassing adherence, social support, and health services delivery. Moreover, the relationships between adherence, social support, and treatment outcomes are not straightforward. For example, adherence to ineffective therapy may have positive benefits such as lowered anxiety and symptoms, and lack of adherence to recommended therapy with serious side effects may involve value-driven tradeoffs between quality of life and survival. There is a large body of literature on social support and health, yet the mechanisms whereby social support confers improved well-being are poorly understood but likely involve neurohumoral, psychological, and instrumental factors.[16] Also, social support can affect adherence. We do not attempt to provide a survey of this literature, but it is important to mention these factors here in anticipation of a more detailed discussion later in this chapter. We also acknowledge that the pathways sometimes are bidirectional. For

example, information is a precondition for, as well as a consequence of, effective communication, and effective management of information may uncover additional information needs.

3.2.1 Improving access to care

Helping patients get the care they need is the first pathway by which communication can improve health. Access to care is poor for a large percentage of Americans, especially racial and ethnic minorities, individuals of lower socioeconomic status, and individuals with low health literacy.[17] Some aspects of poor access are due to lack of insurance and availability of services, but other aspects are remediable through patient education and patient navigation programs. Encouraging patients to report barriers to care, enabling patients to take the first steps in gaining access to health services, and facilitating collaboration among health professionals are three communication activities that can help patients get the care that they need. Hence, clinicians must not only communicate the need for a test, treatment, or referral; they must also help patients actually get such services. This pathway is accomplished primarily through links B, C, and D (Figure 3.1): link B suggests that informative communication helps patients understand the kind of care that is needed; link C connects this understanding to utilization of appropriate procedures and treatments; and link D connects utilization of appropriate services to improved health. However, as is the

case with providing emotional support, clinicians' instrumental help also may directly promote emotional well-being (link E) by reducing patients' distress resulting from worry and confusion as they move through a complex health care system.

Health care systems, hospitals, and clinics can facilitate patient-centered communication in cancer care by providing patients with navigation programs and other instrumental resources. Busy physicians may need social workers, navigators, interpretators, or other professionals to help patients learn about and gain access to needed health services. Given the complexity of different insurance plans and eligibility requirements for government-sponsored health plans, electronic resources (such as websites and automated telephone systems) that provide easy access to integrated and comprehensive information about these services would greatly assist clinicians in helping patients to get access to the care they need.

3.2.2 Improving patient knowledge and shared understanding

Contextualized disease-specific knowledge and shared understanding are precursors of many of the other pathways. Knowledge and shared understanding are essential ingredients of informed decisions,[18] enhancing patients' sense of control, facilitating adherence, and reducing anxiety. In order to be fully knowledgeable, patients and family members should have

timely access to information, the ability to recall it, and an understanding of the meaning of the information in the context of their particular illness, values and life circumstances. Knowledge can lead to shared understanding that builds patients' trust in their clinicians and enhances participation in clinical encounters.

However, clinicians, patients, and families see illness through the lenses of their particular health beliefs. The self-regulation theory by Leventhal and Carr[24] and the explanatory model theory by Kleinman[25] both suggest that patients have illness beliefs and models that are in part conditioned by their culture and prior experiences and, more currently, the Internet. These illness representations are often dynamic and complex, based on "common sense" rather than empirical research or scientific theory, and sometimes reflect a pseudoscientific aura. Nonetheless, they create a sense of threat and imply certain means for reducing that level of threat. Leventhal and Carr further suggest that patient decisions and actions that may seem irrational to clinicians actually may be attempts of the patient to reduce the threat of illness perceived on the basis of his or her own illness representations. These observations provide an explanation for why patients may take medications for hypertension only when they feel "tense"[26] or why patients who believe that surgery spreads cancer[27] may choose radiation or natural treatments. Clinicians also hold some of these

common-sense belief models when it comes to their own or their patients' health.[28] Clinicians often do not uncover these illness representations, and even when clinicians attempt to initiate discussion of these beliefs, patients may not have a coherent way of articulating them.

Thus, shared understanding depends on making sure relevant information is exchanged, evincing patients' and clinicians' illness representations, and, when the representations are in conflict, reconciling them. The mediating effect of shared understanding on the relationship of communication to outcomes, then, is due to knowledge and shared understanding, not simply the exchange and recall of information.

3.2.3 Enhancing therapeutic alliances

A dependable, trusting patient-clinician relationship is particularly important for patients with cancer because of the threat of the illness and the fear it evokes.[29,30] In cancer care, the patient and his or her family typically encounter physicians, nurses, technicians, and other health professionals from multiple disciplines, including radiology, primary care, medical oncology, and surgery. The therapeutic alliance includes the interrelationships among multiple health professionals, the patient, and members of the patient's family. Indicators of a strong therapeutic alliance include mutual trust as well as the patient's perception of

feeling respected and supported emotionally. These alliances are "therapeutic" because the quality of the patient-clinician-family relationships affects health outcomes in two respects. First, a direct link (E in Figure 3.1) suggests that a strong relationship can lead to reduced suffering and increased healing by decreasing anxiety and promoting the patient's sense of feeling known and understood.[31,32] Second, an indirect link suggests that communication that establishes and reinforces a strong therapeutic alliance leads to continuity of care, patient satisfaction, and commitment to treatment plans that can reduce rates of morbidity and mortality (links B, C, and D).

Although we will discuss moderators later, two are worth noting here. First, social distance is an important moderator of the effectiveness of the therapeutic alliance. Patients appreciate clinicians who can understand and have empathy with their life circumstances. This fact may provide an explanation about why some patients are more satisfied in race-concordant relationships.[33] Length of relationship is also a moderator of the therapeutic alliance. Patients tend to choose to remain with physicians whom they trust and tend to seek a different physician when trust is lacking.[34]

3.2.4 Enhancing patients' ability to manage emotions

Patients with cancer and their families often experience a plethora of terrifying emotions as they face the potential for death and suffering

and the fear that help may not be available.[35] Clinicians can help patients manage these emotions in several ways, all depicted by pathways B through E (Figure 3.1). First, when a clinician provides disease-specific information and helps the patient understand the health care system, the patient may experience a greater sense of control, hopefulness, and/or peace.[36] Validating patients' emotional experiences and encouraging them to express these emotions have been linked to lower levels of anxiety and depression.[37-40] Communication that enhances patients' self-confidence, sense of worth, and hope may confer meaning, motivation, and energy needed to pursue work or leisure activities and allow them to enjoy greater quality of life despite the cancer and its treatment. Although patients' emotional distress can originate from many nonclinical sources (e.g., living alone), poor communication with their clinicians can compound this distress.[41] Thus, patient-clinician communication can promote emotional well-being directly or through enhancing the patient's ability to cope with stress, uncertainty, and unexpected setbacks outside of the consultation setting.

3.2.5 Improving family/social support and advocacy

Social support can have a major impact on physical health[16] and quality of life[42] and may improve survival among patients with cancer.[43-47] Social support likely improves health outcomes through several mechanisms (Figure 3.2).[16]

First, social support can reduce physiological arousal, in turn, reducing morbidity and, perhaps, mortality through the hypothalamic-pituitary axis and immunomodulators.[16,48,49] By enhancing a sense of connectedness and providing opportunities to process, share, or discuss difficult situations confronting the patient, family, and friends can help the patient with emotional self-management, which may result in lower levels of anxiety and arousal and associated neurohumoral changes. Second, family and social networks can provide instrumental help, encouragement, and advocacy in gaining access to and effectively utilizing health services and financial resources to accomplish health-related goals. Family members and friends can provide direct (when they are present with the clinician) or indirect (when they suggest topics for the patient to discuss) input into clinical conversations to facilitate communication between clinicians and patients.[50,51]

Third, family and social support networks can enhance patients' efforts for achieving self-care, such as getting information about the illness that can be used as a basis for decision-making, quitting smoking, or adhering to treatment. Sometimes families and friends provide help actively and explicitly, and sometimes their effect is indirect and tacit and is achieved by setting implicit norms for social behavior. All of these pathways may increase self-esteem and reduce feelings of depression for the patient. Few studies have been

designed to simultaneously examine these multiple mechanisms of social support, to explore which aspects are linked to specific health outcomes, and to understand which features are more important in different settings;[42] rather, studies have tended to be designed to examine individual aspects of social support (information[52] or emotional[53,54]) or to create global[55] or aggregate scores.[56-58]

Patient-clinician communication can contribute to improved health through the social support pathway in several ways. First, patient-clinician communication itself is a form of social support that decreases social isolation and provides encouragement and facilitation. Health care facilities can significantly help patients take advantage of social support resources by providing access to social workers, family therapists, and support groups. Second, clinicians and patients can discuss ways of reinforcing patients' social environments and the resources available within these networks (e.g., transportation, emotional support). Third, because cancer survivors with close supportive relationships often adjust better to the disease, clinicians can help direct patients to support groups and other resources, especially when a patient's networks have failed to provide needed support.[59] Face-to-face support groups are inconvenient for many cancer survivors because of the time needed to travel, physical incapacity, or scheduling conflicts, and health care facilities can help overcome these barriers by directing patients to online support groups, which have much greater reach and often produce benefits that are comparable to those of face-to-face groups.[60] Lastly, because some forms of social support may be "negative" (promoting unhealthy behaviors such as smoking or well-intentioned nagging that creates more stress),[61] clinicians can discuss with patients the nature of negative support and ways to manage these problems or can even

Figure 3.2 Several clinician communication behaviors can enhance social support, which improves health outcomes through several mechanisms.
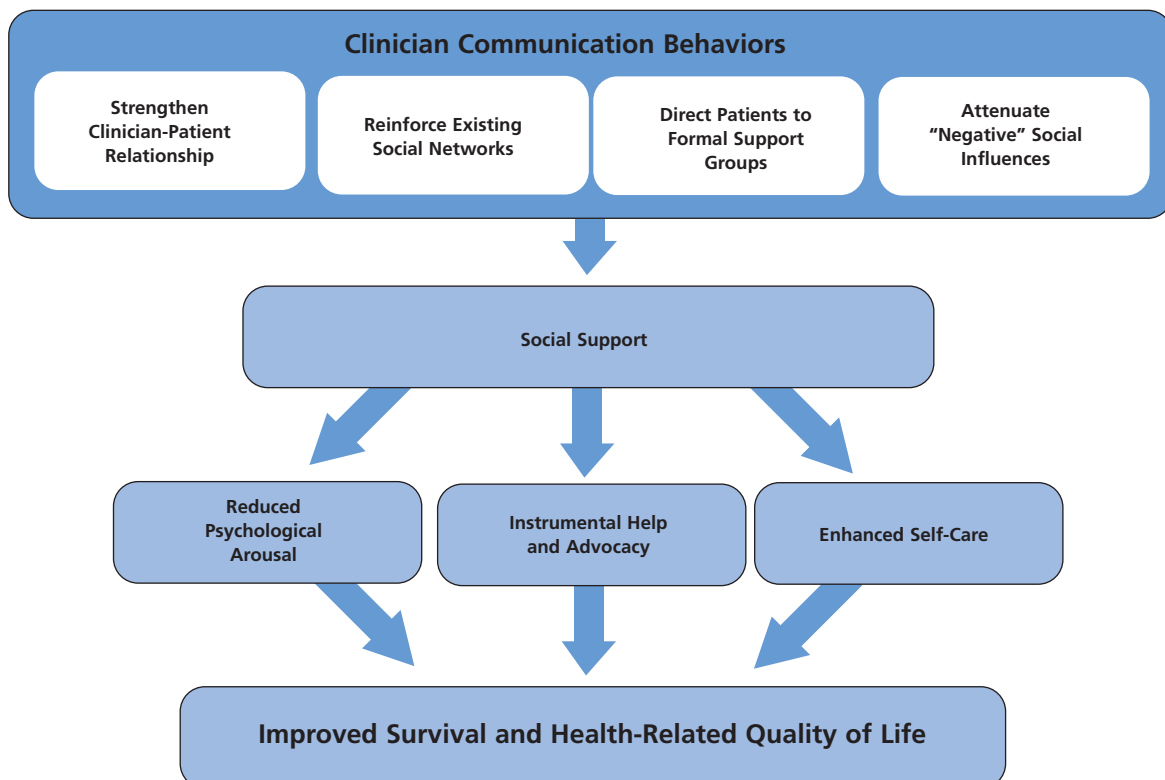
talk directly to family members about how best to support a patient's needs.

3.2.6 Improving the quality of medical decisions

Patient-clinician communication also can improve health to the extent that it leads to the best possible medical decision for the patient. High-quality decisions are characterized by communication that achieves the following:[62-64]

- Elicits the patient's needs

- Presents relevant clinical evidence in a way that the patient understands

- Effectively addresses the emotional aspects of decision-making

- Aligns clinician and patient perspectives so that the decision reached is concordant with the patient's values and with clinical evidence (link B in Figure 3.1)

High-quality decisions ideally improve both survival and multiple dimensions of quality of life.[65]

The path to high-quality decisions is not always straightforward. First, decision-making is difficult when a patient's wishes are unclear or ambivalent, such as when a patient with recurrent cancer wishes to decline additional chemotherapy that has limited effectiveness but does not want to "give up." Second, experts may give conflicting recommendations, forcing patients to choose among different sources of authority. This situation is fre-

quently encountered in the setting of prostate cancer treatment, with urologists favoring surgery and radiation oncologists favoring radiation therapy. Third, the quality of decision-making may be compromised when a patient's decision preferences are in response to "common sense" notions about disease causation[24] and not based on scientific understanding. Patients may choose less effective herbal treatments rather than chemotherapy, for example, because they are "natural."[66] Fourth, difficulties arise when clinicians try to communicate risk,[67-69] as many patients have difficulty understanding numerical presentations of risks and benefits. A lack of understanding may lead patients to make choices that are unlikely to help them achieve their goals. Use of graphical displays can augment clinicians' efforts to explain and understand risk; one especially helpful graphic is the 100-person diagram, in which the proportion of positive and negative results is displayed in the form of stick figures of different colors or faces with happy or sad expressions. These tools improve patient understanding and their ability to use data to guide their choices.[70-73]

Measurable indicators of better medical decisions include the following:

- Consensus on treatment

- Clinician and patient/family satisfaction with their respective involvement in the decision-making process

- Concordance of the decision with the patient's values

- Adherence to evidence-based guidelines

- Feasibility of implementing the decision, given the available resources and the patient's means and capabilities

Patient-centered communication can produce a decision that meets these criteria, but the ultimate outcome of the decision will be moderated by a number of variables, including unanticipated clinical developments, such as drug intolerances; availability of treatments in the patient's home town; insurance coverage; and members within the patient's social network, who may or may not approve of a particular treatment. Little is understood about the role of regret and risk-taking in decision-making, but both are likely to influence choices.

3.2.7 Enhancing patient empowerment and agency

Patient-clinician communication also can improve health by empowering patients to be active, capable agents in managing their health. *Agency* is a psychological construct that describes the ability to work within one's environment to do things on one's own behalf. Agency incorporates motivation, self-efficacy, empowerment, and enablement (Table 3.3) and is a precondition for behavior change, adherence to long-term outpatient treatments, and self-care. The sense of control that patients with cancer feel has been linked to emotional well-being and coping during survivorship.[74,75] In chronic diseases, such as diabetes,[76] self-

management strategies have led to better control of outcomes, improved functioning, and, in some cases, reduced health care costs. Admittedly, some patients are overwhelmed with their disease or other life circumstances that limit their ability to self-manage. In such cases, social support interventions beyond those offered by the patient-clinician relationship may be necessary to develop or restore more effective coping and problem-solving strategies.

O'Hair et al. describe a three-stage process through which communication can enhance patients' sense of agency.[77] At the first stage, patients are confronted with uncertainty as they try to find their paths through unfamiliar and often terrifying circumstances. By managing uncertainty, the problems acquire a structure; they appear manageable rather than chaotic and random. The second stage involves empowerment, which requires advocacy on the part of others (clinicians, family members, support groups, etc.), as well as patients finding and having a voice in the clinical environment, whether that involves seeking information, participating in decisions, or simply expressing feelings. The third stage, agency, involves action, self-determination,[78] self-efficacy in managing one's health,[79] enablement,[80-82] a sense of control, and assertion of one's perspective in both clinical and nonclinical settings.[83] Patients and families who are enabled have the ability to solve problems and cope with health-related complications and to seek and interpret health-related information. They also have the ability and volition to follow through with appropriate treatment recommendations.

Clinicians can help patients acquire agency through many of the components of patient-centered communication, including the following:

- Supporting patient autonomy[84,85]

- Building partnerships[83]

- Managing uncertainty[86]

- Facilitating information exchange

- Providing access to educational and problem-solving resources

- Assisting with effective navigation of the health care system

The Internet is a potential resource for self-care, as it provides access to decision-support tools, information, chat rooms, and other forms of assistance that can enhance (but occasionally complicate) patients' ability to solve problems.[60,87]

3.3 Moderating Factors Affecting Communication Processes and the Relationship of Communication Process to Outcomes

Our model (Figure 3.1) highlights the main effects of communication on proximal, intermediate, and distal health outcomes, as well as the pathways through which communication achieves these outcomes. However, we recognize that the experiences of patients and their families over the course of the cancer care continuum are both dynamic and complex. Hence, any number of variables may moderate relationships between communication and various outcomes.

A moderator is a qualitative or quantitative variable that affects the direction or strength of the relationship between an independent variable and a dependent variable.[88] Moderators themselves may or may not have independent effects on the dependent variable. A variable is considered to be a moderator when its interaction with a main independent variable can predict the outcome variable. For example, if a patient who has considerable trust in his or her clinician was not as anxious as a less trusting patient when the clinician expressed reassurance about a favorable prognosis, then the rela-

Table 3.3 Agency	
Agency	Ability to work within one's environment to do things on one's own behalf
Motivation	Willingness to work toward a goal
Self-efficacy	Belief that one can accomplish a particular goal
Empowerment	Permission and encouragement to accomplish a personal goal
Enablement	Possessing the skills, tools, and abilities to accomplish a goal

tionship between reassurance and lower anxiety would have been moderated by trust. Although in this context trust is considered to be a moderator, in other contexts trust may be a mediator or an intermediate outcome.

We have noted that the research on communication and outcomes in cancer settings is limited, and even fewer studies have been conducted on moderators of these relationships. Moreover, much of the research has been superficial at best, focusing most often on individual differences among clinicians and patients rather than on theoretical reasons explaining *why* these individual differences have a moderating effect. As a case in point, suppose an investigation found that the relationship between a clinician's advice and the patient's subsequent commitment to chemotherapy was moderated by whether the clinician and patient were of the same race. Although racial concordance moderated the effect of communication on adherence in this study, it is not clear why. The patient may have perceived a clinician of the same race to be more trustworthy or empathic and/or similar with regard to language use; each of these factors could account for the moderating influence of racial concordance. Importantly, one could easily identify other variables that may render racial concordance insignificant,[89] such as the duration of the patient-clinician relationship, similarity in age or religion, or clinician skill at finding common ground with the patient.

Moderators rarely operate in isolation of other moderators, although researchers typically focus on only one or two. Many studies have been conducted to evaluate the influence of gender on patient-clinician communication and outcomes in the noncancer setting, and the findings have indicated that female clinicians and their female patients talk about psychosocial topics more often than male clinicians and their male patients.[90,91] One might infer from this finding that patient-clinician communication about emotional well-being and social functioning may lead to better outcomes for women than for men, but other moderators may be equally or more influential, such as the stage of the cancer, the type of cancer, the patient's age, the patient's social support, the degree of patient-clinician familiarity, the type of clinician (nurse, oncologist, family physician), the clinician's age, and/or the patient's personality.

An important challenge for researchers is to uncover the cognitive, emotional, and behavioral processes accounting for the effects of variables moderating the relationship between communication and outcomes, as well as to identify the reasons some moderators are more important than others in certain contexts. Demographic information is easy to acquire, and its moderating influences are easy to analyze. In the absence of other measures, however, researchers often resort to speculation to explain the influence of demographic moderators. To make significant progress in understanding

how patient-centered communication can promote healing and reduce suffering from cancer, researchers must have empirical evidence and theoretical explanations for the variables that moderate the relationship between communication and outcomes.

Within the context of our model, moderators operate at multiple levels, influencing the link between communication and its antecedents, as well as the relationships between communication and proximal, intermediate, and distal (health) outcomes. Although a comprehensive review of potential moderators of patient-centered communication in cancer care is beyond the scope of this chapter (see Appendices A through D for more detailed reviews), we provide an overview of some of these variables, particularly those that we see as particularly important and in need of further study.

We place moderators along two dimensions (Figure 3.3), with one dimension related to the degree to which the factor is intrinsic or extrinsic to clinicians, patients, and their relationship, and the other related to the degree to which the factor is mutable. Intrinsic moderators (Table 3.4) are characteristics of individuals and relationships that either directly or implicitly tap into affective and cognitive processes (Table 3.4). These moderators include the patient's emotional state, health literacy, perceived threat of illness, knowledge about the illness, goals, motivation, and self-efficacy, as well as corresponding clinician factors.

Figure 3.3 In a two-dimensional model of moderation of the communication-outcome relationships in cancer, moderators along one dimension are related to the degree to which the factor is intrinsic or extrinsic to clinicians, patients, and their relationship. The other dimension represents the degree to which the moderator is mutable.

Intrinsic*

Stable		Mutable
Age Race Gender Personality	Health Literacy Self-Efficacy Perceived Risk	
Education Primary Language	Emotional Disorder	
	Clinician Attitudes Self-Awareness	
Family Structure Income	Social Distance Illness Representations	
Cultural Values	Family Functioning Social Support Network	
Type of Cancer Regulatory Factors	Access to Care Media Coverage Stage of Cancer	

Extrinsic

*Intrinsic to clinicians, patients, and other relationships

Extrinsic moderators include disease factors (e.g., type of cancer, prognosis, and stage of disease), the family and social environment, cultural values and beliefs, the health care system, and economic factors. The stable-mutable dimension reflects the degree to which the moderator is susceptible to change. Understanding which factors are changeable and which are not is crucial in cancer care because interventions can be targeted to modifiable factors to increase the likelihood that communication will accomplish desired outcomes. Factors that are more stable (i.e., less modifiable) impose constraints or opportunities that must be taken into account.

For example, health literacy (discussed later) is apt to be an important moderator of the relationship between patient involvement in decision-making and adherence to treatment. Patients who have a better understanding of the disease, their options for treatment, and the risks and benefits of different treatments will probably participate more effectively in the decision-making process. Because health literacy is to some degree mutable, clinicians providing patient education interventions prior to decision-making[92] can optimize the patient's capacity to participate effectively. This enhanced participation could lead to a greater likelihood of completing treatment and thus, longer survival.

The importance of identifying mutable moderators of communication-outcome relationships points to the shortcomings of focusing solely on demographic factors as moderators. Demographic variables are, for the most part, stable. Yet

Table 3.4 Moderators of Relationship between Patient/Family Needs, Communication, and Outcomes

Factors intrinsic to the clinician-patient/family relationship

- Predominantly traits
  - Demographics: age, gender, race, ethnicity (and concordance)
  - Traits: personality, tolerance of uncertainty, risk aversion, attachment style
  - Primary language, English fluency
  - Education, health literacy, communication skills training
  - Cognitive deficits, ability to understand
  - Communication style
    - Linguistic and paralinguistic style (e.g., directness, passivity, eye contact)
    - Adaptability of communication style to different situations
  - Attitudes: general health beliefs, patient-centered orientation
  - Self-awareness
    - Ability to self-monitor
    - Ability to repair miscommunication
- Predominantly states
  - Knowledge about the illness and treatment
  - Attitudes: stereotyping, expectations, health beliefs, perceived threat of illness
  - Well-being
  - Emotional states: anxiety, emotional distress
  - Motivation, self-efficacy

Relationship factors: Patients, multiple clinicians, and family members

- Mutual influence and accommodation
- Family structure and functioning
- Mutual knowledge, duration of relationship, trust

Contextual factors affecting clinician-patient/family communications

- Disease-related factors
  - Type of cancer
  - Stage of disease
  - Comorbid conditions
  - Overall health status
- Social factors
  - Social support
  - Prejudice and bias based on race, ethnicity, social class, or other factors
- Cultural factors
  - Cultural beliefs, values, and expectations
  - Adaptation and assimilation
- Communication media
  - Use of electronic communication
  - Access to and use of the Internet
  - Media coverage of health topics
- Health care delivery factors
  - Environment (noise, privacy)
  - Organization (scheduling, etc.)
  - Access to multidisciplinary teams, hospice, navigation programs, and clinical trial protocols
- Societal factors
  - Access to care, transportation, insurance
  - Legal andregulatory factors (informed consent, disclosure of private information, assisted suicide)
  - Eligibility for specific health services (palliative care)

the reasons they are moderators are often due to potentially mutable factors. Consider, for example, the common research finding that older patients prefer to be less involved in decision-making than younger patients.[93-97] It is unclear whether the relationship between age and preferences for involvement is due to expectations based on previous experience (a modifiable factor), traditional beliefs about control in the patient-clinician relationship (a potentially modifiable factor), or cognitive impairment (a stable factor). It would be important to discover the reason for an older patient's preferences in order to determine whether the clinician should take control of decision-making (if the preference was firmly held) or offer the patient an educational intervention that, in addition to providing information about treatment options, legitimized the patient's involvement and encouraged the patient to par-

ticipate to the degree he or she wished.[92] Moreover, many older patients do want to be involved in exchanging information and deliberating (see Section 2.5 of Chapter 2), even if they prefer that the clinician makes the final decision.[98]

3.3.1 Intrinsic moderators of patient-clinician communication and outcomes

It is beyond the scope of this chapter to provide a comprehensive review of potential moderators of the effect of communication on outcomes. However, we discuss here four intrinsic moderators that are particularly important in cancer care and that are, to varying degrees, modifiable: health literacy, social distance, clinician attitudes toward different patients, and patient preferences for clinician and patient roles in cancer care. We emphasize that these moderators serve as examples from a longer list of modifiers and that these moderators overlap considerably in certain contexts.

Health literacy
Health literacy refers to a person's capacity to obtain, process, and communicate information about health.[99] Health literacy is an important moderator of relationships between communication and outcomes because it affects patients' ability to understand clinical and health-related information.[100] Low health literacy also may restrict a patient's ability to be an active participant in medical consultations because of limited familiarity with health-related terms[83,92,100] and the embarrassment of limited under-

standing.[101] Hence, several of the pathways linking communication to improved outcomes, such as improved patient knowledge and shared understanding, better medical decisions, and enhanced patient agency, may be less effective for patients with low literacy.

The communication challenges facing people with limited health literacy may account for some of the disparities related to race,[102] access to care,[103] and poorer health outcomes among individuals with chronic disease, such as diabetes.[104-106] Moreover, low literacy is associated with lower rates of cancer screening and utilization of health care services.[107,108] Interestingly, Lindau and colleagues[109] found that patient adherence to attending a follow-up visit for abnormal findings on Pap smears was not related to objective assessments of health literacy but was related to physicians' *perceptions* of low health literacy. These findings suggest that communication-related factors (e.g, patient participation, clinician attitudes toward patients) may play an important role in how literacy and related perceptions interact in consultations. Health care facilities can help address barriers related to low literacy by providing patients with educational resources specifically developed for low-literacy populations. Health literacy may relate not only to low educational level but also to culturally reinforced health beliefs. Thus, in addition to including easy-to-understand language, educational interventions also should be culturally appropriate.[110,111]
Although we consider health liter-

acy a mutable moderator, some patients' beliefs may be harder to change, especially those related to long-held illness representations (e.g., "Surgery to remove cancer makes it spread throughout the body.") and mistrust of the health care system (e.g.,"The medical industry is withholding cancer cures for profit.").[27]

Social distance
Although social distance has been conceptualized in a number of different ways, for our purposes it refers to the number and importance of dissimilarities between clinicians and patients. Social distance may be a perception or be based on objective indicators, and the two may or may not correlate. For example, a clinician and patient from different cultural backgrounds may have very real differences in their respective illness representations, primary language, beliefs about personal control over disease, and treatment goals.[112] These differences can create communication problems and may account for situations in which clinicians have difficulty understanding the life circumstances of patients who have cultural and educational differences. On the other hand, differences in race, gender, and cultural background may not translate automatically into perceived social distance. A black female patient with children may find that she has much more in common with a white female clinician of the same age who also has children than with a much younger, single black male clinician.

Social distance is an important moderator of the relationship

between communication and outcomes for several reasons. First, patient-clinician differences in illness representations, use of language, and health-related values create greater risks for misunderstanding or bias (discussed later) that could lead to situations in which patients' needs are not understood and for false assumptions about their values, needs, and capabilities.[113,114] In these situations, communication related to information exchange and decision-making may not involve the patient understanding and shared knowledge pathway to immediate outcomes (knowledge, satisfaction with care) or intermediate outcomes (adherence, high-quality decisions).

Second, social distance can make it difficult to establish effective patient-clinician relationships. Patients appreciate clinicians who can understand and have empathy with their life circumstance[115] and provide them with a sense of being known.[32] Clinician communication intended to enhance the relationship, such as expressions of empathy and shared understanding, may not be as effective in building the therapeutic alliance if the patient does not perceive the communication as sincere or believes the clinician is not capable of empathic understanding. In these situations, the clinician may be less able to comfort the patient and ease his or her distress.

Third, although objective markers of social distance may be difficult to change, perceived social distance is mutable, especially with the effective and sincere use of

patient-centered behaviors (see Table 1.1 in Chapter 1). For example, through nonverbal signals of attentiveness, avoidance of interruption, and questions about the patient's beliefs and values, clinicians communicate concern and an interest in the patient as a person. In turn, when patients share their beliefs, values, and preferences, they are sharing information that provides opportunities for the clinician to understand the patient better and for both parties to discover common ground. The power of effective communication in decreasing perceived social distance is suggested in studies that have shown that patient trust increases during the consultation when clinicians are perceived as more informative, caring, and interested in the patient's views.[15] An increase in trust, in turn, leads to more continuity in the patient-clinician relationship in that patients choose to remain with physicians whom they trust.[34]

Clinicians' attitudes toward patients

Although most clinicians are not deliberately biased in their views about different kinds of patients (according to race, sex, or age), they may have subconscious attitudes that influence how they perceive and communicate with patients.[116] Multiple factors, including power and social roles, lead to unconscious stereotypes and biases that affect clinicians' interpretations of patients' capabilities, character, and symptoms.[114,117] These interpretations, in turn, influence clinician communication, such as following up on the concerns of

some patients but not others, the detail with which clinicians provide explanations about disease and treatment, and the degree to which they offer encouragement and support. Although many of these attitudes may relate to social distance, other factors, such as personality, likeability, and interactional style clearly have a role.

Clinicians' attitudes toward patients may affect the degree to which communication accomplishes desired outcomes in several ways. First, stereotypic attitudes toward patients are overly simplistic. For example, a clinician who assumes a patient is not capable of understanding complex information (an assumption that may be based on the demographic characteristics of the patient) may automatically conduct the consultation in a more controlling manner, especially if pressed for time. Very little of the communication would be patient-centered, thus limiting the potential of activating various pathways toward better outcomes. In addition, many biases are associated with negative perceptions of patients, and thus less likeability. The degree to which clinicians like their patients has been associated with greater patient and clinician satisfaction with their encounter.[118] Negative attitudes about patients may be revealed subtly in nonverbal behavior, such as vocal tone and body orientation.[119] Such nonverbal behavior diminishes the value and sincerity of verbal behaviors that otherwise might be considered patient-centered, such as building partnerships and sharing information.

Moreover, clinicians' attitudes toward patients also may bias their medical judgments, and in such circumstances, there is a greater need for patients to communicate effectively. In one study using hypothetical patients,[9] researchers found that physicians recommended more intensive cancer diagnostic procedures for a white woman regardless of her communication behavior but recommended the same procedures for a black woman only when she was assertive in asking about the tests in the scenario. Clinicians' negative attitude toward certain types of patients may be the reason for the higher number of black patients and poor patients who report that a positive self-presentation is important in getting good medical care compared with white patients and patients of higher socioeconomic status.[120] As a consequence, patients who are socially disadvantaged and are less inclined to assert themselves in clinical situations bear a greater burden for achieving effective communication than do their more socially privileged counterparts.[74,121]

Studies using vignettes often demonstrate evidence of clinician bias. However, several studies of actual consultations have shown that clinicians' communication with and perceptions of patients are more a function of patient participation than demographic attributes, although the latter may have some effect.[122,123] This finding suggests the need for health care facilities to develop educational resources that facilitate active patient participation. Also, inter-

ventions aimed at enhancing clinician self-awareness and cultural competence may help to alleviate unintended consequences of clinicians' attitudes toward patients.

Patients' preferences for clinician and patient roles
Patients have expectations for their own role and the clinician's role in cancer care, especially with regard to what issues are discussed and who has control over decision-making. Patient preferences may be an important moderator of communication-outcome relationships in several respects. First, a substantial number of patients with cancer do not achieve their desired level of participation in the decision-making process,[95,124] which, in turn, can lower satisfaction with care and increase decisional regret and anxiety.[125,126] Thus, a clinician's well-intentioned but mismatched communication behavior, such as partnership building with a patient who prefers clinician control of decisions or assuming decisional control for a patient who wants to be involved in decision-making, may interfere with pathways to better outcomes, such as high-quality decisions, the patient's ability to manage emotions, and a strong therapeutic alliance.

Patients vary with regard to their expectations for clinician and patient roles, a finding often associated with demographic variables. For example, older and less educated patients are more likely to prefer paternalistic decision-making models, whereas younger and more educated patients desire active and collaborative roles.[93-97]

Some evidence indicates that women prefer explicit emotional support from clinicians, whereas men need emotional support but may depend on information for such purposes rather than discussing their feelings directly[127,128]

Patients' preferences are somewhat mutable, as they may change depending on the nature of the illness, the relationship with the clinician, and psychological distress; preferences also may change over the course of consultations. For example, when a patient is sicker or more distressed, he or she may prefer to relinquish decisional control to the clinician.[95,129] Also, patient preferences may change during a single consultation. In one study, patients' perceived role in the consultation—not their preferred role, was the stronger predictor of evaluations of care.[130] Patients who reported a shared role with their physicians were more satisfied and evaluated their physicians' communication more favorably than did patients who perceived that their actual role matched their previously stated role preference. However, preferred-perceived role match was associated with less anxiety following the consultation.[130]

In summary, patient preferences for their own communication as well as that of their clinician vary and can moderate the effectiveness of different patterns of communication for achieving pathways toward better outcomes. Because clinicians are not particularly good judges of patient preferences[131,132] and because patients and clinicians

often do not perceive the decision-making process in the same way (e.g., shared versus clinician control),[97] clinicians should directly assess patient preferences before or early in the consultation. Early assessment will help the clinician to determine how to manage communication over time, to either accommodate the patient's preferences or to discuss these expectations explicitly in order to align clinician and patient perspectives.

3.3.2 Context as an important source of extrinsic moderators

An ecological model of communication suggests that all communication, including the patient-clinician interaction, is situated; i.e., it occurs within multiple layers of context. By context, we are referring to aspects of the disease and the environment that can shape patient-clinician communication but that are external to the patient-clinician relationship (Table 3.4).[133] The same communication tasks, behaviors, and principles may be associated with different outcomes depending on the context in which they occur. Unfortunately, the role of context in clinical encounters has not been addressed in most research on patient-clinician communication. Context is an important component of our model of patient-centered communication in cancer care because it is a source of numerous extrinsic moderators that will influence communication processes and outcomes.

Several contextual elements have the potential to influence health

care, but six require further consideration in cancer contexts:

- Disease-related factors
- Family and social environment
- Cultural context
- Media environment
- Health care system
- Societal factors

Disease-related factors
The type of cancer, stage of disease and phase along the cancer care continuum all influence the types of relevant communication processes and outcomes. Some types of cancer, such as basal cell skin cancers, are little more than a nuisance, whereas others are nearly always fatal. Some cancers involve multiple treatment options, which depend on a complex interplay of disease stage, patient characteristics, and patient preferences. Fewer treatment options are available for other cancers.

Long-term prognosis and uncertainty also differ among cancers. For some cancers, a lack of evidence of recurrence after two years nearly guarantees a cure; other cancers may appear to be eradicated but recur many years later. Still other cancers have strong genetic components, and family members are likely to be affected even if cure is achieved in the index patient. Thus, we cannot assume that the findings of studies of women with breast cancer can be applied to women with lung cancer or leukemia. Chapter 4 includes a detailed discussion of how the goals of communication, the rele-

vant outcomes, and the communication processes that can achieve those outcomes differ at each phase of the cancer care continuum.

Family and social environment
The patient's social environment—consisting of extended family, friends, and coworkers—can both mediate and moderate the relationship between patient-clinician communication and outcomes. Patients who have social networks that provide disease-related information, emotional support, and/or help with household tasks and transportation to medical appointments typically report better mental health and optimism than do patients lacking such social support.[134,135] Social networks also can either reinforce or undermine the decisions reached by a clinician and patient and thus affect adherence and health outcomes. Lack of social support in the form of family criticism is associated with a higher frequency of visits in primary care settings,[136] and the same may hold true for patients with cancer. When family members are present in clinical encounters, family-related factors can also moderate the relationship between communication and outcomes.[15,51] Family members can facilitate the interaction (e.g., help patients acquire and understand clinical information) or impede the interaction (e.g., interrupt the patient to interject their own agenda); in addition, an increased number of participants can complicate the interaction.

Clinicians must conceptualize cancer care as a family issue regardless

of whether family members are present in the consulting room because family members are often consulted by patients before medical visits; visit hospitalized patients and discuss their care; and are the primary caregivers for patients with cancer, offering both instrumental help and emotional support. In addition, family members themselves can be profoundly affected by the patient's cancer; they frequently experience closeness and/or burnout from caregiving.[137,138] Two levels of family input must be considered in improving clinical communication: how to manage office visits or hospital stays when the patient is accompanied by family and how to seek and incorporate family members' perspectives when they are not present. A body of literature addresses the impact of cancer on family members, but very little of it directly pertains to the quality and style of communication.

Cultural context
The cultural context of cancer care is important because of the various ways it can affect patient and clinician communication styles, the interpretation of messages, and subsequent outcomes. Although we have discussed some of these issues as they relate to intrinsic moderators, we consider cultural context to be a source of extrinsic moderators because cultural beliefs, values, and practices extend beyond individuals and characterize larger segments of the population. Perhaps most obvious is that clinicians and patients from different ethnic backgrounds often

speak different languages and dialects, which creates significant barriers to effective communication.[139,140] Even if there are excellent interpreters or if the clinician and patient speak the same language, preferred styles of communicating may vary across different cultural groups, particularly with respect to assertiveness and expressiveness. People from collectivist cultures (e.g., Asians) often have communicative styles characterized by indirectness, respect for authority, and accommodation to others;[141] as a result, they may have more difficulty than patients from Western cultures in being assertive and expressive when communicating with clinicians.[141,142] Western clinicians may interpret this as passivity or agreement.

How messages are interpreted is shaped by culture. "Hearing voices" might be considered to be a sign of insanity by Anglos but interpreted as a religious experience by Mexican Americans.[143] In brief, culture is a complex feature of context. Cultural beliefs about the cause of an illness, personal control over health, and the best way to manage health problems mediate what clinicians and patient talk about, how they talk about these topics, how they interpret one another's communication, and the outcomes resulting from these encounters.[25,142,144]

Media environment
The media environment affects patient-clinician communication processes and outcomes in several respects. Media coverage of a health issue can influence

patients' beliefs and expectations, especially when the media reaches a large audience and addresses a salient issue. This affect was demonstrated dramatically in an Italian study[145] about a widespread media campaign promoting Di Bella therapy, an unproved cancer treatment, which substantially increased expectations and hope among patients with cancer. These hopes were shattered once the treatment was publicly shown to be ineffective.

Pharmaceutical companies use mass media for direct-to-consumer-advertising to prompt patients to ask physicians, physician assistants, and nurse practitioners for these products—a strategy that appears to be successful.[146] Also, the media environment, and the Internet in particular, offer extensive information resources for patients with cancer and their families. On the one hand, patients may benefit from this information by better understanding their conditions and treatment expectations and participating more effectively in medical interactions.[60,87] On the other hand, much of this information may be scientifically suspect and patients often may be overwhelmed with the sheer amount of information available. Changes in ways of accessing information have had a major influence on the dynamics of patient-clinician interactions. No longer are patients only providing information about their symptoms and illness experiences, they are also engaging in a bidirectional exchange of disease-related information, often consulting the Internet prior to the initial meeting with an oncologist.[87]

Health care system

Cancer communication also depends on physical and procedural characteristics of the health care system, which can include ambient noise, privacy issues, and the challenge of navigating a complex health care system. Facilities offering an effective "team" approach may provide care that is coordinated and features good communication among multidisciplinary team members. Such facilities also may offer informational and social support resources to clinicians and patients in person, through shared electronic patient records as well as the Internet. In contrast, loosely integrated care may require that patients use medical services at multiple facilities. Even simple changes in organizational procedures, such as longer scheduled visits, can have a significant effect on patient-clinician communication to the extent they constrain or facilitate patient involvement in the decision-making process. Longer visits are characterized by greater patient participation, and patients control proportionally more of the conversational floor.[147,148] In short, health care systems should take into account the degree to which their organizational procedures affect the quality of patient-clinician communication, especially since problematic patient-clinician communication may lead to poorer outcomes, unnecessary tests, more readmissions, and higher costs.[7]

Societal factors

Although the subject of little research, societal factors, including the regulatory and legal environment, can have a significant effect on patient-clinician communication. Societal norms and legislation affect eligibility for health services, transportation to medical appointments, and payment for prescription medications. Requirements for the informed consent process and disclosure of information provide legal safeguards that are intended to protect patients from abusive or negligent medical care. The requirements help ensure that clinicians are providing legally appropriate care and alert patients to their eligibility for services, such as hospice care. However, the volume of paperwork that must be reviewed and signed often imposes inconveniences that take up valuable time and could detract from clinician and patient goals for the encounter. In addition, a clinician's direct or indirect experience with malpractice claims could influence his or her conduct in the consultation and attitudes toward patients. Many physicians worry about lawsuits, which, in turn, may contribute to a general distrust of patients.[149] Some clinicians may adopt a more cautious and guarded style of communicating with patients because of fear of litigation, whereas others will use more patient-centered communication because these behaviors may lower the risk for malpractice.[150]

3.4 Multilevel Modeling

Given the complexities of factors affecting patient-clinician communication processes, the pathways though which communication achieves desired outcomes, and the moderators of these relationships, researchers should use multilevel modeling in their analytic techniques. Multilevel modeling is one approach to sorting out multiple influences on a clinical interaction and the moderating effects of intrinsic and extrinsic factors on the relationship between communication and health outcomes. These factors will be discussed in detail in Chapter 5, but we highlight five studies here. In two studies, Street[122,123] examined the extent to which physician and patient communication behaviors were related *uniquely* to their own personal characteristics, the other's personal characteristics, and the other's communication behaviors. By using a nested multilevel model, Street was able to discern that the physician's individual style of communicating (a predisposing influence) and the patient's communication behavior (asking questions, expressing concerns) were stronger predictors of the degree to which physicians gave information, issued directives, engaged in partnership building, and provided positive socioemotional responses than were patient characteristics per se (education, anxiety, and relational history with the physician). Of the patient characteristic variables, only level of education uniquely explained variation in the physician's communication; physicians engaged in more partnership building with better educated patients. Street also found that patients did not talk differently to individual physicians per se, but patients did ask more questions and offer more opinions when physicians used partnership-building behaviors more frequently. In addition, patients' communication was

uniquely related, to some extent, to their personal characteristics; better educated patients asked more questions and offered more opinions, and worried patients expressed more concerns.

A more recent study from Street and colleagues similarly involved the use of multilevel analyses to examine variations in patient-physician communication and physicians' judgments of the patients as communicators.[151] The strongest predictors of the physicians' use of patient-centered communication was the physician's individual style, the degree to which the physician had a "sharing" (as opposed to physician-centered) orientation to the physician-patient relationship,[152,153] and the degree to which patients were actively involved and expressed positive affect. Patient-centered communication was not related to patient demographic characteristics. However, physicians' judgments of patients as communicators were more positive for white patients than for black patients and for patients who expressed more positive affect.

In a related study,[154] physicians appeared to give more information to white patients than to black patients. However, when communication variables were entered into the equation, physician information-giving was no longer related to race per se but rather to the degree to which patients were active participants; i.e., black patients received less information because they were less actively involved in eliciting information from physicians.

Another study involved the use of multilevel modeling to ascertain whether patients' ratings in terms of trust in their physician, the physician's knowledge of the patient as a person, satisfaction, the degree of the physician's patient-centeredness, and the level of the physician's supportiveness for the patient's autonomy.[155] The authors used surveys completed by 4,700 patients of 96 physicians to examine the adjusted relationship between patients' perceptions of their physicians and reported changes in health status. Although there were significant adjusted relationships, patients who saw their physicians more favorably in terms of communication and trust had a smaller risk of decline in health status. Multilevel analysis showed significant differences in patients' perceptions of their physicians. These differences were unrelated to reported changes in health status, however, suggesting that unmeasured communication and relationship factors—not physicians' overall communication style—affected health status.

3.5 Conclusion

Models of communication should be simple enough to be understandable and guide empirical research, yet complex enough to approximate clinical reality. We have proposed a model of mediation of communication in which the six communication functions described in Chapter 2 lead to proximal communication outcomes, which themselves act as mediators between communication and intermediate outcomes. We described seven pathways through which effective communication leads to intermediate and distal outcomes, providing improvements in the following:

- Patient knowledge and shared understanding

- Access to care

- Therapeutic alliances

- Emotional self-management

- Family/social support and advocacy

- Quality of medical decisions

- Patient agency (self-efficacy, empowerment, and enablement)

In turn, these pathways lead to better adherence, health habits, and self-care. Studies of moderators of the relationship between communication and proximal, intermediate, and distal (health and societal) outcomes suggest that relationship factors need to be studied in greater depth, including issues such as gender concordance, shared understanding, mutual knowledge, and involvement of family members in care. Furthermore, there may be underlying and modifiable communication factors that account for some of the observed demographic differences in outcomes. Little is known of the moderating effect of different communication media (in person, telephone, electronic, asynchronous, etc.) on the process or outcomes of communication. Changes in the health care system are underway to improve patient safety, quality of care, and communication among

health professionals. The effect of these innovations needs further examination, given the dynamic changes that are likely to continue.

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Key Communication Tasks and Outcomes: The Cancer Care Continuum

4

The cancer care continuum demarcates a patient's cancer experience into six phases. The first two phases, prevention and screening, involve the entire population. The diagnosis, treatment, and survivorship phases eventually will involve all patients with a diagnosis of cancer. The end-of-life phase is relevant for patients who have cancers that cannot be cured but clearly is also relevant to individuals who die of other causes.

The patient's position along the cancer care continuum is one of the most important contextual elements that determine the nature of the concerns raised during clinical encounters, the most relevant health outcomes, and the specific pathways by which communication affects those outcomes. In Chapter 2, we described six functions of communication (Table 4.1) and, in general, the proximal outcomes associated with each function. For example, information exchange would be expected to lead to improved knowledge and shared understanding. In Chapter 3, we described pathways between communication and intermediate outcomes such as self-efficacy and adherence, and distal outcomes such as quality of life and survival. In this chapter, we consider in greater detail how each of the six communication functions affects specific outcomes at each of the

Table 4.1 Six Functions of Patient/Family-Clinician Communication in Cancer Settings

- Fostering healing relationships
- Exchanging information
- Responding to emotions
- Managing uncertainty
- Making decisions
- Enabling patient self-management

six phases of the cancer care continuum.

At all phases, clinicians may have to assess symptoms, foster change in health behaviors, deal with uncertainty, and/or discuss plans for the future. Nonetheless, the relative balance and importance of each communication task changes as each patient moves through the illness trajectory. Early in the continuum, there may be greater need to share information, but later there may be more of a need to deal with uncertainty; e.g., whether the treatment was effective. Similarly, at each phase, different outcomes also assume varying degrees of importance. For example, emotional well-being may be paramount at the time of diagnosis or recurrence, whereas physical functioning may be a more central issue during and after treatment. Although intermediate outcomes,

Figure 4.1 The six communication functions can help to improve survival and health-related quality of life (HRQOL) in each of the phases of the cancer care continuum.
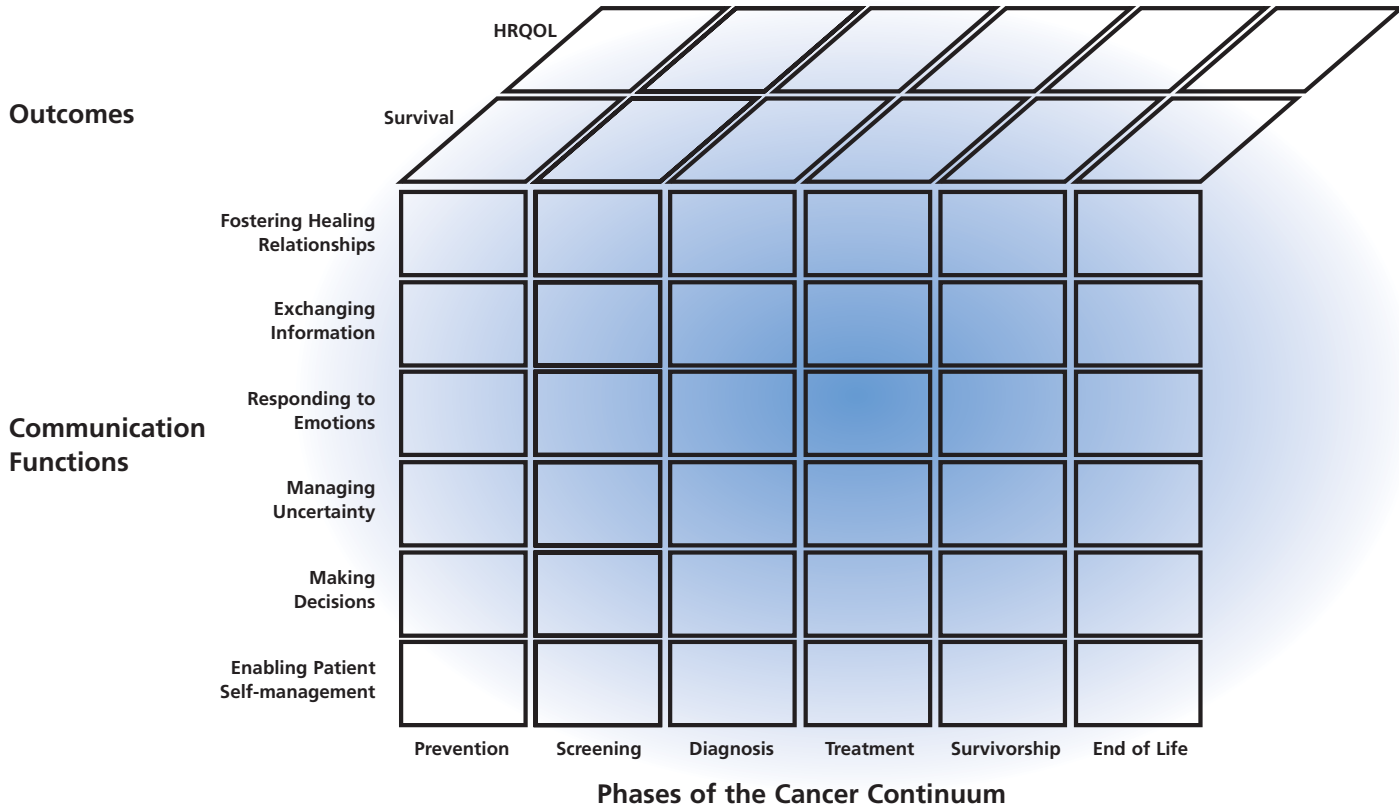
such as adherence to treatment, often are necessary steps to achieve desired health outcomes at some phases, communication itself may have a more direct effect on well-being at other phases.

At each phase, patients normally encounter a new set of clinicians. During the prevention and screening phases, cancer-related communication usually takes place in primary care settings. At later phases, surgeons and radiologists are involved in the diagnosis of cancer, and during the treatment phase, oncologists, radiation oncologists, surgeons, specialized nurses, and technicians are involved. Still later, patients often

return to primary care settings after active treatment and often encounter specialists in rehabilitation and palliative care. Thus, communication research should take into account not only what is communicated but also with whom.

We suggest a taxonomy of research agendas based on the phases along the cancer care continuum, relevant health outcomes, and the six communication functions (Figure 4.1). This perspective is intended to guide research that progresses from generalities about what improves communication to specifics on what will improve outcomes for a particular patient at a given point on the continuum. The taxonomy

indicates, for example, that it may be possible to look at unique pathways and outcomes of information exchange during the treatment phase. It also can help identify gaps in the literature and provide a framework for design of interventions to improve communication.

The proximal, intermediate, and distal outcomes of communication were summarized in Table 3.1 (Chapter 3). The discussion that follows here (and Table 4.2) provides a framework for identifying particularly important outcomes at each phase of the cancer care continuum. Only some of these outcomes have been discussed in the cancer communication literature.

Table 4.2 Examples of Clinicians' Communication Tasks and Outcomes at Each Phase of the Cancer Care Continuum*

Phase of the Cancer Continuum	Physicians' Communication Tasks	Proximal Outcomes	Intermediate Outcomes	Primary Health Outcomes
Prevention	Providing individualized, linguistically accessible information about cancer risks Promoting behavior change and appropriate preventive interventions to reduce cancer risks	Patient understanding and motivation to adopt healthy behaviors	Health behavior change (smoking cessation, improved diet, exercise, etc.)	Cancer prevention Improvement in long-term quality of life
Screening	Providing individualized, linguistically accessible information about the screening test Decision-making about screening when risks/benefits are unclear or when multiple options exist Helping the patient to navigate the health care system to follow-up on abnormal test results Addressing the patient's worries and concerns	Patient understanding of risks and benefits of screening Decision concordant with the patient's wishes and values	Completion of screening according to recommended guidelines	Early detection of cancer (at a curable phase) Improved health-related quality of life, both immediate (e.g., lower anxiety) and long-term (e.g., fewer cancer-related symptoms because of early detection)
Diagnosis	Addressing the patient's anxiety, fear, terror Communicating bad news Promoting recall and understanding of diagnostic information Helping the patient gain access to other diagnostic facilities Discussing probabilistic data Eliciting preferences for role in decision-making Communicating prognosis while maintaining hope Making decisions about anticancer treatments and advance directives Providing support to the patient, family, caregivers, and friends	Patient understanding of the disease, prognosis, and treatment options Patient recall Achievement of preferred level of involvement in decision-making	Satisfaction with choice of treatment Improved social support Self-efficacy Perceptions of control	Timely and accurate diagnosis Improved health-related quality of life (especially emotional well-being)

Table 4.2 cont'd from p 69

Phase of the Cancer Continuum	Physicians' Communication Tasks	Proximal Outcomes	Intermediate Outcomes	Primary Health Outcomes
Treatment	Eliciting the patient's experience of treatment, symptoms, and side effects Presenting information about the effectiveness of treatment Deciding on future or ongoing curative and palliative treatments Eliciting and responding to emotions of the patient, family, and caregivers	Strong patient/family-health care team relationship Patient understanding of treatment and side effects	Completion of treatment at full recommended doses Self-efficacy Motivation	Remission of cancer Improved health-related quality of life (e.g., minimal side effects, optimal physical and emotional functioning, minimized social isolation)
Survivorship (with or without known disease)	Dealing with uncertainty about recurrence Eliciting discussion of the patient's concerns and symptoms Eliciting and responding to the patient's emotions Presenting bad news and making treatment decisions if recurrence or progression occurs Communicating prognosis while maintaining hope	Patient understanding of and comfort with uncertainty Patient trust in clinicians Patient understanding of prognosis	Adherence to long-term treatments Timely detection of treatable recurrence Proactive health management Improved social support	Maintenance of remission Prevention of long-term or late effects of treatment Improved health-related quality of life (e.g., optimal physical, emotional, and social functioning)
End of life	Eliciting the patient's report of symptoms Communicating prognosis while maintaining hope Making decisions about anticancer treatments, life support, substituted judgment, and hospice care Responding to emotions of the patient, family, and caregivers Helping the patient navigate the transition to hospice care	Decisions and substituted judgments concordant with the patient's values and wishes	Appropriate use of palliative treatments Improved access to palliative care and hospice services Improved social support	Improved health-related quality of life (e.g., symptoms, physical functioning, emotional and spiritual well-being)

*These examples are designed to be illustrative and do not represent a comprehensive list of tasks or outcomes.

In discussing each phase, we first describe desirable outcomes of communication, common communication tasks, and the pathways by which communication improves health. We also recognize that other potent factors, such as the patient's prognosis, influence how communication affects outcomes. Starting with current research on patient-clinician communication, we provide a roadmap for future work to study relationships between communication and outcomes.

4.1 Prevention Phase

Effective interventions for prevention involve much more than patient-clinician interactions. Because ideally they involve the entire population, most prevention efforts take a public health approach and use mass media to disseminate information and foster behavior change. Our discussion, however, specifically focuses on how patient/family-clinician communication can reduce cancer risk. Primary care physicians, physician assistants, and nurse practitioners are the major sources of health information related to prevention of cancer in health care settings for all patients except for patients who have a high genetic risk for cancer. Primary care clinicians also have an important role in motivating behavior change.

4.1.1 Desirable outcomes

Effective cancer prevention should ideally result in a lower risk of cancer, as well as a reduction in racial, ethnic, educational, and socioeconomic disparities in cancer prevention. Intermediate outcomes along the pathway from communication at the prevention phase and a lower incidence of cancer among the general population include use of immunizations to prevent cervical cancer and hepatitis B-associated liver cancer and the adoption of healthier habits, such as smoking cessation, exercise, and sun protection.

4.1.2 Communication tasks and functions

A large percentage of the population has behavioral risks for cancer that are difficult to change and require active patient participation and motivation. The patient-clinician relationship has an important role in fostering behavior change. Relationship building during the prevention phase should involve autonomy-supportive clinician behaviors such as active listening and encouraging patients to become involved in their own care, which will help them feel more enabled[1,2] and motivated.[3,4] Clinicians can help patients gain access to information about healthy behaviors and also can explore patients' health beliefs that are not concordant with known prevention strategies.[5]

Patients must make decisions regarding prevention, the most important of which is whether to try to change a behavior at all. In addition, patients encounter decisions regarding immunizations. For example, now that two human papillomavirus vaccines are available, many parents must confront the decision of whether to immunize their preadolescent children and, if so, with which of the vaccines. Clinicians have a role in making choices explicit for patients and helping them decide to adopt healthy behaviors.

Clinicians also should actively help patients adopt healthy behaviors. One method for enabling patients is the 5-A model to guide patients through a behavior change process;[6,7] the process includes the following:

- Asking about the behavior

- Advising the patient to change

- Assessing facilitators and barriers to change

- Assisting (actively) the patient

- Arranging for further interventions and follow-up

Factors related to the health care system are also crucial. Clinical practices that are organized around prevention have been associated with higher rates of recommended cancer screening.[8] Well-functioning health care systems can provide patients access to cancer risk reduction programs, including counseling on diet, exercise, and smoking cessation. In addition, such systems can address clinicians' lack of time and the competing demands in primary care encounters that make it difficult to focus on all relevant health risks. It is important to note that many recommended patient self-management strategies may be inaccessible to patients with low socioeconomic and educational levels unless clini-

cians involve social agencies to assist these patients in following through with their healthy choices.

4.2 Screening Phase

4.2.1 Desirable outcomes

When cancer or precancerous conditions are detected at an early enough phase, they are more likely to be curable. Early detection can also reduce morbidity and suffering for patients who have cancers that are not curable. Thus, the most important intermediate outcome at this phase is the timely completion of recommended age-specific and gender-specific cancer screening, with appropriate follow-up for abnormal results. Communication about risks and benefits of screening generally occurs within the primary health care domain, whereas some screening tests and follow-up of positive screening tests often involve specialty care.

4.2.2 Communication tasks and functions

In the United States, many recommended cancer screening procedures are performed on only a small percentage of the population.[9] Lack of information may be one reason for low screening rates, but more often fear, inconvenience, and lack of access are the reasons patients do not have screening tests. In addition, some patients have health beliefs that cause them to doubt clinical guidelines. For example, patients may believe that mammography can cause cancer or

that recommendations for prostate cancer screening are promoted by special interest groups. It is important for clinicians to understand their patients' health beliefs in order to address them. Some of these beliefs may have some basis in current or historical fact.

Communication about screening must incorporate several steps. Patients must be informed about screening and its effectiveness, make a decision to schedule a procedure, and navigate their way through the health care system to have the procedures completed. Also, because most screening procedures involve some discomfort and inconvenience, clinicians need to address patients' concerns and help make it easier to have the procedure completed. For example, a patient who is avoiding a colonoscopy may benefit from an explicit discussion about the trade-offs: the discomforts associated with the procedure versus the presumed benefits. Some screening procedures, such as determination of serum prostate-specific antigen (PSA), are controversial, with opponents suggesting that the test may actually lead to worse outcomes. Discussions of risks, benefits, fears, and uncertainties involving PSA testing are necessary, although time-consuming. Some patients also fear knowing the result of a screening test, considering ignorance better than bad news. Eliciting and discussing those fears can improve the chance that patients will participate in screening.

Barriers to screening disproportionately affect disadvantaged,

minority, and low-literacy populations,[10,11] in part because they are more likely to experience fragmentation of care, have inadequate transportation, and be unable to take time off from work for medical visits. Racial and ethnic stereotyping and cultural differences in language use can create further communication barriers.[12-14] Knowledge deficits, fear, uncertainty, poor access, and poor understanding of probabilistic estimates of risks and benefits can be improved through effective communication, which includes the following steps:

- Clarify the reason for screening
- Gain the patient's trust
- Offer tangible help for navigating the health care system
- Provide interpreters
- Provide low-literacy, culturally informed educational materials

Involving family members in the consultation also may be helpful in motivating patients to follow through with screening.

4.3 Diagnosis Phase

4.3.1 Desirable outcomes

Effective communication should improve the likelihood that carrying out diagnostic testing, informing the patient of the diagnosis, and determining initial treatment choices will be accomplished quickly, without delays, and in an environment that supports the patient's emotional

needs. Intermediate outcomes include adequate patient understanding and recall of disease-related information, including prognosis and treatment options. Ultimately, patients should be satisfied with their treatment choices and the process by which they reached their decisions. Improved social support, self-efficacy, and a sense of control are important intermediate outcomes as well. Patients with a greater sense of confidence may make better informed choices and may seek the support that they need. Confidence also may help patients anticipate and plan for the disruptions and discomforts of anticancer treatments.

4.3.2 Communication tasks and functions

During the diagnosis phase, clinicians initially must accomplish the following:

- Assess symptoms that raised suspicion of cancer

- Address patients' anxiety, fear, and sometimes terror at the anticipation of a cancer diagnosis, even before communicating bad news

- Communicate bad news clearly and compassionately

- Involve family members in discussions and decisions to the degree that it will be helpful and desired by patients

- Help patients recall important information

- Assist patients with navigating their way through the health care system to gain access to procedures and consultations

- Discuss probabilistic data in ways that patients understand so that they can participate in discussions and decisions about treatment

- Assess patients' desire to participate in decisions

- Communicate prognosis while maintaining hope

- Help patients make decisions about anticancer treatments and advance directives

- Provide support to the patient, family, caregivers, and friends

Mutual understanding and patient involvement in the consultation are also likely to help patients tolerate and follow through with treatment. All of these tasks are complex and apply to the treatment, survivorship, and end-of-life phases as well. Because these tasks often are encountered for the first time at diagnosis, we discuss them in detail in this section.

The first major communication task at the diagnosis phase is either assessing symptoms that have raised the suspicion of cancer or notifying patients of results of a positive screening test. Some cancers, such as cancers of the cervix, breast, and colon are increasingly being diagnosed by routine or targeted screening, whereas other common cancers, such as cancers of the lung and ovary and hematological malignancies, usually are diagnosed in response to patients' reporting of symptoms. The initial process of clinical evaluation involves gathering information from the patient. In later phases, clinicians provide information, but this information often is changing rapidly and is incomplete until the full diagnostic picture is clear. The entire process of diagnosis may take a day or less, but more often, it takes place over the course of several days or weeks. Furthermore, patients may need to choose which (if any) diagnostic procedures to pursue. The choice can be more difficult if the diagnostic procedures are uncomfortable. Patients experience chaos, terror, and anxiety during this phase, which, in turn, affects their ability to assimilate information and make rational decisions. Thus, eliciting and validating emotions may become more important and also more difficult during the advancement toward a definitive diagnosis.

Patients' decisions and understandings are frequently influenced by information from multiple health professionals, which can sometimes be conflicting or unclear. Consider the situation of a patient with a brain lesion that appears unresectable; a neurosurgeon suggests a brain biopsy to establish a tissue diagnosis, but the biopsy is associated with a risk of brain injury, and a radiation oncologist suggests empirical radiotherapy because, in all likelihood, that would be the treatment of choice. This case illustrates that sometimes clinicians cannot provide a definitive diagnosis or prognosis. Although the process of establishing a diagnosis is typically a very

stressful time for patients and their families, there has been almost no research on communication during the diagnostic process.

The second task at the diagnosis phase is delivering bad news. Although almost all patients in Western industrialized countries wish to know their diagnosis, patients vary in their desire for information about treatment and prognosis at the time of the initial cancer diagnosis. Clinicians must assess how much detail patients want. Particularly important is asking patients what role they would like their families to play: what information should be shared, with whom, and when. Ideally, patient preferences should be discussed before diagnostic testing, but in actual clinical practice, that is often not the case. Because recall of such information is typically poor, providing information in small chunks, repeating key points, categorizing, summarizing, and checking patient understanding are key communication skills.[15-19] Audio recordings of consultations[20-22] and written materials[23] may be helpful.

Managing the strong patient emotions associated with hearing bad news for the first time requires skillful clinician use of empathy. Patients' emotional well-being after a diagnosis is enhanced by adequate preparation for the news before diagnostic testing, presence of friends or family members at the consultation, discussion of the patient's feelings, and clear information presented in oral and written formats.[24,25] Patients fear that they will face these challenges alone; they need reassurance that their physicians and other health professionals will be there for them when they need them.[26]

Communicating bad news is never easy and often is done poorly. However, intensive training in this area can improve physicians' ability and willingness to share bad news in ways that optimize information transfer, emotional support, and the patient-clinician relationship.[27-29] Unfortunately, few physicians and other clinicians have participated in such training, and frequently, participants are not those whose skills are the most deficient.

As discussed in Chapter 2, delivery of bad news also may occur later in the cancer care continuum. The recurrence or metastasis of a tumor that had been presumed cured may be emotionally devastating to the patient, require management of information and uncertainty, and involve treatment choices about which less is known than primary treatment at the time of initial diagnosis. Complex navigation of the health care system may be necessary to get additional expert opinions from sources outside the institution.

The third major communication task during the diagnosis phase is making decisions about the initial anticancer treatment. In some cases of slow-growing cancers, patients choose to forgo anticancer treatment entirely or opt for watchful waiting if it is possible that the risk of treatment-related complications will exceed the therapeutic benefit. In trying to measure what constitutes a "good decision," researchers have considered whether the

- Decision is consistent with recommendations
- Patient feels informed and knowledgeable
- Patient later regrets the decision
- Patient participated at his or her desired level of involvement

These intermediate outcomes may contribute to increased motivation, self-efficacy, and a higher likelihood that adequate treatment will be completed.[30,31]

Making decisions depends on the availability of adequate, patient-friendly information.[32] Factors related to the patient, clinician, and health care system affect the type, quality, and quantity of information patients can obtain about their illness and its treatment. Patients who are more active communicators tend to get better quality information from their physicians.[33] In addition to obtaining information from their physicians, patients seek information from a variety of sources: other health professionals, family, friends, the media, books, and, especially, the Internet. Even though patients trust their physicians more than information from the Internet, they tend to go online for information before their initial cancer consultation.[34] When searching the Internet, patients may be frustrated by the lack of useful information, confused by

conflicting information from reliable sources, and/or overwhelmed by the overload of information without clear criteria to judge its quality.[35] Clinicians can help patients interpret and judge the quality of these other sources. However, even clinicians can disagree with each other. In those situations, patients with strong relationships with their family physicians and other primary care professionals may rely on them for advice, or, alternatively, may seek additional opinions from specialists or lay sources.

Presenting probabilistic information about treatment effectiveness and prognosis is challenging,[36] as discussed in Chapter 2 (and in detail in Appendix B). Because patients and clinicians may understand semiquantitative words, such as "rare" and "mild" differently,[36] clinicians should be explicit and use graphics and written materials as well. Patients with low literacy generally need explanations in a face-to-face setting, especially for probabilistic information, and even then may not fully understand.[10] Written, video-based, or Internet-based decision aids can help to clarify options and can affect patients' choices, sometimes paradoxically decreasing willingness to follow recommended guidelines when the absolute reduction in risk is low.[37] An important area for future research is the effect of decision aids on patient-clinician communication; very little is currently known.[38]

Information is necessary but not sufficient for decision-making;[32] patients and clinicians need to interpret information in the context of the patient's illness and his or her values. Few clinicians in North America and other English-speaking countries follow purely paternalistic models, in which the clinician makes decisions unilaterally, or consumerist models, in which the patient is an independent agent who uses the clinician only for advice. Nearly all patients, when given the opportunity to participate and express their preferences, tend to favor some degree of involvement in decision-making. Patients frequently do not want to take the responsibility for making decisions yet want to be involved and to participate in their care in meaningful ways.[39] Patients with recently diagnosed cancer may be cognitively compromised because of the terror of the initial diagnosis, fatigue and other symptoms, family pressure, and information overload. Thus, they may not participate at levels that they might have anticipated.[40] Although patients retrospectively may appreciate clinicians' efforts to help them participate more actively, clinicians also must have the flexibility to recognize when they are imposing an unwanted burden of responsibility on patients.[41] However, reviews of interventions to increase patient involvement in decision-making (summarized in Appendix E) suggest that the degree to which patients achieve their preferred role in decision-making does not always lead to increased satisfaction or a lower level of anxiety. Rather, the quality of the interaction and the relationship may be more important—

whether patients feel heard and understood, whether they have trust in the clinician, and whether they feel enabled to act on their own behalf.[42-46]

4.4 Treatment Phase

During the treatment phase, patients and clinicians continue discussions about planning and participating in anticancer treatments. Patients frequently experience uncomfortable side effects such as fatigue, nausea, and pain, yet these may go unreported or unaddressed. Patients may want to discuss changing or stopping treatment depending on the initial response and side effects.

4.4.1 Desirable outcomes

Effective communication can encourage patients to complete surgical treatment and/or receive adequate doses of chemotherapy agents or radiation. Better communication can lead to lower levels of anxiety and depression, fewer side effects, greater social support, and success in finding meaning.[47] Completion of adequate treatment and attention to psychosocial issues are both associated with improved survival and health-related quality of life. Conversely, poor communication may be partially responsible for the inadequate treatment more commonly seen in minority populations[48] and patients with low health literacy.[10] Patient factors that influence communication include access to care, expectations, trust, and level of activation.

4.4.2 Communication tasks and functions

Clinicians need to understand how cancer and its treatments affect their patients in order to form stronger relationships with them. When patients have strong relationships with members of the treatment team, they may receive information and social support that help them tolerate transient fatigue and nausea and adjust to disfigurement and disability. Patients should feel that information was shared in ways that they could understand and recall to help them make informed decisions. Clinicians can help patients take charge of aspects of their care, gain access to needed treatments and services, and prepare for long-term care and surveillance.

Addressing uncertainty and worries about the future are important at this phase but are rarely addressed. Clinicians often do not detect patients' emotional concerns, often leading patients to stop raising the issues.[49] The nature of worries during the treatment phase may also differ from that during other phases, and patients may be afraid even to mention concerns. Nonetheless, patients commonly ask themselves, "Is the treatment working?" or "Will I experience side effects?" Clinicians should be attentive to indirect cues,[50-52] initiate conversations with patients about their worries, and ask directly about patients' reasons for nonadherence or discontinuation of treatment.[53] Acknowledging patients' emotions,[54] expressing empathy, giving choices to

patients,[55] and offering referrals for counseling are ways of responding to patient distress.

Unfortunately, many patients receive less than optimal anticancer treatment. Clinicians may interpret patients' expressions of discomfort differently based on racial or ethnic stereotyping, misunderstandings, and prior assumptions about treatment effectiveness.[48] These interpretations may result in dose reductions that render chemotherapy ineffective or in cessation of treatment.

For patients, communication-related factors that contribute to these treatment changes include the following:

- Lack of understanding of clinical evidence suggesting that the treatment is effective

- Lack of understanding that lower doses may be equivalent to no treatment at all

- Lack of understanding that side effects may be transient and reversible

- Distrust of the clinician, or feeling "experimental"

- Distrust of the evidence on which treatment decisions are based

- Information and recommendations from other sources (particularly the Internet)

- Not feeling understood by the clinician

4.5 Survivorship Phase

More than 10 million Americans are living with cancer, 14% of whom have cancer that was diagnosed more than 20 years earlier. Survivorship is more common with breast, prostate, colorectal, and gynecological cancers than with other common cancers, such as lung, pancreas, and brain cancer, for example. Currently, 64% of adults with cancer can expect to be alive in five years.[56]

Survivorship has been defined as the time from diagnosis to death[57,58] and is divided into acute, extended, and permanent phases.[59] In this section, we address the extended and permanent phases, which begin after initial treatment with surgery, radiation therapy, and/or chemotherapy has been completed (usually less than one year after diagnosis). Survivors include individuals who have had remission after initial treatment, who will not have treatment-induced remission, and who will have relapsed disease after remission. Survivorship has an impact on family, friends, and caregivers.[60] Many of the communication issues related to survivorship have been discussed in the sections on the diagnosis and treatment phases and will not be repeated here. We address issues that arise for patients at the end of life in the next section.

4.5.1 Desirable outcomes

Ideally, effective communication should result in greater likelihood of maintenance of remission, prevention and treatment of long-term

sequelae of treatment, and improvement in quality of life. Intermediate outcomes include the following: adherence to long-term treatments (e.g., tamoxifen for breast cancer), completion of recommended surveillance testing for recurrence, and treatment decisions made in concordance with the patient's values. Because uncertainty and anxiety are common when active treatment is completed, feeling supported and understood are important intermediate outcomes on the pathway between communication and emotional well-being.

4.5.2 Communication tasks and functions

The greatest gap between the biomedical perspective (cure or remission) and the patient's illness experience may occur at the survivorship phase. Although the clinician may celebrate that the patient has had a response to treatment when the tumor appears to have diminished in size or disappeared, the patient may be experiencing residual symptoms and other effects of the cancer and its treatment. Such symptoms as fatigue, paresthesias from neurotoxic chemotherapy, dysphagia from chest radiation, lymphedema from axillary node dissection, and slowed thinking from brain irradiation are rarely totally disabling, but they have an impact on quality of life and self-image. Many patients must learn to live with the results of disfiguring surgery and may need reconstructive surgery. They may experience late effects of can-

cer treatment, such as secondary cancers, obesity, sexual dysfunction, infertility, and birth complications, which are more common than previously thought.[61] Other consequences of cancer are lower earning potential[62] and difficulty in obtaining health insurance.

Patients and their families continue to need information during the survivorship phase. Patients, their families, and their work colleagues may have the misconception that all cancer is fatal; patients may interpret any new symptom as a harbinger of disease progression and may seek frequent diagnostic testing for reassurance. Clinicians and patients must decide about frequency of follow-up, which tests to use for surveillance, and the advantages and disadvantages of extensively evaluating new symptoms. Further explanations of prognosis may be needed during this phase. Patients often want to know the likelihood of recurrence and, if the cancer recurs, they want to know the effectiveness of treatment*.*

At some point, most patients fear recurrence, and many worry about their children's and other family members' risk for the development of the same cancer. Depression is common at this phase. However, patients may be reluctant to share their feelings because they feel that they should be glad treatment was successful, and others may expect them to feel this way as well. Because patients tend not to disclose these concerns spontaneously, clinicians need to gain patients' trust and to inquire about their concerns. Not surprisingly, a

major communication task for clinicians, patients, and their families, especially during the first few years of survivorship, is dealing with the cognitive and emotional aspects of uncertainty. Achieving an appropriate balance between realism and hope is discussed in greater depth in Section 4.6.

Patients who have had a good response to treatment have less frequent contact with health professionals. Patients may have fewer opportunities to get information and reassurance and at the same time need to re-establish a normal life. Family members may be relieved and may be less receptive to disease-focused discussions. Yet, the patient may continue to feel wounded, afraid, and vulnerable long after the successful treatment has been completed.[59,63] Thus, the clinician's focus must be both on controlling the disease and on healing the patient. Healing begins with the willingness and ability to see the illness through the patient's eyes as well as through a clinical lens and building a network of social supports so that the patient can move ahead with his or her life. Prior patterns of responding to stress, anxiety, and social support may predict how patients face the stresses of survivorship. Currently, however, there is very little empirical literature that can guide clinicians to communicate more effectively with cancer survivors.

4.6 End-of-Life Phase

4.6.1 Desirable outcomes

Palliation, the reduction of suffering related to physical and mental symptoms, should be part of any cancer treatment program, regardless of curative intent. However, quality of life, rather than postponement of death, becomes more of a focus of care for most patients with treatment-resistant cancer. Clinicians should not assume that all patients value particular aspects of quality of life equally. For some patients, the ability to go to a family event may be more important than total relief of pain, and for others the ability to eat may take on particular importance. Thus, clinicians should inquire about quality-of-life issues directly.

4.6.2 Communication tasks and functions

In reviews of the communication tasks in end-of-life care, de Haes and Teunissen [64] and Tattersall et al.,[47] noted that the following tasks are important:

- Eliciting information from patients about pain and other symptoms

- Providing accurate prognostic information while maintaining hope

- Managing strong emotions in patients and clinicians

- Making numerous decisions about initiation and cessation of palliative chemotherapy,

radiation therapy, and life-sustaining treatments

- Deciding where the patient will live and who will care for him or her

- Dealing with patients' fears of abandonment

- Handling requests from the patient and family to use futile therapies, to set unrealistic goals, or to hasten death

Information exchange can be problematic in both directions. Patients are frequently reluctant to report pain for a variety of reasons, often because they believe that reporting pain represents moral failure or weakness. The use of systematic questioning and quality-of-life questionnaires has helped patients to report pain and other symptoms.[65,66] Even when offered the opportunity, however, patients may not report symptoms, and caretakers may take on the role of reporting symptoms and advocating for the patient. Patient passivity may be especially evident if the patient has cognitive decline, which is often noted with advanced cancer; in such situations, caretakers may assume the role of surrogate for the patient during encounters with clinicians. To make matters even more complex, families often do not present a unified view on what is best for the patient.

Handling strong emotions is another important challenge in end-of-life discussions. The patient and family may express strong positive and negative feel-

ings, which can be difficult for even very skilled clinicians. Furthermore, clinician and caregiver burnout may reduce clinicians' and family members' ability to respond to patients' emotions.[67-69]

Managing uncertainty is one of the most difficult communication tasks during the end-of-life phase because it involves balancing two patient/family-clinician dialogues: one about prognosis and one about hope.[70,71] Communicating prognosis has three major challenges. First, prognoses apply to groups, but the illness trajectory will be unique for each individual. Second, patients and their families vary in their wish to know what will happen next. Patients who might tolerate knowing that they have cancer may not want to know that they are dying.[72] Third, patients are often discomfited by physician expressions of uncertainty; consequently, the clinician may feel that he or she has to assume a posture of expressing more than can be known.

The dialogue on hope has similar challenges. Patients generally want to know the truth. However, when asked, patients with terminal illnesses often still express hope for a cure.[73] Physicians often collude with these wishes by exaggerating or avoiding discussion of prognosis[74,75] even when providing palliative treatments. Although clinicians debate whether to present prognostic information directly or to engage in "necessary collusion" to soften the blow of a terminal diagnosis,[76,77] few data support

either method. Regardless of the communication approach taken, however, patients have a right to be informed of a full range of treatment options. Continuing treatment with the illusion of curative intent when the patient is dying or saying that nothing can be done represent paternalism and abandonment, respectively. Although clinical guidelines for skillful communication about these issues exist,[15,78] empirical data are lacking.

A series of difficult decisions is often made during the end-of-life phase, perhaps more so than at earlier phases of the disease—and there is less evidence to guide each decision. Treatment options, including experimental treatments, must be considered one by one. The patient may need to decide which clinical outcomes are most important; for example, longer survival may come at the expense of more treatment-related symptoms. Clinicians should raise the issue of advance directives, as patients do not usually discuss them spontaneously.

Typically, the family becomes more involved during the end-of-life phase. Family engagement in decisions varies according to the culture and the cognitive capacity of the patient. Clinicians must be skilled at keeping the focus on the patient's wishes when communicating with anxious family members whose understanding, concerns, and values may differ from those of the patient.[79] Conflicts within the family about treatment goals, resuscitation, and hospice care are common.

Navigating the health care system is challenging for patients who are weakened by disease and cognitively compromised. Clinicians have an important role in advocating for patients and enabling families to engage hospice and palliative care teams and to manage home services, pain medications, insurance benefits, and other aspects of caretaking. Clear communication among the team and with the patient's family is critical.

4.7 The Real World of Cancer Care

In Chapter 2, we described a general six-function model of communication, and in Chapter 3, we discussed some of the pathways by which communication might affect health outcomes. In the first part of this chapter, we presented a model of how the six communication functions interact with the six phases of the cancer care continuum to affect important health outcomes. In this section, the model will be applied to the specific illness trajectories of two patients. We suggest that this approach not only will bring the model to life but also will indicate how the model itself is dynamic and adaptable to a variety of particular situations.

A model is only as good as its heuristic value. General models should be simple enough to be understood but complex enough to approximate reality and should be applicable to a wide range of situations. All models have limitations, and we assure the reader that the

framework we have presented is no exception. Specifically, we have focused on some aspects of cancer at the expense of others. For example, we might have considered patient culture and ethnicity as a more central factor in our understanding of communication and health.

Both of our cases are based on real patients, and identifying details have been removed (Textboxes 4.1 and 4.2). One purpose of presenting these cases is to indicate that human experience, including suffering and well-being, does not necessarily conform to the models that we create to describe it. Thus, for some patients, what seems like bad news may provide relief that finally there is an explanation for their suffering. In other situations, a single factor, such as lack of transportation, low health literacy, deafness, or cognitive dysfunction may be so powerful that most communication efforts are directed toward overcoming that barrier. In yet other situations, being well educated can be a hindrance because the emotional capacity to deal with uncertainty does not always match the patient's intellectual capacity to gather information. The cases presented here also highlight that families are involved in the care of each patient with cancer in a somewhat unique way and that each patient and family normally encounter multiple health professionals who also are involved in each patient's care in a somewhat unique way. Lastly, in cross-cultural situations, communications that otherwise seem simple

Textbox 4.1 Case of Gloria Rodriguez*

Patient's Cancer Experience	Communication Tasks
Screening phase	
Gloria Rodriguez is a 48-year-old Mexican American factory worker who had a follow-up mammogram one year after she had discovered a lump in the right breast. The right breast was aspirated at that time, and the findings were benign. On the follow-up mammogram, a suspicious two-centimeter lesion was found in the left breast.	**Exchanging information:** Explaining the difference between a positive screening test and actual disease **Managing uncertainty:** Interpreting test results
Neither she nor her primary care physician had detected the mass by palpation.	**Fostering healing relationships:** Establishing trust, understanding clincians' limitations
Ms. Rodriguez was referred to a large inner-city hospital that did not have a regional cancer center and had a lower percentage of Board-certified physicians on staff compared with other hospitals in the region.	**Enabling patient self-management:** Eliminating disparities in access to and quality of care
Diagnosis phase	
The radiologist made an appointment for an ultrasound the next day, but the patient did not understand why an ultrasound was necessary and why she did not have an aspiration, as she had previously. When the radiologist said "suspicious," Ms. Rodriquez thought he was being evasive. She missed the ultrasound appointment because of a lack of transportation. She attempted to call the radiology department to reschedule but was unsuccessful.	**Making decisions:** Involving patients in decision-making. **Exchanging information:** Improving patient knowledge about the diagnostic process **Enabling patient self-management:** Guiding the patient through the health care system
After a two-week delay, Ms. Rodriguez had an ultrasound that suggested a solid mass, and she was referred to a surgeon for needle biopsy later that week. Although the ultrasonographer mentioned that the mass was "solid," Ms. Rodriguez did not know that the term meant that the mass was more likely to be malignant, nor did she realize that it was more appropriate for the diagnostic information to be conveyed by the physician, not a technician.	
Ms. Rodriguez returned to her primary care physician for a routine follow-up visit, but the reports from the ultrasound were not immediately available. Seeing that Ms. Rodriguez was distraught, the physician called the radiologist to obtain the findings.	**Enabling patient self-management:** Communicating within the health care system Coordinating involvement of multiple clinicians for the patient's care **Exchanging information:** Using electronic communication technology **Responding to emotions:** Conveying empathy and taking action
The primary care physician explained the need for biopsy and probable surgery.	**Exchanging information:** Using lay language

Textbox 4.1 Case of Gloria Rodriguez cont'd from p 80

Ms. Rodriguez recounted the story of her mother's breast cancer several years before that was caught "too late"; it had already spread and she died within 3 years. Ms. Rodriguez did not ask any questions about the likelihood that her own cancer would spread, and thus, her unspoken concern was not addressed. She left the visit with the impression that the cancer would be incurable.

Responding to emotions: Recognizing and responding to indirect cues of patient distress.

Exchanging information, fostering healing relationships, managing uncertainty: Discussing genetic testing for the sake of family members at possible risk

Fostering healing relationships, making decisions: Activating patients to ask questions and participate in decisions

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She had a visit with a surgeon, the same one who performed the previous needle biopsy. She had an idea of what to expect because of her prior experience.

Enabling patient self-management: Promoting continuity of care

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She was told that the surgeon would call with the result. However, when the surgeon did call, the message was taken by her 10-year-old child, who transposed the digits in the phone number. After several tries, Ms. Rodriguez did make contact with the surgeon's physician assistant, who informed her that the biopsy was "positive" and that she should plan another appointment with the surgeon and to meet with the radiation oncologist. She was not sure what "positive" meant but assumed it meant that the tumor was cancerous. She was very upset and confused as to what would happen next.

Fostering healing relationships: Considering family and social factors in communication

Exchanging information, responding to emotions: Delivering bad news clearly and sensitively

Exchanging information, fostering healing relationships: Using in-person vs. telephone vs. asynchronous communication

Enabling patient self-management: Coordinating involvement of multiple clinicians

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She met with the surgeon's physician assistant, who explained the options: modified radical mastectomy or lumpectomy with radiation therapy. She was afraid of surgery for three reasons: disfigurement, fear of spreading the cancer, and not waking up. She did not share these concerns with the physician assistant but otherwise found the meeting helpful and informative.

Responding to emotions: Eliciting and addressing patient fears

Making decisions: Facilitating informed decision-making

She was given an informational pamphlet. It contained several words that she did not understand, but with the help of the surgeon's nurse, she was able to get the basic idea to help her decide on lumpectomy plus radiation therapy.

Exchanging information: Using written and electronic media to reinforce information transfer and informed decision-making

Treatment phase

A week later, Ms. Rodriguez had lumpectomy. After the procedure, the surgeon explained that he "got it all"; the margins were clean. She experienced more pain than she was led to believe she would have. She called the surgeon, and her nurse suggested warm compresses. Two days later, the pain increased and the incision reopened, draining a copious amount of purulent material.

Fostering healing relationships, exchanging information, responding to emotions: Explaining and responding to unexpected complications

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Her surgeon saw her later that day but offered no explanation or apology. After a course of antibiotics, the wound healed by secondary intention but left a scar.

Exchanging information: Dealing with adverse outcomes

The patient was not offered reconstructive surgery, but a friend later suggested that she talk with her surgeon again about it.

Enabling patient self-management, exchanging information: Making use of the involvement of family, friends, and advocates

Textbox 4.1 Case of Gloria Rodriguez cont'd from p 81

Pathological findings indicated a 1.8 cm tumor and no evidence of disease in the lymph nodes. Because of the size of the tumor, Ms. Rodriguez was referred to a medical oncologist to discuss chemotherapy. She was puzzled because she thought that they "got it all." No one had mentioned chemotherapy previously.	**Fostering healing relationships:** Optimizing communication among multiple clinicians and the patient
Ms. Rodriguez discussed the advantages and risks of chemotherapy with the oncologist. The oncologist also discussed other alternatives such as oophorectomy and hormone therapy and mentioned that research still is being done to determine the best option. She was given an informational booklet and asked to call once she had decided on the therapeutic option and whether she wanted to proceed. The list of side effects seemed frightening, so she did not make a follow-up appointment. She was also worried by the word "experimental"; she thought that she would be used as a guinea pig. Also, she did not understand the statistics on effectiveness in preventing recurrence.	**Exchanging information:** Offering both information and the skills to process the information Communicating with patients with low health literacy **Responding to emotions** **Making decisions:** Communicating evidence **Fostering healing relationships:** Establishing and maintaining trust
The radiation oncologist explained the course of radiation therapy and its risks, and, after Ms. Rodriguez provided consent, a five-week course of radiation therapy was begun. She came to know and trust the radiation oncology technician, and her brief conversations with her each day provided some comfort.	**Fostering healing relationships:** Lowering the level of patient anxiety

Survivorship phase

Ms. Rodriguez completed treatment and returned to her surgeon, radiation oncologist, and primary care physician for follow-up visits several times in the first year, with no indication of recurrence. Nonetheless, having not received chemotherapy put her at a 5% to 10% higher absolute risk for recurrence. Although she is afraid of recurrence, she and her family never spoke of these fears, and she did not initiate discussions of these issues with her physicians. If the cancer were to recur, she might blame herself, however, for not deciding to receive chemotherapy.	**Fostering healing relationships:** Coordinating communication with multiple clinicians **Responding to emotions:** Addressing fears of recurrence **Managing uncertainty:** Interpreting survival estimates Judging the degree of numerical detail that would be meaningful for the patient

*Although this case is based on a real patient, details have been altered to maintain confidentiality and to avoid any potentially identifying information.

can result in serious misunderstandings. In one of the cases presented, a physician's attempt to be honest in saying that a lesion was "suspicious" was interpreted as evasive rather than informative because the patient had inflated expectations of medical technology. To lose perspective on these individual factors risks missing important aspects of healing and suffering. These cases illustrate how during each patient's individual trajectory, the six communica-

tion functions and the six phases of the cancer care continuum frame the communication challenges and outcomes relevant to the patient, clinicians, and family members.

4.8 Conclusion

This chapter describes some of the desired outcomes of communication during each phase of the cancer care continuum. At each phase, relevant outcomes are different, and the patient's and family's concerns

change over time. Thus, the communication processes that are necessary to lead to those outcomes differ somewhat at each phase. However, the phases have more similarities than differences. At all phases, a strong patient-clinician relationship based on trust and respect is important so that it can, if necessary, accommodate strain at some points and greater family involvement at others. Similarly, although the nature and impact of information change during the can-

Textbox 4.2 Case of Randall Groves*

Patient's Cancer Experience	Communication Tasks
Diagnosis phase	
Randall Groves is a 73-year-old semiretired, divorced professor of economics. His energy has been diminishing over several months and a sense of fullness and bloating developed in the upper left quadrant of the abdomen. On the physical examination, there was tenderness in that area but no mass was palpated. The findings of fecal occult blood testing were negative, as were the results of upper endoscopy and colonoscopy. Blood chemistry levels and cell counts were normal. He began to lose weight. His physician suspected cancer, which he communicated to the patient. He did not communicate that he considered pancreatic cancer most likely.	**Exchanging information:** Deciding how to share information and clinical impressions at different points in the diagnostic process **Responding to emotions, managing uncertainty:** Dealing with anxiety until the diagnosis is clarified
Computerized tomography (CT) of the abdomen showed a large tumor involving the head of the pancreas. The radiologist suggested that it likely was inoperable. This information was communicated to the patient by the primary care physician. Mr. Groves was not surprised by the news. The patient wanted a surgical opinion. He indicated that symptom control was more important than life-extending procedures.	**Exchanging information, managing uncertainty:** Communicating bad news Eliciting patient values and wishes
The surgeon suggested that a Whipple procedure might be possible, but whether it could be done would be known only after the abdomen had been opened. He estimated that the best-case scenario represented a 20% chance of long-term survival and a 30% chance of improved quality of life. Mr. Groves was devastated and terrified. He had not realized that the prognosis was so poor.	**Exchanging information, making decisions:** Framing choices to help patients decide among options Communicating prognosis both accurately and sensitively **Responding to emotions:** Managing terror
Mr. Groves preferred to talk it over with his primary care physician. The patient searched the Internet and found data indicating the prognosis was worse than the surgeon suggested. The primary care physician contacted the surgeon directly, who communicated a more pessimistic picture to the physician than he had to the patient.	**Fostering healing relationships:** Maintaining trust **Exchanging information, managing uncertainty:** Dealing with complex ambiguous medical information
Mr. Groves and his primary care physician discussed and updated his health care proxy and living will. His primary care physician offered to help clarify the patient's choices.	**Managing uncertainty:** Discussing advance care planning and end-of-life issues
Both Mr. Groves and his primary care physician found information about a variety of chemotherapy regimens. A further Internet search by the patient led to 15 recently published reports, each supporting different regimens of palliative chemotherapy. Mr. Groves tried to reconcile the multiple conflicting sources of information about treatment effectiveness and prognosis. Although he was highly educated, he could not always distinguish between terms such as "treatment response," "clinical remission," "radiographic remission," and "quality of life improvement." He felt increasingly confused and anxious; the more he searched, the less sure and more anxious he became.	**Exchanging information, managing uncertainty:** Effectively using information that patients bring to the consultation **Enabling patient self-management:** Using electronic media **Responding to emotions:** Managing anxiety related to uncertainty and cognitive overload
When Mr. Groves consulted with a local oncologist, he was offered one of the palliative chemotherapy options; other treatments were available only through clinical trials in other cities. Mr. Groves opted not to have surgery but chose to go to a major cancer center in another city to discuss experimental options. He would stay with relatives there.	**Enabling patient self-management:** Facilitating family involvement in care; Reducing disparities in access to care

Textbox 4.2 Case of Randall Groves cont'd from p 83

Treatment phase

Mr. Groves started a course of chemotherapy. He had only mild nausea and no other side effects.

Mr. Groves never spontaneously complained of pain and only described a sensation of abdominal "fullness." However, when a daughter visited from out of town, she noted that he seemed uncomfortable and woke frequently at night. His primary care physician consulted the palliative care team, who made a home visit. They suggested a trial of long-acting opioid pain medication, which improved the patient's quality of life and sense of well-being.	**Exchanging information:** Gathering information about the patient from family members and friends **Making decisions:** Discussing palliation while still in the active treatment phase
Forgotten by the physician, but addressed by the home care nurses and clergy, were discussions about the meaning of the illness to the patient, the process of dying, and the role of the family.	**Fostering healing relationships, responding to emotions:** Introducing psychosocial dimensions into discussions

End-of-life phase

Mr. Groves completed three courses of chemotherapy, two weeks apart, but worsened clinically. Jaundice and ascites developed, requiring paracentesis for comfort. He postponed the fourth and final course of chemotherapy, intending to return in a couple of weeks. His appetite and energy waned. He required increasing doses of oral opioids to control his abdominal discomfort. Mr. Groves and his primary care physician discussed hospice care and suspension of further anticancer treatment.	**Exchanging information:** Discussing treatment failure and transition to palliative care **Managing uncertainty:** Helping the patient articulate end-of-life wishes
Previously active in making decisions regarding his care, Mr. Groves relegated these and subsequent decisions to his girlfriend, who also was his health care proxy. He moved to another city (where she lived) and received hospice care in the home.	**Fostering healing relationships:** Accommodating patients' changing wishes for involvement in decision-making, and increased family involvement
Mr. Groves died two weeks later, more rapidly than anyone expected. The day after Mr. Groves' death, the oncologist called Mr. Groves' girlfriend to tell her that he had admired how Mr. Groves coped with his illness and recognized the girlfriend's role in caring for him.	**Fostering healing relationships, responding to emotions:** Communicating with the patient's family and friends after the patient's death

*Although this case is based on a real patient, details have been altered to maintain confidentiality and to avoid any potentially identifying information.

cer care continuum, information still must be delivered clearly and clinicians should check whether patients have understood. Decision-making also changes during the cancer continuum in terms of content, impact, and scope; but, in general, patients want to be involved in some meaningful way at all times.

There is tremendous variability among patients at any given phase of the cancer care continuum. Thus, each clinician should attend to each individual patient's illness trajectory, needs, capabilities, and preferences. Clinical care involves one patient at a time. Importantly, from a research standpoint, each patient represents his or her unique

model for understanding the particular communication behaviors that are necessary to improve his or her survival, functioning, and well-being.

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Methodological Challenges in Studying Clinical Communication in Cancer Care*

5

This chapter focuses on four major methodological issues in studying communication in cancer settings: measurement of patient-centered communication, mediators between communication and health outcomes, moderators of the link between communication and health outcomes, and study design.

5.1 Measurement of Patient-Centered Communication

Psychometrically sound (reliable and valid) measures of communication behaviors are essential for conducting communication research in clinical settings.[1] *Reliability* refers to the extent to which a measure yields the same number or score each time it is administered. Thus, all other things being equal, the measure should reflect true change in the attribute being measured and not an intrinsic flaw of the measurement itself. Reliability is a necessary but not sufficient condition for validity of a particular measurement. *Validity* is the extent to which an instrument measures what it was intended to measure. In order to evaluate and support the construct validity of communication measures, the specific purpose of each measure and hypothesized associations between it and other constructs need to be specified. Also, because some overarching models of communication, such as the

"patient-centered" model, are multifaceted constructs, each measure generally will assess some aspects better than others.

Communication can be measured with use of a variety of methods, including patient report, clinician report, peer assessment, observational measures (direct observation, video or audio recording), medical records, diaries, and unannounced standardized patients (SPs; actors who portray patient roles consistently and reliably and present covertly in clinical practices with clinicians' prior consent). Each method has different strengths and weaknesses and can yield different results. For example, observational measures often do not correlate strongly with patient perceptions of the same encounter as reported in surveys.[2] However, Tisnado et al.[3] found generally good agreement between medical record and patient survey data measures of process of care in a study of 1,270 patients with diabetes, ischemic heart disease, asthma or chronic obstructive pulmonary disease, or low back pain. Concordance was best for areas in which there was little ambiguity, such as medication use, and worst in situations requiring interpretation and judgment, such as having received "counseling." Similarly, in a study of 500 adults presenting with a physical symptom, there was good agreement between clini-

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cian and patient reports of whether a prescription was given, a test was ordered, and a referral was made, with kappa values ranging from 0.83 to 0.91.[4] However, there was poor agreement about whether the clinician communicated a diagnosis and prognosis; clinicians reported communicating this information in 93% and 78% of visits, respectively, compared with patient reports of receiving this information in 63% and 43% of visits. Such studies do little, however, to elucidate the reasons for the discrepancies. It may have been that physician use of jargon or patient cognitive impairment interfered with mutual understanding of the information exchanged. Or, patients may have understood but then forgotten. Also, interpretation of some elements of communication may be broad, leading to discrepant reporting on the same events. For example, clinicians and patients often disagree on whether "counseling" occurred during a particular encounter, or whether "information about prognosis" was provided.

The most commonly used methods in communication studies to date have been qualitative data from interviews and focus groups and both qualitative and quantitative data from direct observation of clinical encounters and from patient surveys. Focus groups and interviews are useful for eliciting perceptions and gaining insight into possible reasons for behavior.[5] These techniques help ensure that what is important to patients and their families is captured. Often,

the techniques become the basis for the development of quantitative instruments or are used to deepen the researcher's understanding of statistical findings.

Observational approaches have the advantage of providing a direct view of a sample of behavior. However, they can require direct observation and audio recording, which some clinicians find intrusive. Also, clinicians who are not confident about their communication skills may be less likely to participate, thus perhaps limiting the degree of observed variability in clinicians' communication behavior. Although direct observation studies capture the immediate experience of the visit, most cannot account for conversations in prior visits, nonverbal communication, and the overall experience of receiving care. For that reason, some studies in which visits are recorded on either audio or video also involve debriefing of clinicians or patients after the visit to clarify the reasons for their own actions and their perspectives on the other's communication behaviors.[6] Some coding systems have third-party coders listen to or view audio or video recordings and then place the clinician's and patient's verbal and nonverbal behavior into certain categories (e.g., providing information, expressing empathy). However, these coding systems are complex and fail to capture the salience of the acts from the participants' perspectives. Coders require substantial training and experience. Few such systems are based on a particular theory of

communication or patient-centered care. Comparing findings derived from different coding systems can be difficult. There are at least two reports of poor correlation among instruments that claim to measure the same communication construct of the same data set (e.g., patient-centered communication, shared decision-making).[7,8] Observed clinical encounters also can be analyzed qualitatively by applying text-based analytic methods to the actual encounter or field notes generated by the observer. These methods encourage new themes and observations to emerge from analysis of the data.

Standardized patients (SPs) have been used to capture clinician behavior in response to nearly identical stimuli. Using SPs can overcome some difficulties in using real patients to study clinicians' communication behavior:

- Clinicians' patients differ in case mix and patient demographics, thus making comparisons among clinicians difficult.

- Real patients and clinicians tend to self-select and accommodate to each others' behaviors over time.

- The condition in question may occur with low frequency, requiring multiple observations in order to find relevant ones for the purpose of the study.

SPs often carry hidden audio recorders, which allows for subsequent qualitative and quantitative analysis of the interaction. This

approach has documented note-worthy differences in utilization of health services, clinician prescribing, history taking, and communication with patients.[9-16] Standardized patients also can report on their own subjective experience by completing some of the same surveys as do patients. Because they learn some principles of communication and present the identical role to multiple clinicians, SPs become "connoisseurs of care."[17] Compared with real patients, SPs tend to rate clinicians more harshly, thus avoiding very high mean scores characteristic of patient ratings (ceiling effects); and rate individual clinicians with higher reliability.[17,18] In addition, there are larger standard deviations in the scores given by SPs compared with those given by real patients, thus discriminating among clinicians to a greater degree. However, there are some limitations of SP-based methods: training and deploying SPs can be expensive, SP visits by nature are first visits to the clinician,[19] some physical signs cannot be accurately portrayed, and SPs normally cannot undergo invasive procedures that might occur in real clinical settings.

Patient surveys allow the patient to reflect on the effectiveness of communication and the nature of the patient-clinician relationship. There are numerous scales that claim to measure different aspects of clinician communication. Although patients may be considered the ultimate arbiters of patient-centered communication by clinicians, their survey responses

are limited by recall and reporting bias. Many measures demonstrate ceiling effects and small standard deviations. Also, patients' responses to survey items appear to reflect global impressions of the clinician and do not discriminate among different aspects of communication; thus measurements of different constructs (e.g., trust, explanations, listening, autonomy support, clinician knowledge of the patient) share a substantial amount of common variance.[20,21]

Ecological momentary assessment is a method of collecting data as quickly as possible after events take place to minimize problems with recall.[22,23] Using pen and paper, the Internet, or handheld devices, a patient can record answers to survey items or narrative impressions. Different studies have used scheduled entries, entries triggered by specific events (such as a medical visit), or randomly prompted entries. Advances in information technology have increased the potential use of other sources of data for diaries, such as entries into shared medical records, e-mail text, and mobile telephone communications. Much more needs to be learned about the unique value of each source of data, however.

Although family members are present in a large percentage of visits,[24-26] their input is often not recorded or analyzed using observation methods, and the ways in which they affect and are affected by the patient's illness often are studied only in the context of caregiving at home and burnout. In

reality, however, cancer care is most often a web of communications: among family members, among various clinicians, and between the patient/family network and the network of clinicians and clinical teams caring for the patient. However, limited attention has been directed at the assessment of communication among patients, family members, and the health care delivery team. When family members are present during one or more clinical encounters, their input contributes to the evolution of the conversation. Studies of family involvement in care often extend beyond the patient's death. For example, family members tended to perceive that their loved one had a "good death" if they also reported that the health care team listened and were effective in explaining the decedent's condition.[27] Similarly, the input of multiple clinicians should be accounted for in some way. In reality, while dyadic communication may occur during individual encounters, normally the patterns of communication over time are much more complex and include the patient, multiple family members (some of whom may also be patients), and a variety of clinicians of different professional training and specialization. Research methods and design should account for the network of relationships of varying intensity between multiple members of the family and the many clinicians comprising the health care team.

Future research on communication in cancer settings must be designed

to evaluate the relative utility of combinations of different data collection methods and sources of information. The best method of gauging communication may depend on a variety of factors, such as which communication function (e.g., fostering healing relationships, exchanging information) is assessed, and what is the most appropriate source of information for a particular aspect of care. A combination of data from multiple sources is needed to portray communication accurately between providers and patients. Studies involving both qualitative and quantitative analytic methods often yield more insight than studies involving either method alone.

5.2 Mediators between Communication and Health Outcomes

Communication sometimes affects health outcomes directly, but more often these effects are mediated through intermediate or proximal outcomes. Pathways between these proximal and intermediate outcomes of communication and subsequent health outcomes are poorly understood. For example, a patient with prostate cancer may decide to stop hormone therapy after completing radiation therapy if he thinks that his continued need to urinate at night means the treatment is ineffective (an illness representation[28,29]). Nonadherence in this case is due to communication problems: the patient made a false assumption about the treatment and did not ask the clinician for clarification. Meanwhile, the clini-

cian did not elicit the patient's understanding of the illness and its treatment and therefore was unable to correct the misconception. Some links between communication and health outcomes may be immediate whereas others are delayed. For example, communication interventions that improve adherence to chemotherapy for breast cancer will increase symptoms and decrease quality of life initially[30] but increase the duration of survival.

Potentially important mediators between communication and health outcomes were described in Chapter 3 and include improvements in patient knowledge, emotional self-management, patient empowerment, therapeutic alliance, quality of medical decisions, access to care, and social support. Mediation can occur through more than one pathway. For example, a study may involve a comparison of two potential pathways explaining the effects of communication on health outcomes: patient acceptance of treatment and patient self-efficacy. Alternatively, the association between communication and health may be mediated by reaching a high-quality decision (i.e., clinically sound and consistent with patient values), which, in turn, may be mediated by better clinician understanding of the patient's disease experience or better patient knowledge about the disease and treatment options.

One or more mediation hypotheses can be tested using a stepwise process (Figure 5.1). The example illustrated in Figure 5.1 is a study

of a patient activation intervention in which patients are coached to be more participatory in clinical settings, by asking questions and participating to a greater degree in decisions, for example. The figure suggests that an association between patient activation and pain may be mediated by patient adherence to treatment.[31] If this were true, visits characterized by good communication would result in improved pain relief only when the patient took medications as prescribed, and no such effect would be noted if the patient did not adhere to treatment. In order to assess mediation, a series of bivariate models can be estimated to see whether patient activation is associated with pain (Model 1, solid line) and adherence (Model 2, dashed line) and whether adherence is associated with pain (Model 3, dotted line). A multivariate model (Model 4) that uses both adherence and patient activation to predict pain should show that the direct effect of patient activation on pain is smaller than it was in Model 1.

In addition to the stepwise process, structural equation modeling can be used to evaluate mediators directly. Structural equation modeling permits the simultaneous assessment of multiple dependent variables and both direct and indirect effects of one variable on another. Each variable can be treated as both an independent variable and a dependent variable. This approach allows the estimation of latent variables rather than only measured variables and

Figure 5.1 One or more mediation hypotheses can be tested using a stepwise process. The question being tested here is Does greater adherence to medication mediate the effect of a patient activation intervention on lower levels of pain? In order to assess mediation, a series of bivariate models can be estimated to see whether patient activation is associated with pain (Model 1) and adherence (Model 2) and whether adherence is associated with pain (Model 3). A multivariate model (Model 4) that uses both adherence and patient activation to predict pain should show that the direct effect of patient activation on pain is smaller than it was in Model 1.
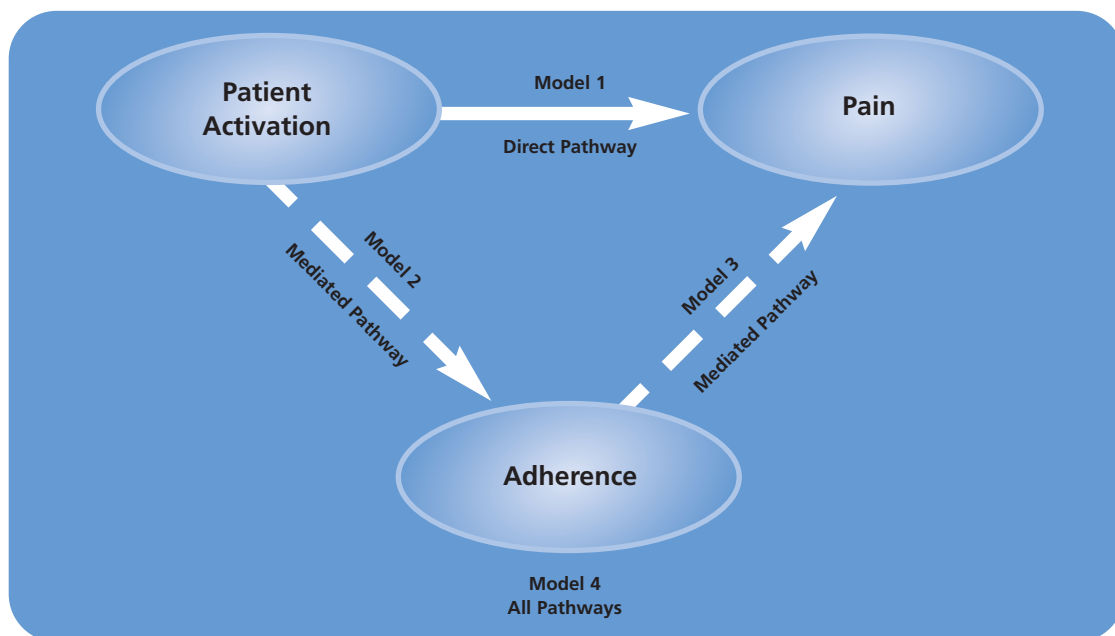
thereby accounts for random error. For example, structural equation modeling was used to provide support for a conceptual model of health-related quality of life developed by Wilson and Cleary.[32] Used with analysis of data on patients after myocardial infarction structural equation modeling demonstrated that the severity of cardiac disease influenced health-related quality of life through two pathways. The first, a direct pathway, was not mediated, whereas the second, an indirect pathway, was mediated by the presence of patient-reported symptoms.[33]

Communication functions also can serve as mediators of health outcomes. A recent study of 272 health plans showed that the percentage of clinical care delivered by staff and group model systems (rather than independent practice association and network models) was significantly related to higher rates of immunization and of screening for cervical and breast cancer, heart disease, and diabetes. However, the type of health care system was not related to patient reports and ratings of care.[34] Thus, although communication may have contributed to better preventive care through other pathways, com-

munication (measured from the patient's perspective) did not explain the relationship between the type of system and preventive care. These findings suggest further research is needed to find changes in health care systems that may be able to enhance the provision of patient-centered communication. These changes may include receiving care at a comprehensive cancer care center, having a health care team to facilitate access to information, and having a "medical home" where the patient could do one-stop shopping for coordination of care.

5.3 Moderators of the Link between Communication and Health Outcomes

Possible moderators of the relationships between communication and outcomes were discussed in Chapter 3 (and listed in Table 3.4). Moderators are variables that qualify associations of independent variables with a dependent variable. A moderator is identified when there is a significant interaction between two independent variables in a regression model. For example, the use of health care navigators to help patients receive adequate follow-up after abnormal findings on cancer screening tests may improve health outcomes for poor patients but not for wealthy patients. Similarly, interventions to improve patient participation in clinical care may have different effects depending on the patient's level of education. Education would be a moderator of the relationship between patient participation in the consultation and subsequent satisfaction with care if patient participation had a positive effect on satisfaction for those with at least a high school degree, and patient participation had a non-significant effect for those without a high school degree.

In research on physiological mechanisms, factors (such as blood pressure) can often be clearly classified as mediators, moderators, or outcomes. In behavioral research, however, the situation is more complex.[35] Patient trust in the physician, for example, can be considered a mediator, moderator, or outcome, depending on the situation. If trust mediates the relationship between information sharing and subsequent agreement to participate in psychotherapy for depression, patients presented with information about depression will choose to undergo psychotherapy only if their level of trust is sufficient. In other circumstances, trust in the physician may be a moderator; trust would moderate the relationship between recommending treatment and actually taking it, if, for example, patients with high levels of trust are more likely than patients with lower levels of trust to take medication as prescribed. Trust is also an intermediate outcome if it is on a pathway linking communication with a health outcome such as lower levels of anxiety. Decisions about whether a particular variable is a mediator or moderator may be based on theoretical reasons, such as testing a model predicting either the mediating or moderating effects of trust, or on empirical evidence, such as trying to uncover reasons why a hypothesized communication-outcome relationship did or did not occur.

5.4 Study Design

Most research on communication in cancer settings is cross sectional, primarily because such studies are less expensive and easier to do than longitudinal studies. In contrast, longitudinal studies provide a stronger basis for demonstrating the development of patient-centered behaviors over time and for drawing causal inferences between communication processes and health outcomes.

By virtue of their rigorous experimental design, randomized clinical trials provide a strong basis for causal inference about the effects of communication function on outcomes. Variables other than the randomized factor(s) that can affect the outcome are controlled by the random assignment of patients to conditions. But randomized controlled trials of communication interventions are challenging because of the complexity of interventions that involve patients, clinicians, and health care systems. In some situations, clinical trials can be impractical, impossible for ethical reasons, or prohibitively expensive. Most randomized clinical trials represent a distortion of clinical practice in a number of ways. They can give a false impression of the effect of treatment at a population level. Also, care provided in the context of a randomized trial is more consistent and more closely monitored than care in the community. In addition, participants who have characteristics that might complicate the interpretation of intervention effects (e.g., other comorbid illnesses commonly associated with the index condition) are excluded. As a result, the participants in clinical trials differ substantially from patients who do not participate.[36] Hence, randomized clinical trials can only suggest what is possible (i.e., efficacy) rather than what actually will happen when an intervention is implemented beyond the confines of the trial. The findings might not generalize to care once it is implemented in other less controlled settings.

Nonrandomized study designs are used when randomized clinical trials are not possible or feasible. The intention of effectiveness research is to document variations in the real world, including factors that are not under the investigator's control (e.g., delays in care, inability to afford a medication), in order to provide a basis for plausible inferences about underlying mechanisms. Because of the weaker study design, making sense of associations is more difficult in nonrandomized studies.

Case-mix adjustment can help by statistically equating naturally occurring groups on variables such as age, education, and indicators of health (e.g., comorbidity) that are measured at baseline. But case mix cannot account for some factors, such as unmeasured burden of illness; in effect, the observed differences are the result of an unknown combination of disease state, treatment effect, and patient and clinician behavior. These factors make inferences about the effects of an intervention difficult. For example, in the Medical Outcomes Study, detection of depression was not significantly related to mental health outcomes. This nonsignificant result was due in part to the fact that sicker patients tended to receive more intensive care, which, in turn, increased recognition and treatment of other conditions such as depression. Because the Medical Outcomes Study measures of sickness failed to fully capture this factor,[37] standard analyses showed no effect. Standard analyses also can show a paradoxical

relationship in which more intensive and higher quality care appears to be associated with worse outcomes.[38] Sophisticated analytic methods such as instrumental variable models may help account for unmeasured burden of illness.[39]

Multicomponent interventions are likely to be more successful than testing of individual elements ("molar" approach). Although each individual element may have a small effect, interventions that focus on synergistic approaches at multiple levels of the health care system (patients, clinicians, care managers, system design) may have a cumulatively larger effect. For a variety of reasons, studies of interventions targeted to more than just the patient or the clinician are rare, as are interventions that include family members and multiple clinicians. Because patients with cancer meet with multiple health professionals, studies of patients' experiences over time require designs of clinicians nested within patients; most prior studies have designs in which patients are nested within clinicians. Also, the unit of analysis for system interventions generally should be the health care system.

5.5 Conclusion

For designing studies in cancer communication research, much can be learned from innovative approaches to measurement, conceptual models, and study design in other areas of research. The role of mediating and moderating vari-

ables has not been explored fully. Longitudinal designs and novel methods of data collection have been used in only a few studies. Sophisticated analytic methods, including multilevel modeling, structural equations, and instrumental variable models may help sort out the complex network of factors that influences the relationship of communication behavior to subsequent health outcomes.

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Summary, Conclusions, and Future Directions

This monograph provides a framework for understanding how patient-centered communication can further the National Cancer Institute (NCI)'s mission to improve survival and enhance quality of life for those affected by cancer. In particular, *health-related* quality of life can be improved when clinicians are attentive to patients' symptoms, functioning, and well-being in the physical, emotional, and social domains[1] across the cancer care continuum. However, improvements in survival and quality of life require effective communication among clinicians, patients, and family members in a health care system that fosters continuous healing relationships and care that is customized to meet patients' needs.[2]

Patient-clinician communication is especially important in cancer settings because of the levels of stress, uncertainty, complex information, and life-altering medical decisions that exist in such settings. Effective communication can ameliorate suffering directly, by enhancing the patient's emotional well-being, and indirectly, mediated by factors such as social support and adherence. Thus, it is important to understand how to improve communication between patients and their family members and the health care delivery team. The importance of communication as a means of achieving the best

health outcomes for patients is further underscored by the Institute of Medicine (IOM) report, "Crossing the Quality Chasm," which identifies "patient-centeredness" as one of six key ways to improve health care and notes that "continuous healing relationships" are a means for achieving that goal.[3]

This monograph has focused on optimizing the communication process between the patient/family unit and the health care delivery team. Because the family is central to patient care and because patients normally are seen by clinicians of different disciplines at various phases of the illness, we have used the term *patient-clinician communication* throughout the monograph as a proxy for communication between the patient/family and the health care team. By clinicians, we refer to all professionals who provide care to patients within the cancer context. By family, we refer to people in the patient's social circle who are most relevant to the patient, regardless of whether they are biologically related. Patient-clinician communication was discussed within the context of the phases of the cancer care continuum, primarily the phases from screening to survivorship and end of life. Cancer prevention is important but is beyond the scope of this monograph.

This chapter provides a brief summary of the overall monograph, a discussion of the gaps in the litera-

ture on patient-clinician communication, and an overview of the priorities for future research.

6.1 Summary of Chapters 1 through 5: Basic Principles, Functions, Mediators and Moderators, and Methodological Challenges

Chapter 1 presents the basic principles of effective communication in cancer care. These principles are based on a philosophy of patient-centered care that embraces three core values: considering patients' needs, perspectives, and individual experiences; providing patients with opportunities to participate in their care; and enhancing the patient-clinician relationship.[4] Patient-centered communication is characterized by verbal and non-verbal behaviors that are intended to accomplish the following:[4-6]

- Elicit, understand, and validate the patient's perspective (e.g., concerns, feelings, expectations)

- Understand the patient within his or her own psychological and social context

- Reach a shared understanding of the patient's problem and its treatment

- Help a patient share power by offering the patient meaningful involvement in choices relating to his or her health

- Build strong patient-clinician relationships characterized by mutual trust, respect, and commitment

Table 6.1 Examples of Behaviors that Clinicians and Patients/Family Must Engage in for Effective Communication

Clinicians	Patients/Family
Listen	Disclose needs
Avoid interruptions	Share information about symptoms and concerns
Organize the visit	Share information about family, culture, and context
Solicit patient's beliefs and preferences	Discuss expectations
Elicit and validate patient's emotions	Voice concerns
Provide clear and jargon-free explanations	Discuss options
Offer encouragement and support	Ask questions

Table 6.2 Examples of Important Outcomes Related to Effective Patient-Clinician Communication

	Outcomes
Proximal	Accurate transfer and understanding of information
	Recognition of and appropriate response to emotional distress
	Establishment of trust and respect
	Mutual and cooperative participation in the consultation
Intermediate	Adherence to clinical guidelines
	Patient satisfaction
	Patient self-efficacy
Distal (Health)	Improved survival
	Enhanced quality of life
	Reduction in health disparities
	Improved quality of care
	Decreased health care costs

Table 6.3 Six Fundamental Functions of Patient-Clinician Communication

Function	Clinician's Role	
Foster healing relationships	Establish mutual trust, rapport, understanding, and commitment	See Appendix A
	Patient-clinician agreement about each others' roles and expectations	
Exchange information	Recognize patients' information needs	See Appendix B
	Integrate clinical information with the patient's illness representations (explanatory models)[7-9]	
	Acknowledge both the content and process of information exchange	
	Use Internet-based resources[10]	
	Communicate prognostic information accurately while also providing hope	
	Overcome barriers related to low health literacy and poor understanding of statistical information	
Respond to patients' emotions	Elicit patients' emotional distress	See Appendix C
	Communicate an understanding of the patient's emotions to him or her	
	Respond with legitimation, validation, empathy, and support	
Manage uncertainty	Acknowledge uncertainty, to allow space for hope[11]	
	Recognize that uncertainty often cannot be eliminated	
	Help to manage uncertainty by providing information, support, and cognitive strategies	
Make decisions	Consider the active involvement of the patient and family in the information-exchange and deliberation stages of the decision-making process	See Appendix D
	Identify who is responsible for the final decision	
Enable patient self-management	Advocate for the patient, including help in navigating the health care system	
	Support patient autonomy	
	Provide guidance to patients about finding information, developing coping skills, and taking actions to improve their health	

To communicate effectively, both clinicians and patients need knowledge, skills, and motivation, as well as a health care environment that facilitates communication (Table 6.1). (See Figure 1.1, page 3.)

Individual communication skills alone are not sufficient. Clinicians, patients, and families must align themselves toward common goals; adapt their communication styles to achieve mutual understanding; be willing to reconcile differences due to beliefs, language, or culture; and deliberate together over difficult decisions. Although individual behaviors have been the subject of communication research, the process of alignment rarely has been studied. Communication should be oriented toward outcomes, especially health outcomes, such as improved survival and meaningful enhancements of health-related quality of life (Table 6.2).

Chapter 2 sets forth a framework for research on patient-centered communication in cancer care, with a discussion of six fundamental functions of communication. These functions are not necessarily hierarchical; rather, they overlap and interact (Table 6.3). (See Figure 2.1, page 19.)

Chapter 3 explores pathways by which communication can lead to improved outcomes, including *mediators* and moderators. (See Figures 3.1 [page 41], 3.2 [page 47], and 3.3 [page 52]; Tables 3.1 [page 40] and 3.4 [page 53].) Two sets of pathways were discussed—those that lead directly from communication to health outcomes, and

Table 6.4 Some Moderators that Influence the Relationship between Communication and Outcomes

Type of Moderator	Variables
Intrinsic	**Relatively immutable**
	Age
	Sex
	Personality
	Health beliefs
	Potentially mutable
	Illness representations
	Knowledge
	Attitudes
	Relationships among the patient, family members and health care team
Extrinsic	Nature and phase of the illness
	Cultural factors
	Social support
	Health care system
	Medium of communication (e.g., electronic, face-to-face)
	Legal and regulatory factors

those that are mediated, i.e., pathways consisting of one or more links between a communication act and a given outcome of communication. Proximal outcomes form the first link and might include improvements in the following:

- Access to care

- Patient knowledge and shared understanding

- Therapeutic alliances (i.e., patient and clinician commitment to the relationship)

- Emotional self-management

- Family/social support and advocacy

- Quality of medical decisions (e.g., informed, clinically sound, concordant with patient values, and mutually endorsed)

- Patient agency[12] (self-efficacy, empowerment, and enablement[13-15])

These pathways link effective communication to intermediate outcomes such as improved adherence, health habits, and self-care.

Chapter 3 also addresses *moderators,* factors that influence the relationship of communication to proximal, intermediate, and distal (health) outcomes. (See Table 3.4, page 53.) Moderators are either

intrinsic (variables intrinsic to clinicians, patients/families, and their relationships) or *extrinsic* (variables external to the individual qualities of clinicians, patients/families, and their relationship) (Table 6.4). Researchers often identify fixed moderating variables such as age and gender, but little is known about *why* such variables affect the relationship of communication to patient health outcomes. For example, age may moderate the relationship between communication and health outcomes because of cognitive decline, low health literacy, lack of shared health beliefs, or limited access to the Internet.[16]

Chapter 4 places each of the functions and pathways described in Chapters 2 and 3 in the context of each phase on the cancer care continuum and provides details about the communication needs; mediators, moderators; and proximal, intermediate, and distal (health) outcomes at each phase (Table 6.5).

Also discussed are important factors that determine the content of communication at each phase. For example, although the *type* of cancer may shape the timing, content, and process of communication to an important degree at the diagnosis phase, it may be less crucial during the end-of-life (palliative care) phase.

Chapter 5 discusses methodological challenges to studying communication in cancer settings. Most descriptive studies have been cross-sectional and have relied on survey methods. Longitudinal studies, mixed-method studies, and studies involving multiple sources of data are relatively uncommon but are needed to establish causal links between communication and outcomes. Measuring communication is challenging because of several factors: the lack of theoretically driven measures, discrepancies in findings depending on how observational data are coded and analyzed, and relatively weak correlations between ratings of audio recorded encounters and patients' subsequent ratings of the same encounter. The chapter also discusses the need to develop more robust measures of proximal, intermediate, and distal (health) outcomes and of the processes accounting for the effects of moderators.

Table 6.5 Examples of Clinician Communication Behaviors that Can Improve Survival and Enhance Quality of Life during Each Phase of the Cancer Care Continuum

Phase	Clinician Behavior
Prevention	Foster health behaviors and promote prevention interventions as appropriate
Screening	Promote efficacious cancer screening practices and follow-up
Diagnosis	Provide emotional support and information Discuss areas of uncertainty and prognosis Encourage patient participation in care
Treatment	Provide emotional support Provide treatment-related information Encourage patients to complete treatment regimens Enhance social support
Survivorship	Help patients manage uncertainty Facilitate coping, functioning, and well-being Watch for signs of recurrence Help patients adhere to recommendations for ongoing surveillance, prevention and treatment
End of life (palliative care)	Help patients make decisions concordant with their values Involve and address the concerns of family members Provide optimal palliation to improve overall quality of life

6.2 Gaps in the Literature and Important Areas for Future Research

6.2.1 Theoretical issues: From descriptive to prescriptive models—Implementing theories of patient-centered communication

From a theoretical standpoint, three issues require further study: the descriptive models of patient-centered communication, communication improvement models, and communication theories that incorporate and inform general theories of health behavior and health psycholog*y*.

Descriptive models of patient-centered communication must be developed more fully. Although there is general agreement about the goals and components of patient-centered communication,[4,6,17] defining it as a set of discrete behaviors is difficult because communication is always interpreted individually within its context. Patient perceptions of care do not completely characterize patient-centered communication either. Their perceptions may relate more to overall impressions of their care and the clinician than to specific features of patient-centered communication.[4] In addition, the elements of patient-centered communication are not necessarily correlated, suggesting that patient-centeredness is a multidimensional construct. For example, a clinician expressing empathy and support is practicing a form of patient-centered behavior. However, this behavior may occur independently of other types of patient-centered communication, such as providing clear, understandable explanations and working in partnership with the patient.

There is a need for a *communication improvement model* that defines specific measurable elements of communication empirically linked to outcomes. These elements should then guide the development of interventions. Thus, the model should be evidence-based as well as theory-driven. To that end, effective communication would be judged on the basis of its ability to achieve a particular intermediate outcome or distal (health) outcome and provide a plausible explanation for this effect. For example, decision-making processes may be defined as patient-centered if they result in improved rapport, shared understanding, and appropriate follow-through. Ingredients of a "good" decision may include patient-clinician discussions of values, goals, clinical evidence, and illness representations and risks and subsequent patient-clinician agreement that the best possible decision was reached.

Theories of communication that incorporate and inform general theories of health behavior and health psychology[7] are needed to explain the relationship of communication to outcomes. Consider examples of such integration. Through their interactions with family, friends, various media, and clinicians, patients construct illness representations,[18] otherwise known as explanatory models[9] or "lay" or "common sense" models of health and illness.[8,19,20] They are an attempt to develop a sensible narrative reconstruction of the patient's life, disease, and illness experience.[18,21,22] These representations are important in cancer care because they influence health decisions (e.g., whether to seek or follow through on care) and coping mechanisms. Communication is linked inextricably to illness representations because these lay models can be constructed, reinforced, or modified during patient-clinician encounters. Moreover, discrepancies between clinicians' views of the patient's health and the patient's own health beliefs can contribute to poor outcomes, such as inappropriate decisions, poor adherence to treatment plans, anxiety and distress, and disparities in care. These discrepancies are more likely in cross-cultural settings, further emphasizing the need to incorporate cultural competency into general communication skills training.

Communication concepts also should be integrated with theories of self-efficacy,[23] self-determination,[24] enablement,[13-15] and agency[12] to show how communication might transform patients from passive recipients to active participants in care and enable them to take a more active role in managing their own illnesses. Relationship-centered care is another construct that may contribute to a theory of how communication contributes to health outcomes.[25]

Table 6.6 Recommendations for Populations and Settings to Be Studied

Patients and families
- Greater attention to
  – Men
  – Racial and ethnic minorities
  – Low-education and low-literacy populations
  – Older patients
  – Gender concordance between clinician and patient
  – Family members and different family structures
  – Wider variety of cancers

Clinicians
- Continue to study oncologists
- Greater attention to
  – Surgeons
  – Radiation oncologists
  – Interventional radiologists
  – Primary care clinicians
  – Nurses
  – Hospice workers

Settings
- Continue to study settings of outpatient oncology offices and clinics
- Greater attention to studies in
  – Hospitals
  – Hospice settings
  – Long-term care facilities
  – Patient homes

6.2.2 Populations and settings studied

Patients and families
Patients most commonly studied are middle-age, middle-class, white women, with at least a high school education. *Racial, ethnic, and educational factors* contribute to significant disparities in access to care, delayed diagnosis, and completion of treatment,[26-34] yet only a few studies in the literature on cancer prevention and decision-making have been designed to evaluate communication factors that may contribute to those disparities.[35] Although studies have tended to focus on middle-age adults, *older patients* have different types of cancer and these cancers follow a different clinical course. Younger and older patients with cancer appear to have contrasting communication styles, yet few studies compare their communication needs and behaviors.[16] Even fewer studies have examined *why* the communication styles of older patients differ from those of their younger counterparts. As previously noted, reasons might include educational, cognitive, attitudinal, or disease-related factors.

Gender and gender concordance have been studied in greater detail, but reasons why these affect communication and outcomes have not been studied. *Families* are essential sources of information, support, and caregiving for patients with cancer, yet communication between family members and clinicians has been studied inadequately.[36] Little is known about how different family structures influence communication in cancer settings. In summary, research is insufficient to guide communication interventions involving patients and families who are non-white, members of ethnic minorities, older than age 70, or have lower educational levels and low health literacy. By understanding pathways that contribute to such disparities as different illness representations, literacy levels, and health care system factors, interventions can be developed to reduce or eliminate disparities in care.

Cancer communication studies in clinical settings have primarily focused on patients with specific types of cancer, especially breast cancer and, to a lesser extent, prostate and colorectal cancer. Fewer studies have involved patients with more lethal cancers, such as cancer of the lung, pancreas, or ovary. The type of cancer is an important element of context that likely affects patient-clinician communication and the relationships between communication and outcomes. Research should include patients with a wider variety of cancers.

Clinicians
The majority of cancer communication studies have involved medical oncologists. Fewer studies have included surgeons and fewer still, radiation oncologists, interventional radiologists, primary care clinicians who care for cancer survivors, and hospice workers. A substantial body of nursing literature on cancer communication exists, but few of the studies involve large enough samples to

link communication to outcomes, and few links have been made between the nursing and physician literatures. There is a clear need for research that focuses on the health care delivery team as a whole, beyond the interactions of individual clinicians with patients and their families. Clinician stress and burnout appear to have a negative effect on the quality of care.[37-39] Healthy approaches to stress theoretically can be developed through clinician, patient, and system interventions,[40-42] but these have not been studied in-depth.

Settings
Settings for communication research generally have been outpatient oncology offices and clinics. However, hospitals can be even more stressful for patients and families, and research should be done with patients in that setting. Studies should also be done in other settings, including homes, hospice settings, or nursing homes to get a richer understanding of communication.

6.2.3 Descriptive research (Table 6.7)

More often than not, descriptive research on cancer communication has been cross-sectional, has been conducted in outpatient settings, has involved patients during the diagnosis and treatment phases, and has focused on a few specific communication tasks, such as the following:

- Patient self-assessed information needs and availability of and preference for different information sources

- Patient recall of information discussed in outpatient consultations

- Differences between clinicians' actual methods of delivering bad news and patients' preferences for delivery of ad news

- Accuracy of physician statements about prognosis and patient preferences regarding frank disclosure of prognostic information

- Correlates of patient preferences for and achievement of preferred roles in decision-making and the effect of different decision-making styles on proximal communication outcomes

- Clinician elicitation of and response to patient expressions of emotional distress

Most descriptive studies of cancer communication have involved patients with breast cancer, followed by patients with colorectal and prostate cancer, with few studies involving patients with forms of cancer that carry poorer prognoses. Cross-sectional communication studies have involved the use of patient surveys and the analysis of audio recordings of consultations with utterance-based coding

Table 6.7 Recommendations for Descriptive Research
- Characterize and study effects of continuous healing relationships
- Analyze patient narratives of illness experiences
- Understand effects of family involvement in clinical consultations in the interpretation of information, involvement in decisions, and caretaking
- Characterize current use of electronic media as an adjunct to or instead of face-to-face communication, including e-mail, shared medical records, and the Internet
- Understand how patients experience and deal with information overload and associated confusion and anxiety
- Understand how communication affects social support within and outside the patient-clinician relationship
- Explore the process of decision-making, including the limits of the concept of shared decision-making
- Investigate the effect of decision aids on communication
- Observe how health care systems currently foster or impede patient/family-clinician communication
- Characterize situations that require dealing with uncertainty and how clinicians and patients discuss uncertainty
- Explore how clinical communication affects patient agency, enablement, and self-care
- Understand the effects of clinician well-being, self-awareness, and burnout on communication

schemes. Some longitudinal studies have documented changes in patients' information needs and their preferred role in decision-making over time. The findings of a few studies have suggested that effective communication about bad news and treatment choices is associated with improved quality of life.

We suggest the following topics as areas for future descriptive research:

- Continuous healing relationships

- Communication environment

- Family involvement in clinical consultations

- Use of electronic media

- Information overload

- Social support

- Decision-making

- Health care systems

- Uncertainty

- Agency, enablement, and action

- Clinician well-being and burnout

Continuous healing relationships
Patients focus on many aspects of their relationships with clinicians—not just communication. Qualitative studies suggest that patients value physicians' enduring characteristics (e.g., caring, connection, knowing the patient as a person) more than specific communication techniques (e.g., expressing empathy, partnership building).[43-49] Collectively, and over time, however, these specific techniques likely contribute to patients' perceptions of clinicians' enduring characteristics. One way in which communication builds healing relationships, for example, is through clinicians' understanding of the way patients make sense of their illnesses (illness representations).[8,9,18-20,50] When clinicians understand these illness representations, patients feel recognized, accompanied, cared for, and healed.[18,51] Qualitative reports can further elucidate the way patients understand their own illnesses and feel understood by their clinicians. In turn, such reports can inform future research on ways of improving and monitoring the quality of continuous healing relationships.

Although communication research primarily addresses single discrete clinical encounters, patients experience visits with clinicians in a more "narrative" way. Over time, a story unfolds, with each contact framed by history, anticipation, and retrospect. By taking a historical and longitudinal approach, some of the paradoxes noted in communication research—such as the relatively low correlations between observer-coded measures and patient self-reports of communication—may be better understood. The goals set out by the IOM's "Crossing the Quality Chasm" report include continuous healing relationships characterized by trust and feeling understood.[3] Longitudinal research enables the study of these relationships as they unfold over time.

Communication environment
Not only do patients have visits over time, they also meet with various clinicians and staff at different phases of the illness. Yet, our knowledge is limited about how patients experience these different personnel and what value they place on these relationships. Studies should examine all interactions in cancer care and, at minimum, assess patients' perceptions and evaluate how different patient-clinician relationships relate to proximal, intermediate, and distal (health) outcomes.

Family involvement in clinical consultations
Cancer has a major impact on family life.[36] Family members attend most cancer consultations in which diagnostic, prognostic, and treatment discussions occur[36] and typically visit frequently when patients are hospitalized. Yet, only a few in-depth studies have considered the essential role of family members in remembering and interpreting information, discussing treatment options with and without the presence of clinicians, providing social support, and providing "terror management" to buffer the effect of devastating news.[36,52-54] Families play a crucial role in improving clinical communication in cancer settings. Clinicians' attitudes toward family involvement generally are positive,[53] but family members can disrupt the patient clinician relationship, lengthen visits, interject their own values, and lead clinicians to offer less emotional support.[55] Clinicians currently make poor use of family

members' potential to improve care and cancer outcomes.

Electronic media

Patients with cancer and their family members often consult the Internet before and between contacts with health professionals.[10] Little is known about how this information shapes patients' illness representations, makes its way into clinical conversations, or influences subsequent patient behavior and well-being. Another type of electronic communication, e-mail, is being used more often by clinicians and patients/families, and the impact of such communication likely will change important processes of care. Although e-mail communication can increase patient access to clinicians, it also may increase clinician workload and lead to stress and burnout. More research is needed on the ways in which electronic resources and e-mail can enhance the care of patients with cancer.

Information overload

Communication research generally has used an information-deficit model, which focuses on patients' expressed needs for more information about an illness and its treatment, prognosis, and psychological impact. Paradoxically, a new generation of Internet-savvy patients and families find themselves with seemingly unlimited access to information and now need help judging its quality and relevance. Information overload can also be a source of anxiety. Often, contradictory or ambiguous information requires clarification by clinicians.

Research may suggest areas for improvement, interventions, and the role of health care systems in providing access to relevant, understandable, high-quality information.

Social support

Clinicians provide social support during their interactions with patients and also facilitate patients' access to social support. How clinical communication can result in increased social support and how social support might mediate the relationship between improved communication and improved health outcomes is poorly studied. Likely factors include neurohumoral and immunological responses to (lack of) social isolation, logistical and financial support, emotional support, and promotion of healthy behaviors through social norms and encouragement. A large body of literature documents the need for and influence of social support, but very few studies have specifically addressed the role of communication.

Decision-making

Several studies on decision-making address the balance of power between patients and physicians in making decisions under uncertain circumstances.[56-62] (See Appendix D for a more extensive review.) However, few of these studies have addressed *how* decisions actually are identified and made in clinical practice. Future research should describe the process by which decisions are addressed, how patients participate in discussions,

and the role of family members in the decision-making process. Determining whether a decision is "shared" may be complex. Observers of the interaction may rate the level of sharing differently than the protagonists,[63] perhaps reflecting differing ability to distinguish acquiescence from agreement. Further exploration of the nature of clinical decisions is needed to guide future interventions. Decision aids, written or video materials designed to enable patients to make independent choices among treatment options, present opportunities to help patients and families participate in the clinical interaction and deliberate when confronting difficult decisions.[64] However, the role of decision aids in facilitating communication is not well studied.

Health care systems

The role of health care systems in fostering communication has been explored minimally, although their role seems pivotal. In one way or another, health care systems control access, the flow of information, use of time, financial incentives, and the structure of health care teams, all of which have an impact on communication and quality of care. Descriptive research on clinical communication in health care systems that have adopted structural changes to improve quality of care would inform future communication efforts. These changes might include implementing team approaches to care, self-management programs, Internet classes for patients, and patient access to electronic medical records.

Uncertainty

From a theoretical and practical standpoint, management of the inevitable uncertainties in cancer care is poorly understood.[65-67] Recent neurobiological research suggests that neurohumoral responses are activated not only in response to but also in anticipation of imagined unpleasant events.[68] These responses lead people to make hasty choices to avoid the imagined pain and anxiety of prolonged uncertainty. Further research can explore how communication raises awareness of, frames, reduces, and/or fosters acceptance of uncertainty across the different phases of the cancer care continuum.

Agency, enablement, and action

There is very little research on how patient-clinician communication is translated into patient action. Descriptive research can elucidate how patients are motivated to self-manage aspects of the illness, acquire information, garner social support resources, and navigate the health care system with and without help from health professionals and family members.

Clinician well-being and burnout

Clinician well-being has a direct impact on the quality of care patients receive.[38,39] Caring for people with cancer is emotionally taxing, burnout is not infrequent, and personal wellness strategies seem to have a positive effect on reported quality of care for patients.[38,40,69-73] However, clinicians' emotional needs and their feelings toward their patients are often not addressed.[74,75] Further descriptive research can explore which self-care strategies and institutional environments foster well-being, reduce burnout, and enable clinicians to deliver higher quality care.

6.2.4 Intervention research (Table 6.8)

Intervention research in cancer communication largely has focused on providing information, enhancing patient recall of information, improving the delivery of bad news, eliciting and responding to emotional needs of patients, advancing patients' information-seeking skills, and increasing patient control of the decision-making process. An overview of intervention research is provided in Appendix E.

A fresh look at improving communication in clinical cancer settings may be needed to meet the goals of improving patient survival and quality of life. As described in Section 6.3.1, the development of a *communication improvement model*, not just a descriptive model of communication, is needed to further intervention research. Although descriptive models are useful for research purposes, health care system planners and change agents need a model to guide interventions; this model should focus explicitly on elements that are likely to make a difference. The research framework should take into account the desirable outcomes and identify theoretical and empirical links between communication and desired outcomes. Planning of interventions should take into account factors related to health care systems—an intervention should be designed and deployed within an environment that can sustain it. Interventions should address several questions:

- *Who* should be the targets of the intervention?

- *What* skills, attitudes, and content areas should be addressed?

- *When* is the intervention most likely to have an impact?

- *Where* should the intervention take place?

- *How* should the intervention be conducted?

The areas for descriptive research listed in the previous section are also areas for potential interventions, but they will not be discussed again here. Four additional considerations should guide future interventions:

- Combining interventions involving health care systems, clinicians, and patients

- Focusing on improving patient access and agency, not just attitudes and knowledge

- Incorporating family and social systems to optimize patient care

- Using all possible communication media to foster continuous healing relationships

To whom interventions should be directed and what behaviors and skills should be targeted

Communication research should test combined interventions that include health care systems changes in addition to targeting clinicians, patients, and ancillary personnel. Research should also focus on families and social systems, not just individual patients.

Most cancer communication studies to date have focused primarily on changing clinicians' (especially physicians') communication behavior.[76-78] Fewer studies have involved patients, and studies involving health care systems are rare. To provide a rationale for combined interventions involving patients, clinicians, and the health care system, we first present a brief overview and explain the limitations of interventions involving only clinicians, patients, or ancillary personnel.

Clinicians

Interventions generally consist of seminars for clinicians that are of three hours to three days in duration. Areas of focus include skills for eliciting patient concerns, expressing empathy, responding to patient cues, handling psychological distress, dealing with emotions, breaking bad news, helping patients manage pain, and working with patients who have limited literacy. The most effective training programs are long-term, involve multiple pedagogical methods, allow for rehearsal, provide timely feedback, and allow clinicians to work in groups with skilled facili-

tators.[76-81] These interventions result in better elicitation of and response to patients' fears and concerns, as well as clearer delivery of information. In addition, the findings of some studies have indicated that the patients of physicians who have undergone such training consequently felt better informed, less depressed, and more in control.[82,83] However, many of these studies are characterized by a small sample size. Use of different measures of communication and health outcomes makes comparison across studies difficult. Furthermore, without incentives to participate, only interested and motivated clinicians attend communication skills courses, leaving the majority—and often those who need it the most—without training. Because experienced clinicians have usually developed rather stable routines for interacting with patients, communication training interventions need to be introduced early in the medical school curriculum.

Changing the behavior of practicing clinicians presents an important challenge for two reasons. First, patient-centered communication represents not only a new set of behaviors and skills but also a fundamental difference in outlook on the patient-clinician relationship, in which the clinician's task is to explore emotional aspects of suffering, not just physical aspects, and to empower—not just inform. Second, it is likely that many clinicians believe that they are "patient centered" because they are caring, thorough, and involved. However, a closer look at their communication patterns reveals otherwise.

It is clear that more intensive clinician interventions yield more substantive and long-lasting results.[76,84] Technology and economy of scale may make some of these interventions more user-friendly, accessible, and affordable. Also, a better understanding of the fundamental skills that clinicians need will help to focus interventions on those skills and attitudes that will truly affect patient outcomes. For example, there is sufficient current evidence to suggest that clinician interventions should ensure that clinicians at least learn to accommodate patients who wish to participate in their own care.[85] However, the effectiveness of these interventions will be diminished if patients are not prepared to participate in their visits or if health care facilities do little to encourage or sustain these training programs. The cost of providing communication training to clinicians should be considered in the context of the suffering and expense incurred by poor communication and the cost of the use of unnecessary or inappropriate cancer treatments and technologies.

Patients

Such interventions as in-person coaching, interactive computer programs, videos of role models, and question prompt sheets provide patients with tools to learn about the disease, ask questions, and participate in decision-making.[86-88] The interventions can improve information-gathering,[88] decrease anxiety, improve recall,[89] and stimulate discussion.[90] Decision aids are used increas-

ingly, but there have been virtually no studies on the role of the aids during clinical visits.[64] Audio recordings of clinical consultations can help improve patient recall and assimilation of information.[91-93] They also raise patient satisfaction[94] and may increase patients' participation at later consultations.[95] Patient interventions paradoxically may decrease patient satisfaction and not affect *clinicians'* communication patterns if the clinicians are not "in tune" with the goals of the intervention, suggesting that combined interventions may have positive effects on communication that clinician and patient interventions alone cannot demonstrate.

Ancillary personnel
Numerous interventions for depression, diabetes, asthma, and other chronic illnesses have involved the use of care managers and/or navigators to educate, motivate, and activate patients to improve their own self-care and to help patients move through the health care system. While some research has examined the role of lay health educators to help patients with cancer manage pain,[96] to date, none has specifically examined how ancillary health workers affect communication between clinicians and patients with cancer.[97] Clearly, if these interventions are to have a future, their incorporation into routine clinical care is essential. It is not clear if care management interventions will work in the long-term as stand-alone interventions in the absence of interventions at the cli-

nician, patient, or health care system level. In addition to such specialists, the role of volunteers, other patients, electronic information systems, and members of the health care team in improving patient navigation should be explored further. Perhaps care managers and navigators may become unnecessary if appropriate changes to health care systems are made.

Health care systems
System-wide interventions have the potential to incorporate and build on interventions for clinicians and patients by coordinating approaches, a variety of health professionals and staff, and financial incentives. The chronic care model provides one way of understanding how health care systems can optimize care, including communication.[98,99] The model includes self-management support, decision support, clinical information systems, delivery system design, and community resources and policies, all of which are aligned to optimize care. Coupled with clinician and/or patient training, improved communication with patients is a likely but unproved outcome of such systems. System-wide interventions benefit from attention to the following:

- Providing leadership to clarify roles and set expectations for good communication

- Setting incentives in the form of compensation, recognition, and job satisfaction

- Involving patients in the redesign of health care systems

- Changing the physical environment, especially in inpatient and emergency room settings, to foster better communication

- Making sure time during a clinical encounter is used to focus on substantive issues rather than administrative tasks

- Developing systems for monitoring the quality of communication

Potential interventions at the practice level include the following:

- Restructuring appointment systems to improve access to health care

- Providing telephone information lines

- Implementing health information systems that provide patients with easy access to health and disease-related information (e.g., patient-friendly websites);

- Implementing shared electronic health records

- Providing cultural competency training for all clinical staff

- Providing interpreters

- Giving patients choices of physicians and health care team members

- Training patients to request appropriate treatment

- Using family meetings routinely

Communication training for clinicians and patients will continue to be essential, but some interventions at the health care system level are likely to change face-to-face communication even without such training. For example, the use of question prompt sheets in the waiting room or health-related websites that can be accessed from patients' homes in anticipation of a clinic or hospital visit can jump-start important clinical conversations. Health care systems also can supplement face-to-face communication by adopting electronic communication systems that support patient-clinician interactions. Allowing patients to write in their personal medical charts also bolsters communication.

Parallel interventions for clinicians and patients may improve the likelihood that clinicians will enthusiastically support patient efforts at self-management. Interventions at the health care system level can improve communication among multiple clinicians by providing a common information system, structural features that facilitate communication, care teams, and shared medical records. These measures are not a remedy for lack of clinician and patient communication skills, however. Combined interventions may be synergistic and should target more than just one of the elements (clinicians, patients, or health care systems). No single element necessarily may be effective alone, just as single-agent chemotherapy often has minimal or short-lived responses.

In order to design and execute communication interventions at the health care system level, programs should involve multiple layers of expertise on health care system administration, health economics, patient advocacy, information technology, and communication technology. Changes that are designed to improve patient-centered care also should measure the effect of these interventions on the quality and ease of communication.

Families and social systems
We noted in the section on descriptive research that family members are frequently present during inpatient and outpatient consultations. How family involvement and family dynamics affect communication and health outcomes is not known. Intervention research can help family members assist the patient in gaining access to care, encourage healthy behaviors, and remember important details that might be forgotten by a patient in distress. Yet, in a recent review,[36] no clinical trials to improve family-clinician communication were identified. The nature of family interventions could include the following: providing information to the family; using prompt sheets and coaching similar to those received by patients; conducting group visits that include patients, families, and clinicians (similar to such visits patients with diabetes);[100] and offering family members the opportunity to write in the patient's medical record (while also ensuring confidentiality). Family interventions may be especially appropriate for patients who lack functional or cognitive capacity, patients who present language barriers for clinicians, and patients from more family-centric or sociocentric cultures.[101] Patients' social networks help improve communication, as well as lend instrumental and emotional support, and should be explored early in the illness. Interventions to improve family-clinician communication should include skills for managing family dynamics and conflict.[53] Outcomes of family interventions should also include measures of family functioning.

Which communication behaviors and outcomes should be targeted

Communication research in the cancer care setting should broaden the focus on several behaviors:

- Establishing continuous healing relationships, not just single encounters

- Helping patients be effective consumers of knowledge, not just passive recipients of information

- Improving social support within and extrinsic to the patient-clinician relationship

- Managing uncertainty

- Process of deliberation for treatment decisions, not just who decides

- Partnership and agency, not just self-efficacy or satisfaction

Fostering continuous healing relationships
We discussed the importance of narrative, history, and longitudinal relationships in the section on

descriptive research. Patients derive comfort and hope simply knowing that a clinician and the staff care about them and will be there when times are difficult. Intervention research to improve communication should target the strengthening of these relationships. At the health care system level, patients should have improved access and continuity. Research should study the mediating effects of the therapeutic alliance on the relationship between communication and outcomes.

Continuous healing relationships involve more than the patient-clinician dyad. As noted previously, interventions should include attention to family members and other members of the health care team. Structuring and evaluating such complex interventions will require qualitative as well as quantitative approaches.

Continuous healing relationships should involve optimal use of all possible communication media. Very little is known, however, about how to incorporate even simple technology, such as e-mail, seamlessly into clinical practice. As information technology continues to change and is incorporated more often into practice settings, it becomes an opportune time for large-scale longitudinal research on the impact of information technology on healing relationships.

Longitudinal studies of relationships will require innovative data collection techniques to reduce the burden on study participants and to obtain high-quality data. In addition to traditional survey and observational methods, data collection can include use of e-mail, Web-based diaries and surveys, text messaging, and mobile telephones. Follow-up intervals must account for the effects of interventions as relationships evolve over time. Also, interventions may have to *occur* over time. Patients' needs, wishes, preferences, and emotions vary during the course of the cancer experience, and this could limit the effect of any single training intervention.

Helping patients be effective consumers of knowledge

With increased access to the Internet, shared medical records, and other resources, clinicians will have to help patients sort through information and put it into the context of their own illness. Clinicians and patients can be trained to engage in more productive sharing of information, but training would be optimized in a health care system that provides access to high-quality health-related information.

Improving social support within and extrinsic to the patient-clinician relationship

Social support has powerful effects on health, yet the potential of patient-clinician communication to broaden social support has not been explored in-depth. The mediating effect of social support on the relationship between communication and outcomes may be best explored in intervention studies that include components that enable patients to better use their social networks and form new ones.

Managing uncertainty

By moving beyond a model that attempts to minimize uncertainty, interventions may be able to help patients and clinicians tolerate and work with uncertainty. These interventions should have both affective and cognitive elements. Particularly important is the avoidance of anxiety-driven premature closure of decisions that would otherwise benefit from more discussion and deliberation. Realistically framing uncertainty as providing both threat and hope can lower anxiety over the long run. In contrast, reassurance often leads to a transient reduction in anxiety, followed by a quick rebound to previous or higher levels.[102] Very few studies have been done on eliciting the patient values that would influence the outcome of decisions made under uncertainty. Presenting clinical evidence to patients in ways that can be easily understood and incorporated into decisions is also crucial to managing uncertainty.[103] For example, recent studies demonstrate that the use of graphical displays can enhance patient understanding and reduce reliance on anecdotal information during discussions of risk.[104-107] Further studies might explore how the use of graphics influences oral communication and whether electronic and paper media for displaying graphics are equally effective.

Four types of uncertainty have been proposed by Saunders:[108]

- Interpersonal uncertainty or uncertainty in communication occurs when people do not say

what they mean or the intended message is understood by the receiver in more than one way.

- Uncertainty arising from lack of knowledge occurs when the clinician or patient is unsure, but there is an answer available that can reduce uncertainty.

- Uncertainty in application occurs when the available scientific evidence is known, but there is still doubt about what to do because the populations studied differ from the patient in important ways, the findings are conflicting, or there are no data on outcomes of importance.

- Moral uncertainty occurs when the goal of the clinical intervention is unclear, such as whether the patient wants aggressive treatment with a known probability of effectiveness even if it might involve greater discomfort.

Each of these types of uncertainty requires a different approach to communication.

Improving the process of deliberation for treatment decisions
As noted previously, most decision research in cancer has focused on *who* makes the decision, presuming that there is conflict between, or mutual ignorance of, patients' and clinicians' values. However, optimal decision-making is a process that achieves mutual understanding by revealing the clinicians' and patients' respective thoughts and reconciling differ-

ences between the two. Although there have been calls to study deliberations during decision-making,[57] few studies have been done in cancer settings, and no interventions have been directed at both clinicians and patients.

Enhancing partnership and agency
Self-management programs for patients with chronic disease focus on several features that may optimize outcomes in cancer settings. (See Tables 4.1 [page 68] and 4.2 [page 70]). Although empowered patients have a sense of self-efficacy, they also need the means to identify problems, set goals, actively access resources, solve problems, and use physicians and a variety of other health professionals as partners in care. It remains unclear, however, which clinician communication behaviors promote self-care and self-management, and what combination of patient, clinician, and health care system interventions is necessary to transform fundamentally clinician-directed care to partnerships. Further research should identify the phases of cancer self-management during which interventions are most appropriate and most likely to influence health outcomes.

Which phases of the cancer care continuum should be targeted

Most cancer communication studies involve patients making decisions about screening or patients with newly diagnosed cancer considering treatment choices. Additional intervention research is needed at these phases, but perhaps

more important is the strikingly low number of studies that have explored communication issues for cancer survivors experiencing anxiety about recurrence and functional disabilities as a result of the disease or its treatment. When patients are dealing with recurrence and treatment failure, they frequently must decide between third-line treatments with limited or unproved effectiveness and comfort care. But clinicians have very little research to guide them in presenting information and helping with these difficult decisions. In addition, few interventions address patients' needs for information and emotional support, decision-making, and managing uncertainty from diagnosis through survivorship.

Longitudinal interventions with reinforcement and accommodation to changing clinical realities may provide patients and families with needed continuous healing relationships. Just as cancer treatment involves different modalities offered sequentially—some of which are intensive and some of which take years—sequential longitudinal communication interventions may yield the best outcomes.

How and when interventions should occur

Drawing from complexity theory articulated in the IOM's "Crossing the Quality Chasm" report,[109] the timing and context of interventions may be as important as the interventions themselves. As mentioned previously, clinicians develop rela-

Table 6.8 Recommendations for Intervention Research

Whom and what to target
- Develop inexpensive, user-friendly, accessible, and affordable clinician interventions
- Study patient interventions in a wider range of clinical settings, with use of electronic media, and in combination with clinician interventions
- Study the effects of care managers, navigators, and other personnel on the quality of care and patient outcomes
- Focus on families and social systems, not just individuals
- Focus on health care systems, not just clinicians, patients, care managers, and navigators
- Develop system-wide interventions to incorporate and build on interventions for clinicians and patients
- Consider self-management support, decision support, clinical information systems, delivery system design, and community resources
- Study combined interventions rather than single elements

Which communication behaviors and outcomes to target
- Focus on continuous healing relationships, not just encounters
- Focus on helping patients be effective consumers of knowledge, not just passive recipients of information
- Focus on improving social support within and extrinsic to the patient-clinician relationship
- Focus on managing uncertainty
- Focus on the process of deliberation when making important treatment decisions, not just who decides
- Focus on partnership and agency, not just self-efficacy or satisfaction

Which phases of the cancer care continuum to target
- Continue current research topics
  - Screening decisions
  - Treatment choices for patients with newly diagnosed cancer facing treatment choices
  - Palliative care decisions
- Future research topics
  - Communication during the treatment phase
  - Survivorship, including the experiences of cancer survivors who have recurrence
  - End-of-life care
  - Longitudinal interventions across phases

tively stable communication styles during training, and it may be more difficult to change in later years. Thus, early intervention at the medical school or residency level is likely to have a greater impact on overall communication style. Patients, on the other hand, generally have little experience with physicians, and training may be more effective when they are confronting a serious illness later in life. Although this concept appears logical, communication improvement models would depend on knowing when these interventions actually have the greatest effect.

6.3 Methodological Issues in Communication Research in Cancer Settings (Table 6.9)

6.3.1 Study design

Most descriptive research in cancer settings is cross-sectional. Longitudinal studies illuminate the development of patient-centered behaviors over time and facilitate causal inferences linking communication processes with patient health outcomes. Despite calls for longitudinal studies for more than 20 years,[110] these studies are rare, probably because of their expense and complexity. Randomized controlled trials of communication interventions are challenging because of the complexity of interventions that involve patients, clinicians, and health care systems. A considerable number of randomized trials have proximal endpoints that measure only communication

behaviors and immediate outcomes, not intermediate or health outcomes.

Because patients with cancer meet with multiple health professionals, studies of patients' experiences over time may require designs of clinicians nested within patients, the opposite of the traditional patient-nested-within-clinician design using a convenience sample. Also, health care system interventions ideally would use the system as the unit of analysis. Patients' experiences are, by definition, incompletely captured using rating scales. Hence, a qualitative component of intervention studies can provide valuable information about how the intervention is received. There exists a considerable body of knowledge involving design of mixed-method studies in primary care that can be applied to cancer settings,[111] including randomized controlled trials of health care system interventions. There are limitations to the use of real patients, including differences in clinician case-mix and self-selection of clinicians and patients. Observational studies and randomized trials can be conducted with use of standardized patients to overcome some of these challenges, and this topic is discussed in Section 6.4.7.

In some cases, randomized controlled trials are impossible for ethical reasons, are impractical, or are prohibitively expensive. In those cases, it is possible to carry out carefully designed cohort or descriptive studies using qualitative and mixed-method methodol-

ogy borrowed from educational program evaluation.[112]

6.3.2 Interventions

As noted previously, multicomponent interventions are more likely to be successful than a molar

approach of testing individual elements. Although each individual element may have a small effect on communication and outcomes, synergistic approaches at multiple levels of the health care system may be more effective.

Table 6.9 Recommendations for Methodological Issues

Study design
- Randomized trials
- Mixed qualitative-quantitative studies
- Longitudinal design
- Intermediate and distal outcomes
- Nesting clinicians within patients and nesting patients within clinicians
- Evaluation of educational programs

Theoretically informed choice of pathways and intermediate and health outcomes
- Improved patient knowledge and shared understanding
- Improved access to care
- Improved therapeutic alliances
- Improved emotional self-management
- Stronger family/social support and advocacy
- Improved quality of medical decisions
- Improved patient agency

Data sources
- Current
  - Patient surveys
  - Interviews
  - Focus groups
  - Observations (direct or audiotaped) of practice
- New methods
  - Patient or clinician diaries
  - Entries into shared medical records
  - E-mail text
  - Critical incident reports
  - Unannounced standardized patients

6.3.3 Defining relevant pathways and intermediate and health outcomes

There is a need to explore *which* intermediate outcomes best reflect (and are most sensitive to) changes in communication and which are most closely associated with health outcomes. These intermediate outcomes then can be used as indicators of future changes in health outcomes or as proxies for the moment-to-moment behavior that occurs in clinical settings, which can otherwise be difficult to measure. For example, consider the case of a man with prostate cancer who stops hormone therapy after treatment with radiation has ended because he thought his continued need to urinate frequently at night indicated that the treatment was ineffective (an illness representation). In this case, poor adherence, which also leads to poorer outcomes, is a result of communication failure because the patient is making false assumptions about the treatment.

Another question to explore is *which* intermediate outcomes are most closely associated with improvements in quality of life and survival. Different intermediate outcomes may link various communication functions with various aspects of health-related quality of life. Also, some links may be immediate and others, delayed. For example, communication interventions that improve adherence to long-term hormone therapy for breast cancer will likely improve survival but may increase symptoms and thus decrease quality of life in the short-term.

Research should explore the following hypothesized pathways between communication and health outcomes:

• *Improved patient knowledge and shared understanding*

This pathway encompasses the translation of information into useful knowledge, the effect of useful knowledge on anxiety and well-being, and the attainment of a shared understanding when clinician and patient understand and align illness representations.

• *Improved access to care*

This pathway encompasses societal and health care system issues, navigational resources, and patient empowerment and enablement.

• *Improved therapeutic alliances*

As stated previously, one of the functions of communication is to foster continuous healing relationships. Once formed, the therapeutic alliance may also have a mediating effect on the pathways from communication to health outcomes. Studying this pathway should incorporate mixed-method research, given the discrepancies noted between what patients report in unstructured qualitative interviews and the content of commonly used survey instruments. (See Appendix A for a more extensive discussion of healing relationships.)

• *Improved emotional self-management*

Emotions have an important effect on well-being; however, only a few of the many possible mechanisms that help patients make sense of the terrifying events surrounding the diagnosis and treatment of cancer have been explored. Enhanced social support is one of those mechanisms. Equally important may be provision of timely information, a continuous relationship with a health care team, and assistance in navigating the health care system. Also, the ability to manage uncertainty depends on and also affects the patient's emotional state.

• *Stronger family/social support and advocacy*

There is a large body of literature linking social support to health.[113] However, of the four mechanisms described in Chapter 3 (and Figure 3.3), it is not clear which of these is most appropriate at each phase of the cancer care continuum or with different types of patients and settings. Social networks can improve health outcomes by setting social norms for and facilitating healthy behaviors, offering financial assistance, providing a sense of connectedness, lowering physiological arousal, and increasing self-efficacy. However, there is a need to understand *how* communication affects social support and which communication-related changes in social support, in turn, affect health outcomes.

• *Improved quality of medical decisions*

Criteria for high-quality decisions should include evidence that the decisions are clinically informed, concordant with the patient's values, and mutually endorsed.

• *Improved patient agency*

The links between self-efficacy, empowerment, and enablement are poorly understood. Measures of the latter two constructs have been developed only recently, yet are important in understanding how communication might lead to improved adherence, health habits, and self-care.

6.3.4 Defining and describing important moderators of the relationship between communication and health outcomes

Space limits our ability to discuss all of the potential moderators of the relationship between communication and outcomes. (See Table 3.4, page 52.) However, we consider three moderators to be particularly important and in need of future research: social distance, health literacy, and social networks.

Social distance
Social distance is the discordance between clinicians and patients with regard to interests, values, beliefs, and assumptions. This moderator may provide an explanation for effects related to differences in educational background, social class, race, ethnicity, and gender. The general communication literature suggests that patient reports of lower satisfaction with greater social distance may not be supported by direct observations of communication behavior.[114] This raises two questions: Are we looking at the right elements of communication? Is social distance the moderator of the observed effects,

or are there other factors more proximal to the communication behaviors that might be more relevant?

Social distance can be seen as a combination of several demographic characteristics that may not occur independently; that is, differences between two ethnic groups may also include differences in skin color, language or dialect, economics, and educational background. Also, social distance is associated with other moderators that have a more direct theoretical relationship to communication, such as increased anxiety in the presence of someone who seems different, lack of a common illness representation, and misunderstandings due to different word usage.[115] Supporting that view is the observation that disparities in communication related to social distance may be the result of a patient's prior impressions based on stereotyping, which change only gradually as he or she gets to know a clinician better.[116] As another example, although age has been associated with a more passive decision-making style and fewer requests for information,[16] age-related differences may be far less or even disappear when highly educated, literate, nondepressed, cognitively intact seniors who use the Internet are compared with similar younger counterparts. By framing the moderators as behavioral variables, they may be perceived as amenable to change, in contrast to demographic characteristics, which are not. Thus, it is not unreasonable to propose that bias related to the

initial perception of social distance can be attenuated through patient-centered communication. Greater cultural competency may manifest as a reduction in the moderating effect of social distance on the relationship between communication and outcomes.

Health literacy
The effectiveness of interventions to improve patients' communication skills, agency, and self-care may be moderated by health literacy.[117] Similarly, a balanced presentation of treatment options may also increase patient participation in decision-making more for literate patients who have sufficient background knowledge to understand the health issues involved.

Social networks
Social networks may moderate as well as mediate the relationship between communication and outcomes.[113] For example, the degree to which a patient follows through with a treatment plan may be moderated by the degree of others' support for the plan. Although identification of moderating variables is important, it is equally important to understand *why* these variables have a moderating effect.

6.3.5 Study populations

Most patients enrolled in cancer communication studies represent a narrow spectrum of patients and families affected by cancer. Men and family members of patients with cancer are studied less frequently than women. Members of linguistic, ethnic, and racial minorities, and patients with low

literacy and educational levels are under-represented in cancer communication research; these patients typically have worse prognoses with similar illness burdens. Also, more studies are needed involving patients with cancers associated with poor prognosis. These studies should address the survivorship phase, time of relapse, process of considering experimental therapies, and palliative care.

6.3.6 Data sources

Currently, patient surveys and audio recordings of clinical consultations constitute the majority of communication data in quantitative studies, and interviews, focus groups, and audio recordings or direct observations of practice dominate qualitative studies. However, the use of other sources, such as patient or clinician diaries, entries into shared medical records, e-mail text, standardized patient encounters, and critical incident reports, is now more feasible, given advances in information technology. Diaries allow for moment-to-moment assessments of "life as it is lived"[118] by sampling patients' emotional states, physical symptoms, or critical experiences shortly after they happen. Longitudinal data obtained from studies involving diaries often reveal patterns not seen in retrospective reports. Unannounced standardized patients—actors who present covertly in clinical practices with clinicians' prior consent—have been used in health services research to document important differences in prescrib-ing, history-taking, and communication behavior.[119-125] Standardized patients offer the advantage of presenting clinicians with nearly identical patient presentations, thus eliminating variability due to case mix, patient and clinician self-selection and accommodation, and other sources of unexplained patient variance. Standardized patients can be deployed in a variety of settings and are detected less than 15% of the time. Other data sources, such as shared medical records, are still relatively undeveloped. The utility of these different data collection methods and sources needs to be examined in future research on communication in cancer settings.

6.3.7 Measurement tools

General principles
Measures should be based on theory and theoretical relationships among communication functions, pathways, and outcomes. Obviously, richer qualitative description of some elements will always be necessary.

Measurement of communication: directly observed and patient-reported
Communication measures can be general, applying to all communication situations in health care, or specific to particular contexts, such as delivery of bad news or decision-making. They also can be process-oriented, categorizing the type of linguistic event (e.g., asking questions, social talk), or content-oriented (e.g., providing prognostic information). We have identified six key communication functions in this monograph, and psychometrically sound measures of all six functions are lacking. Oftentimes, existing measures use similar nomenclature to measure distinct behaviors and/or use different nomenclature for similar behaviors.[4] Measures based on audio or video recorded coding schemes of the actual interaction often do not correlate strongly with measures that are based on patient perceptions of the same encounter noted in surveys.[77] In order to successfully monitor and improve the delivery and impact of communication in clinical practice, measures of the key functions must capture, over time, in a reliable and valid manner, the interactions of patients and their families with multiple members of the health care delivery team.

Following are some considerations drawn from a recent set of published recommendations:[4]

- Communication measures should be theory based and empirically validated. Particular attention should be focused on correlations between the specific measure and future intermediate and distal (health) outcomes. The aspects of communication being measured should be clarified; "patient-centered communication" currently has so many connotations that measures of it are likely to represent very different aspects of a multifaceted construct. Components of a measure should be described, and the

theoretical links between those components should be made explicit. Also, theoretical and empirically derived pathways from communication to outcomes should include a theoretically plausible link as well as measures of proposed mediators along the pathway.

- Communication measures should reflect what is important to patients and families. Researchers have noted differences between the way patients describe their experience of care in qualitative studies and the findings of surveys or observational coding of clinical encounters. Thus, there is an important role for focus groups, cognitive interviews, and ethnography in the development of measures.

- Measures should account for all relevant participants in the interaction. When family members are present or there is more than one clinician involved in the patient's care, their contributions to the conversation should be recorded and analyzed. Also, patient's perceptions of communication should include observations of their interactions with other relevant health professionals. Surprisingly, even though family members are present in most interactions in which diagnosis and treatment options are discussed, their contributions rarely are acknowledged and thus, important data and interactions are missed.

- A balance between general and disease-specific or function-specific communication measures should be sought. Communication measures should be individualized for the purpose studied. Attempts to create single measures encompassing all relevant elements of communication have not been sufficient and have often yielded paradoxical results that cannot be explored in greater depth. However, general measures can allow for comparison across settings. A similar set of principles also applies to the measurement of outcomes, mediators, and moderators.

- Outcomes measures should be standardized. There are numerous measures of health-related quality of life, both general and disease-specific or situation-specific.[126-133] Different measures will likely be sensitive to various communication interventions for different diseases at distinct phases on the cancer care continuum. However, this creates difficulties extrapolating results from one study to another in different contexts. The Functional Assessment of Cancer Therapy (FACT) scales offers a partial solution by providing a "family" of scales, each of which incorporates common general outcomes measures as well as disease-specific or situation-specific outcomes.[132-135]

- Measures of relevant mediators and moderators should be

standardized. Standardized measures of social support or agency/enablement may allow for comparisons across studies. Measures of the structure and functioning of health care systems are needed to monitor the effects of interventions at the system level. Although instruments to capture patients' subjective experience of care are available,[136] they do not identify structural elements, such as availability of multidisciplinary teams and shared medical records.

6.4 A Timeline for Future Research

A solid framework of interaction-based descriptive research and randomized trials indicates that communication is a central feature of high-quality care for patients and families affected by cancer. The field is ripe for interventions to improve the survival and quality of life of people affected by cancer, including patients, their families, and clinicians. However, several elements need to be better developed to improve the likelihood of success of large-scale interventions and further descriptive research. These elements include the following:

Defining pathways from communication to health. Research design should be informed by an understanding of which factors mediate and moderate the relationship of communication to subsequent health care and health outcomes. Some of these factors could be

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studied in naturalistic descriptive investigations. Others require pilot trials of interventions, particularly to study innovations such as the use of electronic communication media or rarely encountered behaviors such as use of empathy. These likely would be single-institution endeavors initially. Understanding these pathways will then inform what types of measures should be developed to describe relevant communication behaviors, intermediate outcomes, and health outcomes.

Creating better infrastructures for data management. Longitudinal studies involve ongoing interventions, continuous data collection, and long-term surveillance of outcomes and communication behaviors. Data from current and past communication research tends to remain where it was collected and does not include standardized measures, limiting the usefulness of the data to other researchers. In the future, data should be sufficiently standardized and easily accessible so that multiple outcomes can be studied over time. Surveillance can be applied to communication (e.g., What percentage of patients with cancer are being told accurate prognoses? To what extent do clinicians assess patients' understanding of these estimates?) in the same way it is applied to other clinical variables.

Creating research networks and consortia. Interventions at the health care system level likely will require large numbers of participants. Thus, consortia of clinicians, clinical practices, and health care

systems will improve the chances for success. These consortia can be at two levels. First, networks of cancer clinicians, including surgeons, interventional radiologists, oncologists, radiation oncologists, nurses, and technicians, can facilitate clinician and patient interventions across institutions. Because only the largest health care systems in the United States would have sufficient patients, resources, and clinicians to conduct large longitudinal trials, consortia of health care systems will be necessary to study systems interventions in most settings.

Creating programs of research. Communication research should graduate from the cottage industry of individual studies to linked programs of research. Currently, funding for communication research that involves studying interactions between clinicians and patients is supported by grant mechanisms, which, by nature, have a three-to-five-year horizon. Cancer, however, can be a disease that affects people for many years or decades, taking into account long-term sequelae of the disease, its treatment, and the uncertainty of a cure. Programs could be positioned to create longitudinal data warehouses accessible to investigators nationwide and to tackle some of the difficult issues in the long-term care of patients and families affected by cancer.

6.5 Conclusion

Cancer will affect 40% of individuals in the United States at some point in their lifetime if current trends continue, and 64% of them will survive five years or more

after diagnosis. Currently, 10 million Americans are living with cancer or are survivors of cancer, accounting for 3.5% of the population.[137] Reducing mortality and relieving suffering associated with cancer requires effective communication between clinicians and their patients and family members in the context of a health care system that supports these efforts. Communication is ubiquitous during all phases of the cancer care continuum, from prevention through survival and end-of-life care. Currently, patient-clinician communication occurs most commonly in face-to-face outpatient and inpatient settings. However, this is changing, and electronic communication will play a greater role in the future. When effective, communication creates shared knowledge and understanding, reduces clinical errors, leads to medically sound decisions concordant with patients' values, facilitates participation in care and follow-through, and helps patients cope and find meaning. Communication is a *sine qua non* of cancer care.

This monograph has provided a preliminary roadmap for understanding how communication can improve health and health care for all Americans facing cancer. The field of cancer communication research has provided important insights into how effective communication can meet patients' information needs, assist with decision-making, and provide emotional support. Historically, research has been hindered by several factors:

- Lack of coherent theoretical and conceptual frameworks: we have attempted to provide the latter and have suggested the means for developing the former.

- Lack of common measures: we have suggested principles for developing measures of communication.

- Lack of agreement on relevant outcomes: we have provided a framework of proximal, intermediate, and distal (health) outcomes that can guide future research,

- Focus on only a few patient populations, types of cancer, and phases of the cancer care continuum: we have suggested expanding research to include all types of cancer and phases of the continuum.

- Interventions that concentrate on either patients or clinicians and not both: we have suggested mixed and synergistic interventions involving clinicians, patients, and families.

- Lack of considering factors related to health care systems that may improve communication: we have suggested some organizing principles for involving health care systems factors in communication research.

Researchers also should turn their attention to communication challenges faced by minority and disadvantaged populations, patients in the survivorship or end-of-life phase of the cancer care continuum, and family members and friends. Communication interventions should focus on creating continuous healing relationships, helping patients and family members to be effective consumers of health-related information, improving social support, managing uncertainty, activating patients to take a greater role in clinical consultations and their own self-management, and preventing caregiver and clinician burnout. Interventions must also target or take into account health care systems factors that can support or undermine efforts to improve clinicians' and patients' communication skills.

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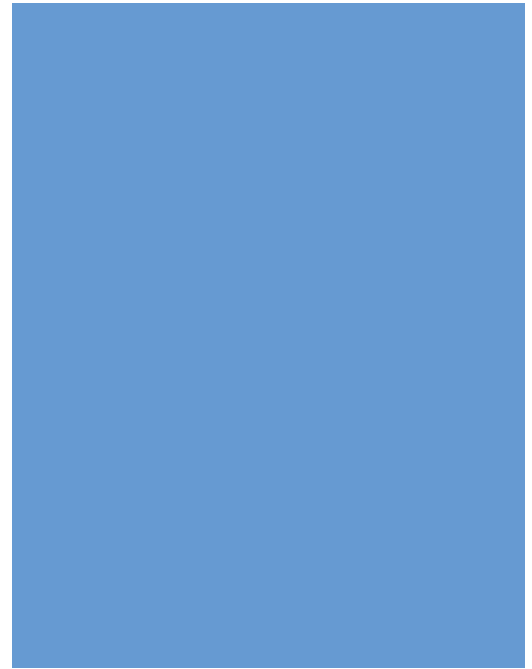
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Appendices

Communication and Healing Relationships in Cancer Settings

The literature on how patient-clinician *relationships* affect patient-clinician *communication* (and vice versa) is sparse, and even less is known about the patient/*family*-clinician interactions in cancer care. What follows is a review of selected relevant articles from the cancer literature as well as the general communication literature.

A.1 Understanding the Patient-Clinician Relationship

Most quantitative studies of communication focus on the accomplishment of specific communication tasks (e.g., delivering bad news, sharing information, or making decisions), but qualitative studies of patients and families dealing with cancer have tended to characterize the ways that these behaviors occur within relationships with clinicians. Clinicians are more than sources of information and expertise; they provide emotional support, guidance, and understanding.[1-3] The findings of several studies have suggested that patients with cancer value clinicians' enduring characteristics more than specific communication techniques.[4-6] For example, Butow et al.[7] reported that the most important factors in communication of prognosis to patients with metastatic cancer was that the communication be within a caring, trusting, long-term relationship and that there be open and repeated negotiations for patient preferences. Salander and Henriksson[8] found that patients reported that being "connected to health care" and "acknowledged as a person" by their clinicians' as the most important features of their care, more so than the provision of information. Patients' perceptions of their clinicians' overall interpersonal style can be quite nuanced. Some patients, for example, distinguished among "inexperienced messengers," "emotionally burdened," "rough-and-ready experts," "benevolent but tactless experts," "distanced doctors," and "empathic professionals" when discussing transitions to palliative care.[9] These perceptions may partially account for patients' tendency to rate clinicians according to an underlying global sense of the clinician rather than according to specific behaviors, even when those behaviors are explicitly listed as items on a survey.[10]

Therapeutic relationships with clinicians can help patients adjust better to their illnesses.[3,5,11,12] However, the mechanisms by which an enduring, strong relationship is formed and how a trusting relationship facilitates communication and helps patients adjust to their illnesses, is poorly understood. Some clues to the interactions between communication and

relationships have been explored qualitatively. For example, communication may lead to a patient's greater sense of "being known"[13] by his or her clinician. Warmth, caring, and confidence may be communicated more through nonverbal channels than through verbal ones Physicians' tone of voice may affect patients' confidence in them and has even been correlated with the likelihood that a physician was sued.[14] Effective communication presumably is a key to strengthening relationships and providing patients with a greater sense of support.[1] Conversely, a global sense of trust, warmth, and caring also may allow for forgiveness for, and repair of miscommunications and medical errors.

A.2 Patient Participation in Care

Regardless of their preferred roles in making medical decisions, patients generally want to be involved in the process of care, be informed of all their treatment options, feel as if they were listened to, and feel as if their physicians know them as people not simply diseases.[15-17] In order to be involved and feel understood, patients must be able to effectively and actively communicate their needs, concerns, and perspectives.

From a communication perspective, active patient participation may be defined as the extent to which patients produce verbal responses that have the potential to significantly influence the content and structure of the interaction, as well as the clinicians' beliefs and

behaviors.[18,19] Particularly powerful linguistic behaviors include asking questions, being assertive (e.g., offering opinions, introducing topics, making requests), expressing concerns and feelings, and telling one's health story (i.e., discussing health within the context of daily living). In general, compared with less assertive (passive) patients, patients who use these behaviors more often[20-24]

- Have increased satisfaction with care

- Receive more information and support from clinicians

- Are more committed to treatment plans

- Have a better understanding of treatment options

- Experience greater improvement in health

Although clinicians sometimes complain about overly talkative and controlling patients, many clinicians believe patients' communicative openness is desirable.[25] Clinicians report that active communication reveals valuable information about patients' health needs and beliefs[26,27] and contributes to treatment recommendations better suited to an individual patient's life circumstances.[28]

In order to be more active communicators, patients need to have sufficient cognitive and linguistic resources and skills, believe in the legitimacy of their participation, and interact with clinicians who support their involvement.[18] In studies that have included use of

observational and self-report measures, cancer care and cancer prevention settings, patients are more active participants when their clinicians use more partnership-building and supportive talk (e.g., reassurance, encouragement).[29-32] Other communication strategies of clinicians that encourage greater patient involvement include explicit agenda-setting, active listening, checking of understanding, and nonverbal behaviors conveying empathy and warmth.[33] Even if they wish to be actively involved, patients with low health literacy may lack sufficient knowledge to adequately understand treatment information[34] and lack the linguistic repertoire to produce elaborated, fluent conversational contributions.[35] This fact may explain why the findings of one study indicated that educated patients with breast cancer were more actively communicative in their cancer consultations than were less educated patients.[30] Patients' communicative self-efficacy is also related to their perceptions of greater participation in cancer care consultations.[29] Some patients, especially older patients[36] and patients from Mediterranean and Asian cultures,[37] are more likely to prefer passive roles and paternalistic relationships with clinicians. However, there is substantial variability among members of these groups, and it is not clear how fixed their preferences actually are.

The quality of the patient-clinician relationship and the degree of patient participation in cancer consultations are inter-related. As an

example, a patient's greater trust and rapport with his or her clinician lead to more openness and a willingness to discuss personal and sensitive topics.[38] This assertion is supported by observations that black patients often have less trust in physicians and the health care system, which in turn, may be one reason black patients may be more cautious and less engaged in their interactions with clinicians compared with white patients.[39] On the other hand, trust may create less of a need for information.[4]

A.3 Clinician Self-Awareness and Well-Being

Communication requires clinicians' ongoing capacity for self-monitoring.[40,41] Identification of patients' concerns,[42] recognition of changes in clinical status, exploration of patients' emotions[43] and early recognition of errors[44,45] in care all likely depend on clinicians' ability to be attentive, curious, and perceptive.

Clinicians' ability to be attentive and perceptive is related to their own well-being. Clinicians who report burnout or job dissatisfaction also report lower quality of clinical care and demonstrate decreased capacity for empathy.[46-55] Correspondingly, clinicians' ability to self-monitor, their availability of means to improve personal well-being and job satisfaction, and their ability to derive greater satisfaction from the patient-clinician relationship have all been noted as possible avenues for improving the quality of care, including commu-

nication with patients. A 1990 survey of physicians identified several means to reduce stress and improve well-being: [56]

- Self-awareness
- Sharing of feelings and responsibilities
- Self-care
- Development of a personal philosophy
- Balancing of work and home life

However, few of these approaches have been studied formally.

Some studies have shown benefit of education and training in self-awareness, communication skills, and ways to promote well-being. Multiday workshops for oncologists that included self-awareness sessions and communication training had a positive impact on burnout and self-rated communication skills.[57,58] A descriptive study of workshops for residents suggested that previously unrecognized negative attitudes interfered with learning communication skills, and consciously addressing those attitudes facilitated future learning of communication skills.[59] A before-and-after study of an eight-week workshop on stress reduction through the use of meditation techniques showed increase in the capacity for empathy in a group of nursing trainees.[52] In qualitative studies, mindfulness and self-monitoring were linked to better conflict-resolution skills[60] and more compassionate hospice care.[61] Personal wellness strategies

among oncologists were associated with better job satisfaction and a lower rate of burnout.[47] In the only study of patients' reports of physicians' mindful actions, a survey of 5,000 patients suggested that patient-perceived physician mindfulness is highly correlated with satisfaction, patient trust in their physicians, and physicians' respect for patients' autonomy.[62] It is clear that research in this area is quite preliminary and in need of further attention.

A.4 Implications for Future Study

Qualitative data have pointed the way to future quantitative and epidemiological studies of the patient-clinician relationship. Effective communication and relationships are generally mutually reinforcing. Nevertheless, a strong relationship does not ensure that difficult and emotionally charged issues are managed effectively. The effects of conversation on control of chronic diseases [63,64] have not been studied in cancer settings. In some cases, the perceived qualities of that relationship may be more important to outcomes than the specific communication techniques used. Conversely, communication may serve to strengthen the patient-clinician relationship, which, in turn, may have a direct effect on quality of life, adherence to treatment, and control of disease. These mediating and recursive influences of patient-clinician relationships on communication warrant further study.

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Information Exchange in Cancer Care*
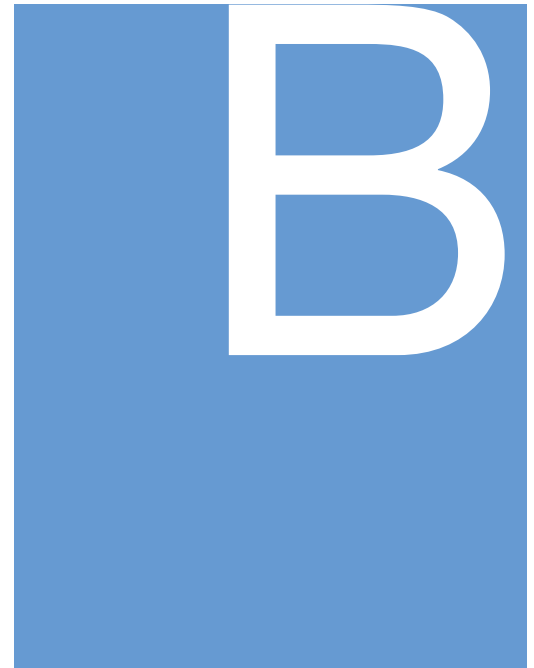
I nformation exchange accounts for a large percentage of the time in clinical consultations. The first part of this appendix is a review of selected recent literature regarding the way information is managed in general, centering on four themes: patients' information needs, patients' sources of information, information exchange, and patient recall and understanding. The second part of the appendix addresses two specific areas in which there has been more intense research: communicating bad news and discussing prognosis.

B.1 Patients' Information Needs

Patients with cancer seek information about the cause, diagnosis, treatment, prognosis, and psychosocial aspects of their illness, but these needs vary among patients and change over time.[1,2] Although most research has focused on delivery of information at or shortly after initial diagnosis, patients' information and education needs persist throughout the cancer care continuum.[3] Attending to patients' information needs is important not only in conveying the facts of the illness to the patient but also in developing a strong patient-clinician relationship and improving patients' psychosocial well-being and coping abilities.[4,5] Information given

to patients with cancer should be tailored to the type and stage of cancer that they have and should also consider personal characteristics such as age, sex, and cultural identification.[6] The availability of information has increased over the past decades, but many patients and family members remain dissatisfied with the information they are given and when they are given it.[7]

Researchers have measured the information needs of patients with cancer through the use of self-report surveys, individual interviews, and descriptive narratives in qualitative studies. Specific instruments have been developed to identify the general and diagnosis-specific information needs of patients with cancer. Some, but not all, of the instruments have been validated. The information needs of patients with breast and prostate cancer have been well described, whereas the information needs of patients with head and neck, lung, colorectal, gynecological, and testicular cancers have been less well described. In particular, the information needs of patients with breast cancer have been high.[8,9]

Younger patients and those with breast, prostate, gynecological, or testicular cancer reported needing more information regarding sexuality, sexual functioning, fertility,

and self-esteem than patients with primary cancers at other sites.[8,10-14] Many patients report that sexuality has not been adequately addressed[15] and cannot recall any information regarding sexuality given to them by clinicians.[16] About two-thirds of patients with prostate cancer surveyed desired more information pertaining to the effects of brachytherapy on sexual function and on treatment options for erectile dysfunction.[17] Younger patients with prostate cancer have had greater general information needs than their older counterparts.[18] In general, sexuality was often addressed later in the course of the illness than patients would have preferred.

During the treatment phase, patients have valued detailed information about their treatment plan, potential side effects, and the potential impact of these on their quality of life.[19-22] Patients with cancer frequently arrive at the consultation with expectations of side effects from treatment,[23,24] and such expectations actually increase the likelihood of experiencing those side effects.[24] Accurate information may help to decrease patients' negative experiences and increase their participation in consultations.[23,25] Information on pain management also is often lacking from discussions with patients,[26,27] as is information regarding possible emotional reactions, alternative treatments, and the long-term effects of cancer treatment.[16]

Patients with cancer have used information not only to address their physical needs but to their psychological needs as well.[28] Patients have indicated that their psychosocial information needs are not always adequately addressed by clinicians; if these needs were met, patients may be better able to cope with their illnesses.[29-33]

In general, the benefits of providing patients with information include increased satisfaction with and participation in the consultation, decreased anxiety, and increased ability to cope.[34] Patients with cancer often use their information resources not only to understand their disease but to find hope as well.[35,36] When surveyed, more than 80% of patients with cancer said they wanted as much information as possible regarding their cancer diagnosis and treatment options.[16,37] The more information patients received, the more satisfied they were.[38,39] However, some patients with cancer avoid information as a coping mechanism.[40] Although information-seekers should be given larger amounts of information, doing the same may overwhelm information-avoiding patients.[41] Interestingly, the greater the information needs of patients with cancer, the more anxiety, depression, and psychosocial concerns that they tended to have.[42] Patients who were more dissatisfied with the information they received tended to have more information-avoiding behaviors.[43]

Information needs change over time.[44] At the time of diagnosis, patients may want full disclosure but they may need some time to absorb the details and implications. During the period between diagnosis and treatment, patients often want more detailed information in discussions of their prognosis, treatment options, side effects, and changes to their daily living. After patients have had treatment, the amount of information they need may be less but the topics—psychosocial issues, rehabilitation, recovery, and recurrence—are no less important to them.

Barriers to information-gathering have been the source of some frustration for patients with cancer.[45] Patients with breast cancer who experienced barriers to accessing information had decreased sense of functional, emotional, social, and family well-being.[46] Patients encountered problems if they were unable to access the information, if they had communication difficulties with their clinicians, if they experienced information overload, if they had difficulties with information retention, or if the information they were given was inaccurate.

Patients' recall of information is variable. Patients especially may not recall discussing psychosocial issues, sexuality, or sexual dysfunction.[16] Patients' ability to understand and retain information may vary depending on the format of the information and how easy it is for them to extract it.[47] Written materials and audio recordings of consultations tend to improve recall and are discussed in detail later.[48-51]

B.2 Patients' Information Sources

The findings of recent reviews and studies suggest that patients most often used information they received from their clinician and preferred information from this source.[52,53] Generally speaking, patients with cancer continue to believe that their physician is the most highly trusted information source, even though 48% consulted the Internet before seeing their physician.[53] Print resources are also commonly used,[54] but use of this type of material has decreased since the availability of online access to health information. Although information-seeking behavior in general decreases with age,[55] most patients with cancer are particularly interested in information regarding treatment and side effects.[21,56,57]

Whether or not patients are satisfied with the information that has been presented to them by clinicians, they often use the Internet to confirm or expand on that information.[58,59] Some cancer centers have created their own educational programs to instruct patients and their family members on how to use the Internet.[60] Although there is concern about the quality of information found on the Internet,[61,62] there is little evidence of adverse outcomes related to inaccurate information from the Internet. Patients with cancer use the Internet not only to obtain general information on a cancer diagnosis and its treatment but to also gain access to other patients with cancer and support groups where they can share their experiences through electronic mail, blogs, and chat rooms.[63,64] Mass media have played a role in influencing information-gathering, patient-clinician interactions, and decision-making roles of patients.[65,66] Also, advertisements have increased the use of the National Cancer Institute Cancer Information Service by patients with cancer, their families, and the general public.[67,68]

Until recently, print information resources have been second only to information obtained from clinicians. Although the findings of some studies suggest that print materials can have a positive effect on patient recall and satisfaction,[47] others have found that patients with cancer may be satisfied with this information source but it does not appear to have a significant impact on recall.[69] The format of information sheets may affect the usefulness of these materials for patients.[70] Literacy limits the usefulness of written materials for large portions of the population.[71-73] Low-literacy print materials or videos help increase patients' knowledge.[74]

Telephone help lines can be a useful source of information and emotional support for patients with cancer.[75,76] The National Cancer Institute Cancer Information Service (CIS) telephone help line has provided cancer information support services[68,77,78] and outreach services for patients with cancer and their families.[79,80] Individuals with a recent cancer diagnosis often use the service to obtain treatment information to prepare for speaking with their clinician.[81,82]

B.3 Information Exchange

The goal of information exchange is for patients to understand and to be understood. Clinicians often have a flawed understanding of patients' information needs and consequently do not provide enough information or the kind of information patients find useful.[83-90] Correspondingly, patients do not always immediately disclose substantive information about their symptoms or concerns; clinicians play a key role in helping patients to self-disclose.[1] Clinicians do not always appreciate the complexity of concerns that patients have[91,92] and thus may not explore areas important to their patients.[93]

Clinicians overestimate their own informativeness[94] as well as the level of understanding of their patients with cancer.[94,95] While imparting information, clinicians often use medical terms that patients do not understand, and they do not check patient understanding.[96,97] Clinicians also may not be aware of their patients' information-seeking and information-avoiding coping styles and thus may not tailor the manner of information delivery accordingly.

The breast cancer literature, in particular, includes descriptions of the importance of the flow of information among clinicians, patients,[98-101] and patients' spouses.[102] Patients have viewed sharing information as an attempt to share power and control in the interaction.[103] The

literature is sparse about information-sharing in the setting of other types of cancer. Patients with prostate cancer have appreciated obtaining as many facts as they could from their clinicians.[104] Among patients with lung cancer, many did not understand their situation well enough to make independent decisions and physicians were not aware of the information gap.[105] Not only do patients with lung cancer express greater satisfaction with physicians who are informative, they also trust these physicians more than do patients who perceive their physicians as less informative.[106]

Given that patients with cancer with more concerns are also more likely to have poorer quality of life,[107,108] clinicians need to engage in behaviors that encourage patients' disclosure of these concerns. Patient-centered communication is characterized by effective efforts by clinicians to elicit patients' fears and concerns[109] and encourage more active patient participation in the consultation.[110] Patient-centered communication has been associated with higher patient satisfaction with the clinician, and better coping, adherence to treatment, and quality of life in populations with and without cancer.[111-113] Poor patient-clinician communication has sometimes led to patients' poor understanding of their disease and the process and intent of staging and treatment; as such, they may lose confidence in their medical care team.[114] In one study, patients and family members generally preferred a patient-centered approach when presented with recordings of different consultation styles.[115]

B.4 Patient Recall and Understanding

Interventions to improve communication are discussed in Appendix E, but mentioned here are prompt sheets, audio recorded consultations, and patient-held records. Prompt sheets used by patients with cancer can improve their ability to gather information during the consultation.[116-119] When physicians addressed concerns on patients' prompt sheets, patients' anxiety decreased and their recall improved.[120] Physicians also said that they thought that prompt sheets stimulated useful discussion.[121]

Audio recordings of clinical consultations have been helpful for patients' recall and assimilation of information.[48,122,123] Such recordings also increase patient satisfaction[51] and may increase their participation at later consultations.[124] Recordings, however, have had inconsistent effects on anxiety and psychological distress in patients.[50,125] Most of the studies on audio recordings were done with initial consultations only; the findings of some studies have suggested that using audio recordings would be beneficial for all consult visits.[122] Physicians have become more accepting of audio recorded consults,[126,127] and although it is unclear if audio recordings can improve physician-patient relationships,[128] one study demonstrated that they led to increased patient participation in the clinical encounter.[124]

Giving patients access to their own medical information (in the form of patient-held records, patient information files, or log books) has helped patients and clinicians communicate more efficiently with one another.[129-131]

B.5 Implications for Future Study

Information needs, information resources, patient recall, and patient-clinician information exchange are all areas that require further study. The limitations of many of the studies to date have been that they have involved small sample sizes; patients with a limited number of types of cancer; few minority, non-English speaking, and low-literacy patients; and a focus on the initial phases of the illness. The information needs of patients with forms of cancer other than breast, colorectal, or prostate cancer warrant additional exploration. Further longitudinal studies may help track patients' information needs over time and patients' recall and understanding of the information provided to them. Lastly, cancer survivors will need better sources of information about rehabilitation, surveillance for recurrence, and late effects.

B.6 Communicating Bad News

Communicating bad news has been the subject of some of the earliest cancer communication research. Although no communica-

tion intervention will take away the life-changing impact of a cancer diagnosis, effective delivery of bad news can result in patients who are the following:

- Better informed

- More motivated to follow through with further evaluation and treatment

- Less emotionally distressed

- Better able to ask questions and participate in the clinical encounter

- Better prepared to make treatment decisions

- Better able to navigate the health care system

- Clear about the level of uncertainty of the diagnosis

However, the authors of a recent review concluded that despite a large body of literature with seemingly sensible recommendations for delivering bad news and an increasing number of courses to train students and residents, the delivery of bad news continues to be stressful for clinicians and ineffective and/or traumatic for patients.[132]

Clinician-related factors in communicating bad news

Beginning physicians, residents, and medical students often deliver diagnostic information without having had training or support in the task.[133,134] Most physicians were untrained in communicating bad news at the time they were first required to deliver it, and many

report having felt overwhelmed and traumatized by their early experiences.[134] Clinicians may know how they should deliver bad news but do not follow through because of their own discomfort, fear and anxiety,[135,136] and lack of forums to deal with their own feelings. Correspondingly, it is not surprising that patient reports of cold, impersonal, blunt, evasive, tactless, indirect, jargon-laden, and poorly timed delivery of news still appear in the popular press and the medical literature. Clinicians' actions may favor their needs to reduce their own anxiety and uncertainty and bring the visit to closure rather than address the needs of patients.[137]

Patient-related factors in communicating bad news

Communication at the bad news visit is affected by patient-related psychological factors, cognitive functioning, and health literacy. Patients report that they felt upset or overwhelmed anticipating devastating news or after hearing it, making assimilation and recall of additional information difficult. Patients may function at a much lower cognitive level when they are critically ill than when they are well.[138] Low health literacy may lead to confusion; for example, the word "positive" may connote something good to a patient unfamiliar with the reporting of test results.[72]

Social, cultural, and family-related factors in communicating bad news

Culture, social distance between clinician and patient, and relationships between the patient and family members play important roles in the communication of bad news and prognoses. In many Mediterranean, Latin American, black African, and Asian cultures, it is still common for clinicians to disclose cancer diagnoses to family members and not the patient.[139-142] Although younger patients increasingly say that they want information, it is also common for even these patients to relinquish some control to family members. There is controversy about how to reconcile views about patient rights and autonomy as articulated in mainstream Anglo-Saxon culture with the views and values of individuals from other cultures. It is often recommended that the patient should initially be given the choice about what they wish to know; the consequences of this approach have not been studied.

The diagnosis of cancer is often delayed in racial and ethnic minorities and individuals of low socioeconomic status.[143-149] One factor affecting this delay is a relative lack of trust and therefore less open communication between black patients and white clinicians compared with racially concordant pairs.[150] Further research can clarify whether providing easily understood information in the context of a trusting relationship when cancer is first suspected

will lead to earlier completion of diagnostic testing and initiation of treatment.

Health care system-related factors in communicating bad news

Health care system-related barriers to timely and confidential provision of bad news include discontinuity of care, lack of access, lack of a private space, and environmental noise. Scheduling of same-day face-to-face meetings is difficult within most health care systems. Because of this, when patients want to know test results as soon as possible, it is often necessary for clinicians to communicate with patients by telephone—a method that both agree is suboptimal. When bad news is communicated by phone, other members of the health care team may be unaware of what has already been discussed with the patient.[151] Team-related issues have rarely been the subject of empirical studies.

Effect of poor delivery of bad news on patients

Poor delivery of bad news appears to have important effects on patients' subsequent coping and anxiety.[132] However, it is unclear whether following recommended methods for delivering bad news affects satisfaction, knowledge, ability to make decisions, or follow-though with care. Further research can determine the optimal balance and degree of flexibility needed in the elicitation of patient perspectives, provision of information, and reassurance that the

patient is receiving the best care and emotional support. Few longitudinal studies of patient satisfaction with the delivery of bad news have been conducted; clearly, the immediate impact of bad news and later reflection may be different.

Training for clinicians

The curriculum at many medical schools in the United States now includes sessions on giving bad news. Intensive training courses of several days' length designed to help residents and clinicians improve their skills in communicating bad news have a lasting impact on skills,[152,153] but the majority of less intensive courses have been evaluated only in terms of satisfaction of participants and intention to use the learned skills.[132] The exploration of clinicians' emotions is a key feature of effective training courses. Future research can identify other key elements, with the hope of accomplishing training using less intensive and more cost-effective interventions.

Training for patients

In medical encounters not involving cancer, training, guidance, or information for patients in anticipation of a clinician visit has shown promise in improving the outcomes of the consultation.[154,155] Patient interventions, including decision aids and prompt sheets, have been used to help patients decide about cancer screening.[156] However, there have been no studies about interventions for patients undergoing diagnostic testing for

cancer with the possibility of bad news. In planning future research, the AIDS literature may be instructive. Guidelines for counseling before HIV testing include suggestions for anticipating and managing anxiety, discussing how the diagnosis might affect the patient's life, legal ramifications, and social support.[157]

Implications for future study of communicating bad news

Although there is a substantial body of descriptive, attitudinal, and intervention literature on the delivery of bad news, several issues remain unstudied, including the following:

- Long-term impact of different types of delivery

- Patient satisfaction with the timing and manner of communication

- Management of patients' anxiety following the initial disclosure of bad news

- Role of family members in such discussions

- Means of reducing physicians' anxiety so that such discussions can flow more openly.

Studies of delivery of news of tumor progression after remission and treatment failure are also needed. The impact of communication among clinicians caring for the same patients and health care system factors on the delivery of consistent information are poorly understood.

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B.7 Communicating Prognosis

Delivery of bad news is closely linked with the discussion of prognosis. Information on prognosis helps patients make choices among treatment options, plan their lives, and receive optimal palliative care. Communicating prognosis, thus, depends on the physician's ability to estimate the expected lifespan of patients with cancer, the patients' desire to know the prognosis, and the physician's willingness to disclose the true prognosis. Considering the goals of information exchange, clinicians discussing prognosis with patients and families must choose what to disclose, when disclosure should occur, how to disclose prognostic information, and to whom the information should be disclosed.

Much of what follows here is a summary of the review by Hagerty et al.[158] of studies published before 2004, in which those authors suggested important themes in discussing prognosis with patients. Most of the studies reviewed had involved patients with early stage cancer and focused on the initial diagnosis and treatment decisions. The largest number of studies has been conducted in Australia, with the United States, the United Kingdom, Japan, and continental Europe also represented. Given large cultural differences among English-speaking, Mediterranean, and Asian cultures in discussing prognosis, and perhaps differences within the English-speaking world, many of these findings need further investigation to determine their generalizability.

Frequency of discussion

Data on the frequency of discussions of prognosis is mixed and difficult to compare across populations.[158] In one study, most patients with breast cancer knew their prognosis,[159] but more recent studies of patients with melanoma and advanced cancer indicate otherwise,[137,160,161] suggesting that uncertain or serious prognoses are withheld more often. There appears to be both a norm of silence[161] and a norm of vagueness[162] among physicians, patients, and caregivers in which euphemisms and discussions of treatment plans overshadow more frank discussions of difficult topics. When discussions of prognosis do occur, they are usually initiated by physicians.[163]

What patients want to know

In responding to surveys, patients tend to endorse wanting information about prognosis[44,97,137,164-168] and value clear and straightforward presentations of data. However, in a study in the United States in which additional details about patients' preferences were sought, many patients expressed reservations and qualifications about universal disclosure of quantitative survival estimates and many preferred qualitative rather than quantitative estimates;[168,169] surveys of patients in Australia have shown no preference.[170] Patients' views may be ambivalent and inconsistent. They may reinforce physician avoidance by suggesting that they want full information but did not want to know about a "bad prognosis."[169] Even among patients receiving palliative care only 55% of patients in the United States wished to have discussed life expectancy with their physicians,[169] and only 59% of patients in Australia wanted to know their prognosis at the time of diagnosis of metastatic disease.[170] Many patients preferred to be asked what information they wanted before it was disclosed and also wanted to be asked when the disclosure should take place.[170] Patients with depression appeared more interested in knowing the most dire possibilities, whereas patients who were not depressed were more likely to want information about the maximal possible survival or wanted no information at all.[170] Anxious patients, however, generally avoided discussions about prognosis and were more likely to prefer that clinicians disclose that information to family members.[168,171] The findings of studies involving convenience samples suggest that women tend to want more information than men do,[166] but these findings were not adjusted for actual expected prognosis. Most studies were conducted considering preferences without necessarily considering the context and nature of the patient-clinician relationship. It may be that the nature of the communication process also influences patients' preferences and responses and should be studied in greater depth.

What physicians believe that patients should know

While physicians usually provide accurate, complete information to patients about their diagnosis and treatment options, physicians still commonly have difficulty providing prognostic information for several reasons. First, physicians' prospective estimates of prognosis are usually more favorable than indicated by the actual course of the disease.[172] Second, although the vast majority of physicians favor truth-telling, many feel uncomfortable about discussing dire prognoses[173] and intentionally exaggerate prognoses when communicating with patients and families.[174] Correspondingly, patients frequently report not knowing their prognosis[95,175] or overestimate their prognosis, even when provided accurate information.[95,105,176-182] In these studies, higher educational level, lower levels of depression, and higher patient ratings of their physician were associated with better understanding, but further research is needed to examine causal relationships among these factors.

Participants in discussions of prognosis

Some literature exists on family involvement in cancer care, but little has been written explicitly about sharing of prognostic information.[170] Although most patients prefer to have a family member present during discussions of prognosis,[164,171] patients do want control over the information that family members receive.[169] Moreover, when caregivers have prognostic information first, they may be reluctant to share it with patients.[183] One study found that disclosure of prognosis to family members first and using euphemisms diminished a patient's hope.[35] Disparities in provision of prognostic information has been a concern. Although most studies suggest that white patients of higher socioeconomic status tend to get more information than poor black patients, one qualitative study suggested the opposite outcome with regard to prognosis; poorer and nonwhite populations reported having more discussions of prognosis.[184]

The results of several studies suggest that patients get information about prognosis from several members of the health care team, and that such information may be complementary or sometimes haphazard[151] and contradictory. In one study, an organized team approach, in which the patient presumably received well-coordinated information increased patients' understanding of their illness, including prognosis.[185] Our understanding of specifically how teams can improve understanding and recall of prognostic information is limited, however.

Elements of effective discussions of prognosis

Although most studies focus on the content of discussions of prognosis, patients frequently suggest that the manner of presenting the information and the relationship with their clinicians is equally important. In qualitative studies, patients reported that they valued communication of information within clinical contexts in which they felt known, connected, and acknowledged.[186]

Communicating clinical evidence is challenging, raising questions about framing, use of visual aids, and communication of risk.[187] Patient and clinician understanding of statistics may be limited, and misunderstandings about median or mean survival may lead to overly concrete interpretations.[97,167] Graphical displays are increasingly used to improve patient understanding of statistical data, but the findings of at least one survey suggested that patients preferred words to pictures.[170] In that study, however, health literacy was not assessed. Patients tended to favor framing estimates in positive terms (survival) rather than in terms of mortality. Use of a mix of positive (survival) and negative (mortality) language may enhance understanding. Other recommendations from the literature conform to principles of general patient-centered communication skills and have few elements specific to cancer communication or prognosis: summarizing and checking understanding, active listening, privacy, adequate time, and honesty.[35]

Increasingly, the Internet and patient advocacy organizations provide more ready access to prognostic information. Until recently, no studies have been conducted on reconciling physicians

as a source of prognostic information with other sources. Patients, however, choose to discuss this information with their physicians on the basis of trust and need to resolve uncertainty.[188] Although most patients though that contradictory information would not undermine their trust in their physicians, a significant minority felt that it might. Those patients also tended to express that there was one correct answer to the question and reported discomfort with uncertain or contradictory primary data. Patient access to primary data on prognosis and ways to discuss this data effectively with health professionals is an important area for future research.

The communication of hope is frequently encountered in the context of the discussion of prognosis.[189] However, patients' experience of hope is related both to the process of communication as well as to the content of communication. Providing up-to-date information, answering questions, and offering emotional support are often seen as engendering hope, whereas a cold, impersonal clinical style appear to diminish hope.[190] This finding implies that frank and honest discussion of prognosis need not diminish hope if it is conducted in a patient-centered manner. In some situations, the dialogue on hope appears detrimental to the discussion of prognosis.[191] Some patients think that the burden of maintaining the appearance of a "fighting spirit" limits discussions of their fears and concerns, including about prognosis and quality of life.

Cultural factors

As with the disclosure of bad news, patients and physicians from Anglo-Saxon cultures favor disclosure, whereas individuals in other cultures do not.[158] However, there is significant change in some areas. Family members may take a more primary role in information exchange in Mediterranean and Asian cultures compared with Anglo-Saxons. In Spain,[192] for example, over the past 10 years, there has been a radical shift from nondisclosure to disclosure. Relevant to settings in the United States, however, is recognition that several factors could contribute to patients' desires for information about prognosis, including culture of origin, health literacy, educational level, prior illness experiences, and degree of cultural assimilation. Generalizations can be made on population levels, but they may not apply to individual patients; clinicians must be prepared to inquire about individual beliefs and values. We have not encountered any published work suggesting how the level of a clinician's cultural awareness affects discussions of prognosis.

Outcomes of discussions of prognosis

Few outcome studies have separated discussions of prognosis from discussions of bad news or other aspects of cancer care. The results of studies that have been published suggest associations between recalled discussion of prognosis and increased satisfaction, as well

as lower levels of depression, anxiety, and hope. Compelling qualitative data suggest that toxic effects of intentional deceit can lead to heightened anxiety and distrust.[193] However, there is disagreement whether collusion should be broken down quickly[194] rather than maintaining "necessary collusion" temporarily[195] to soften the blow (by delaying disclosure until it can be more easily assimilated). The cross-sectional design and plausible bidirectional causality make it difficult to draw conclusions from the current literature. Future research on the relationship between discussions of prognosis and quality of life is needed.

We are aware of no interventions designed specifically to improve the delivery of prognostic information. However, inference might be drawn from intensive workshops to improve delivery of bad news, which have enhanced clinicians' communication skills for at least 12 months following the intervention.[152,153] The most important intervention in the United States was a large randomized trial for patients with a prognosis of no more than six months.[196] Specially trained research nurses provided information about the disease, treatment, and prognosis, convened individual and family meetings, and discussed and documented patient and family preferences with the goal of improving communication about advance directives, improving pain control, and lessening the likelihood that patients would receive unwanted intensive care. The trial yielded completely nega-

tive results for all outcome measures, including communication. The large body of literature that has attempted to explain and learn from this trial indicates that interventions must focus on patient-clinician relationships and involve repeated contact and reinforcement in order to be effective.[197]

Implications for future study of communicating prognosis

Physician optimism and reluctance to paint a grim picture, along with patients' highly variable desire to hear complete prognostic information, create a complex set of factors to consider in discussions of prognosis. Communicating statistical information is challenging especially with patients of low health literacy and low numeracy; there is very little empirical research to draw on in determining how best to communicate clinical evidence with these patients. Research should also address cultural values and beliefs and family issues. Patients need hope, but it is not known the degree to which skilled clinicians can provide hopeful messages without distorting prognostic information. Studies to date have addressed only parts of this complex picture, which may explain failure of even large innovative studies to improve communication about prognosis and advance care planning.

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Recognizing and Responding to Emotional Distress in Cancer Consultations

One of the most important features of patient-clinician communication and cancer care is affective communication, an arena of particular salience, as patients are confronting a life-threatening diagnosis, treatment of uncertain effectiveness with potentially debilitating side effects, and an uncertain future. Patients experience and often express a variety of emotions in their interactions with clinicians, including fear,[1] humor,[2,3] nervousness, worry or sadness, or fatalistic thinking.[4,5]

It is particularly important to understand the factors that lead to recognition of and response to patients' emotional states, given their potential effect on treatment outcomes. Depression, anxiety, and adjustment disorders have a major effect on quality of life.[6-11] In addition, depression has been found to influence responses to chemotherapy, risk of death,[12] and experience of pain.[13] Anxiety has been shown to be a predictor of clinical response to treatment.[12] Early recognition of depression and anxiety is crucial for reducing the risk of suicide and social isolation and for initiating pharmacological and psychological treatments that improve quality of life. Most patients with cancer who have mental disorders have adjustment disorders and not major depression or severe anxiety disorders.[9] Recognition of these disorders may lead to mobilizing social support[14] and psychotherapeutic interventions that could improve quality of life and perhaps increase the likelihood that cancer treatment would be completed.

However, the diagnosis of depressive and anxiety disorders is often missed in oncology practice. The findings of one large study demonstrated that emotional distress was recognized by physicians in 29% of affected patients,[15] and results of another study showed that oncologists correctly identified 17% of patients who were found to be anxious and 6% of those who were found to be depressed on a standardized anxiety and depression scale.[16] Communication barriers influence the diagnosis of mental illness,[17-21] and some issues are particularly salient in the cancer setting. Many common symptoms of depression are also symptoms associated with cancer or its treatment, including fatigue, lack of energy, insomnia, and loss of appetite. Thus, clinicians must rely to a greater degree on elicitation of the patient's emotional state and maintain the possibility that these physical symptoms may also signify underlying depression.

Research to date on the role of emotion in cancer care primarily has focused on three issues: the psychological benefits of patient expression of emotion during the

consultation, how clinicians respond to patients' emotional state, and emotional well-being as an outcome of patient-clinician communication.

C.1 Benefits of Patients' Emotional Expression

Patients who share their emotions and feelings during medical consultations often experience therapeutic benefits. The use of humor has been found to decrease stress, increase comfort levels, and restore immune function.[2,3] Patient narratives about their illness experience help to decrease emotional distress.[22] Conversely, patients who restrain the expression of their negative emotions may become more anxious, depressed, and confused after receiving a cancer diagnosis.[23] Disclosing emotions may even contribute to improvements in physical symptoms.[24] The written disclosure of emotion can also buffer the negative effects of the inadequacy of social support.[25]

Although emotional expression can have positive benefits, patients appear to vary in the kind and manner of emotions expressed. For example, humor in consultations can be either positive or negative. Patients with testicular cancer have reported that humor in the consultation can dispel tension and make them feel "normal," but, if such humor is managed poorly, it can be a source of humiliation or stigma.[26] Just as disclosing emotions may have cathartic effects, failing to disclose emotions may hurt emotional processing. Patients may fail

to disclose fears because of low social support, low emotional well-being, or the belief that the clinician is not responsible for helping with emotional concerns.[11,27] Undisclosed fear can cause patients to underreport their difficulties with cancer to their clinicians.[28] In one study, the worry of appearing disrespectful to clinicians caused some patients to withhold their feelings about wanting to reconsider decisions about treatment.[29]

C.2 Clinicians' Responsiveness to Patients' Emotional States

Most patients with cancer respond favorably when clinicians are receptive and interested in their emotional states and well-being. In one study of patients terminally ill with cancer, the patients perceived their clinicians more positively when they offered more emotional support.[5] In another study, oncologists' affective tone and socioemotional behaviors were associated with greater patient satisfaction.[30] Facilitating patients' emotional processing helped them to participate more effectively in making decisions about palliative care.[31] Because cancer also has a significant emotional impact on patients' family members, clinicians may need to help families address their own emotional distress and experiences.[32]

Clinicians typically are not effective at recognizing patients' emotional cues or at uncovering their fears and concerns, although some clinicians may be minimally receptive to patients' emotional

expressions.[1,33] Clinicians' difficulty in recognizing emotional cues may, in part, be related to Patients' tendency to articulate concerns that are informational rather than emotional in nature[34] and to disclose physical symptoms rather than psychological problems.[35] Adding to the difficulty is that the patients who are the most anxious or depressed are often the least likely to disclose their emotional concerns.[35] The findings of one study found that nurses were not accurate in identifying patients' concerns and most could not even identify the patient's three primary concerns.[36] Nurses were biased toward concerns about physical symptoms and medical treatment compared with emotional and other psychosocial issues.

The lack of communication skills, time, and a quiet private environment in hospital settings appear to be barriers to clinicians' validation of and responsiveness to patients' emotions.[37] With respect to skills, the findings of several studies demonstrate that educational interventions could help clinicians become more adept at addressing the patient's emotional needs.[38,39] Clinicians can elicit the fears and concerns of patients with cancer more effectively with use of patient-centered communication tactics such as open-ended questions, focusing on and clarifying psychological issues, and empathic statements.[18] In contrast, disclosure is less likely when clinicians use leading questions, focus on physical aspects of health, and prematurely move into giving advice and reassurance.

It is important to recognize that the relationship between patient-clinician communication and patients' emotional states can be quite complex. The body of literature in this area is small and most of the studies have focused on patient-clinician communication during the survivorship phase, with emphasis on the management of anxiety related to uncertainty and on the process of reassurance. Cancer survivors with disease in clinical remission are often anxious and present physical symptoms that clinicians interpret as requests for reassurance. However, in other settings, clinicians' expression of reassurance to patients without obvious disease can sometimes heighten the patients' anxiety.[40-42] In one of the few studies of reassurance, Stark et al.[43] reported, not surprisingly, that in more than 90% of posttreatment oncology visits, clinicians attempted to provide reassurance, either spontaneously, or, more commonly, in response to patient-reported physical symptoms. These attempts at reassurance often produced initial lowering of the anxiety level followed by paradoxical worsening of anxiety. Spontaneous reassurance ("you look well") increased anxiety in the most anxious patients before their next scheduled visit, and offering a treatment plan without explanation raised the level of anxiety in all patients within one week after the consultation, regardless of the baseline anxiety level. Moreover, providing reassurance may worsen outcomes if it appears to avoid the focus of the patient's

anxiety or is offered before the patient can express his or her concerns. The imperative to reduce anxiety may also drive diagnostic testing, some of which is not medically indicated, in an attempt to provide reassurance. If extrapolations from studies of populations without cancer hold,[41,42,44] clinicians' reporting of normal test results may provide only temporary reduction of anxiety. In contrast, providing simple reassurance while offering clear explanations has a more neutral effect on anxiety.[43] Through effective communication, clinicians can contribute at least temporarily to a transient decrease of patient anxiety, but the long-term effects of communication on anxiety in cancer survivors are unknown.

C.3 Emotional Well-Being as an Outcome of Patient-Clinician Communication

In the previous sections, we examined patients' emotional expressions and clinicians' responsiveness to these cues, but other elements of patient-clinician communication can also influence the affective states of patients with cancer following the consultation. For example, the way clinicians manage information can have a significant effect on patient emotions. Research has shown that less anxiety and depression were experienced by children with cancer in the initial stages when clinicians were open about the diagnosis and prognosis.[45] Information about diagnosis may lead to greater hope, although the time between

diagnosis and disclosure may moderate that relationship.[46] These findings are consistent with those of other studies in which patients' perceptions of being told "everything" led to an increase in patient satisfaction.[47]

Clinicians' communication style can directly influence patients' emotional well-being. For example, the degree to which patients perceive their clinicians' communication as patient-centered and facilitative may decrease postconsultation anxiety, although this relationship was weaker for patients with more advanced disease.[48] Communication that can help reduce anxiety included preparing the patient for diagnosis, giving the patient clear information, providing written information, discussing questions and feelings, encouraging the patient to be involved in decision-making, and being reassuring.[47] Additionally, compassionate communication and empathy from clinicians also may play a role in reducing patient anxiety and emotional distress.[49,50]

Other variables that may affect patients' emotions after the consultation visit revolve around the patient's participation in decision-making. As patients participate in treatment decisions, they may feel more anxiety regarding their responsibility in the outcome of that treatment. However, if patients are more satisfied with their increased level of involvement, then increased patient participation is associated with reduced emotional distress.[50]

C.4 Implications for Future Study

Eliciting, acknowledging, normalizing, and empathizing with patients' emotional expressions have positive effects on patients' subsequent functioning and quality of life. Yet, clinicians rarely engage patients in discussions about their fears and worries. Emotional dialogue is embedded in other communication activities such as exchanging information, making decisions, and providing access to care, yet the interface of instrumental and affective communication is poorly understood. For example, is patient involvement in decisions facilitated by emotional dialogue and understanding, not just the provision of information and choices? Interventions to improve emotional responsiveness in clinicians have been successful in small-scale studies, but future research should identify and overcome barriers to participation in these interventions and provide means for sustaining the positive effects.

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Decision-Making in Cancer Care*

Much of the research on decision-making in cancer care has focused on three issues:

- Patient preferences for involvement in decision-making

- Relationship between patient involvement in decision-making and postconsultation outcomes

- Understanding of the correlates of patients' decision preferences

Three phases of the cancer care continuum are predominant in the literature on decision-making: screening, treatment, and end of life. Decisions to screen for specific cancers arise when there is a choice of screening method (such as for colorectal cancer screening) or debate about the overall value of screening (such as with prostate cancer screening). Decisions about treatment arise when several treatment options are available and no single option is best for all patients (as often occurs with breast cancer). At the end of life, decisions involve discontinuing anticancer treatment, advance directives, treatment setting (including hospice), and assisted suicide. Decision aids are included in the discussion on interventions in Appendix E.

D.1 Decision-Making in the Screening Phase

Cancer screening programs—specifically those designed to detect breast, prostate, cervical, and colorectal cancer—aim to sort asymptomatic people who have cancer from those who do not. Increasingly, efforts have been made to promote informed decision-making on the part of the health care consumer and the clinician when discussing and evaluating screening options. Decision-making about screening often involves complex personalized discussions with eligible individuals about the risks and benefits of screening procedures.

Communication about Risk

Screening programs and clinicians vary in how they communicate, especially the degree to which they promote informed decision-making with eligible individuals. A 2002 Cochrane review addressed the effects of personalized versus general risk communication on individuals' decisions about whether to participate in health screening programs.[1] The specific goal of that review was to see whether personalized communication about risk for disease influenced any of several possible outcomes. Personalized communication was defined as information tailored to an individual's personal history or medical conditions that affect his or her risk of cancer. Personalized risk communication varies in detail and complexity as

well as in the medium used to communicate (e.g., direct mail campaigns, face-to-face discussion, or electronic media). The outcomes were categorized into the following groups:

- Behavioral, such as actual receipt of a screening test or adherence to choice regarding screening

- Cognitive, such as knowledge of risk or accurate risk perception

- Affective, such as anxiety, emotional well-being, satisfaction with decision made, or decisional conflict domains

The review included randomized controlled trials of people who were involved with "real life decisions" about whether to undergo screening, studies in which there was a risk communication information component to the intervention, studies that addressed decision-making about screening programs, and studies that included any of the aforementioned outcome measures. Of the 13 heterogeneous identified studies that met the inclusion criteria for the review, 10 addressed personalized risk communication related to breast cancer screening and one each, to cervical, colorectal, and prostate cancer screening. Only some studies incorporated patient-clinician communication; others focused on mass media and tailored communication interventions. In the six studies in which the intervention included a component of counseling (usually a health educator or graduate stu-

dent), the participants' accuracy of risk perception and use of appropriate cancer screening services usually increased. There was no evidence that this increase in uptake of services was due to informed decision-making. An interesting finding was that if the personalized information was more detailed or numerically specific relative to the patient's own risk, there was *less* receipt of cancer screening than when the information was provided in a more general way.

Patient involvement and postconsultation outcomes

Studies on decision-making about screening thus far have primarily focused on breast cancer compared with other types of cancer. The studies have tended to include only a limited number of outcomes, usually, the actual receipt of screening services. Knowledge of the processes by which communication and decision-making informs other screening-related outcomes remains limited, yet these other outcomes may also be responsive to change. Effect modifiers (such as high risk status) may also contribute to decision-making regarding cancer screening and detection. Research published since 2002 has involved examination of aspects of communication and decision-making processes about screening for types of cancer other than breast cancer) and have also included diverse populations.

More recent studies have yielded additional information about com-

munication and decision-making about screening for colorectal cancer. In a qualitative study of members of an African American church in rural North Carolina,[2] the quality of the communication with their physicians influenced patients' decisions to undergo colorectal cancer screening. In a larger cross-sectional survey (397 individuals) following the qualitative phase of the study, participants who reported that they had good communication with their clinician were more likely to have been screened (36%) according to the recommended guidelines than were participants reporting poor communication (17%). The strongest predictors of colorectal cancer screening or intent to complete screening among individuals with low income included higher baseline risk of disease, self-efficacy, and recall of physician recommendation.[3] This finding was further explored by Manne et al.,[4] who collected data from 534 siblings of individuals diagnosed with colorectal cancer and found that physician support, family support, and cancer-related distress were related to perceived benefits of screening.

In another study, the desired and actual levels of patient control over decisions regarding prostate-specific antigen (PSA) screening were examined.[5] Both before and after visits, patients expressed a preference for a shared approach to the actual decision. The study focused on decision-making outcomes and role preferences when encountering differing communi-

cation styles and media. The intervention included different scripted communication ("discussion") elements. The participants wanted to share decision-making more than they had, yet the actual decision was shifted toward greater patient control. Twenty-five percent of men reported having *greater* decisional control over the PSA test than they had wanted, and 30% of men who wanted a shared approach made the decision themselves. The findings of another study[6] demonstrated that the rate of PSA screening decreased from 98% to 50% when information was given with greater intensity and through a higher number of media (in person, video, etc.).

Correlates of patients' decision preferences

Another line of research has involved evaluation of the role that belief systems and sociocultural characteristics play in decision-making about cancer screening. Among black women, for example, those who had had mammography were more likely to report having had recent contact with a physician; not surprisingly, they tended to believe that screening should be done annually and that early detection improves outcomes.[7] In a study about barriers to screening in rural Appalachia,[8] physicians identified such barriers as time constraints and conflicting guidelines. Physicians' perceptions that patients do not value prevention had a negative impact on communication about cancer screening.

Implications for future study

The focus of studies thus far has been on risk communication and role preferences for decision-making about cancer screening rather than the development of a trusting relationship, clinician responsiveness to patients' concerns, and understanding of the patients' views. Future work on decision-making in cancer screening needs to explore other outcomes, such as the cognitive and affective pathways of decision-making, rather than measuring only the receipt of screening service. Also, measures or tools to assess decision-making, rather than just personalized risk communication per se, are needed. The association between more detailed information and lower uptake of screening services is a curious finding that deserves further study, suggesting there may be a "dose-response" relationship to information about personalized risk and intention or receipt of cancer screening services. Perhaps more detailed communication about the relationship between one's personal risk and population-wide benefits of cancer screening may attenuate one's sense of personal need to undergo screening, given the marginal personal gain. Thus, increasing the communication may have the paradoxical effect of lowering an individual's use of cancer screening services. Other poorly characterized factors may also be effect modifiers on decision-making about cancer screening.

D.2 Decision-Making in the Treatment Phase

High-stakes decisions about treatment choices that are either reversible (such as initiation of chemotherapy) or irrevocable (such as mastectomy vs. lumpectomy) dominate the cancer communication literature. The most difficult decisions are those that involve tradeoffs between quantity and quality of life and those that involve small but statistically significant difference in clinical outcomes.

Patient preferences for involvement in decision-making

The findings of surveys of patients with cancer regarding their preferences for involvement in treatment decisions suggest that patients' wishes are often difficult to predict and that they change over time. Some studies have indicated that most patients prefer an active or collaborative role,[9-13] and other studies have demonstrated that patients generally prefer the physician to make the final treatment decisions.[14-16] More importantly, evidence suggests that patient preferences are affected by a number of factors. In cancer care, one of the key factors is the severity of illness. Patients who are sicker and/or more distressed generally prefer to relinquish control of decisions to clinicians.[17,18] Patients who are older and less educated also are more likely to prefer paternalistic decision-making models, whereas younger and more educated patients desire more active and collaborative roles.[14,18-21] In one

study, women were more likely than men to prefer shared decision-making with the physician.[22] However, there was more heterogeneity within groups than between them. Although a patient's health literacy has not been clearly linked to patient preferences for involvement, it is related to their ability to actively participate in these interactions,[23,24] an issue discussed later.

The wide variation in patients' preferences regarding involvement in decision-making has prompted some investigators to call for tailored approaches to assessing patient preferences.[9,25] Support for this position is found in several studies that have indicated that a substantial number of patients with cancer do not achieve their desired level of participation in the decision-making process.[15,18] Butow[26] found that most patients with breast cancer did not obtain their preferred level of involvement (29% and 37% were more and less involved than preferred, respectively). Patients who had a mismatch on preferred and actual involvement expressed greater anxiety following the consultation. Physicians are not particularly good judges of patient preferences[9,27] nor do patients and physicians perceive the decision-making process in the same way (e.g., shared or physician control[12]).

Patient involvement and postconsultation outcomes

A number of studies have been conducted to examine the relation-ships between the decision-making involvement of patients with cancer and a variety of postconsultation outcomes. The authors of early studies reported that simply offering patients with breast cancer a choice for initial treatment (e.g., breast removal or breast conservation) was correlated with a short-term reduction in depression and anxiety following treatment.[28,29] However, in another study, the perceptions of patients with breast cancer regarding the choice of adjuvant chemotherapy were not related to subsequent quality of life.[30] The findings of another study showed that the degree to which patients with early breast cancer actively participated in their treatment consultations was related to the degree to which they assumed responsibility for the decision one year following treatment.[31] The patient's self-report of involvement in the consultation at the time of consultation also was predictive of having a choice for treatment one year later. In turn, decision responsibility and perceived choice were predictive of health-related quality of life at one year.

Patient satisfaction with care and decisional regret has been the subject of considerable attention in research on communication between clinicians and patients with cancer. Some evidence has indicated that the greater the match between the preferences for involvement of patients with breast cancer and their perceived actual involvement, the less decisional regret and greater patient satisfac-tion with care.[32] However, the results of one study showed that patients' perceived actual role in the consultation, and not the preferred role, was the stronger predictor of evaluations of care. Patients reporting a shared role with the physician were more satisfied and evaluated their physicians' communication more favorably than did patients reporting that their physicians exclusively made treatment decisions.[33] Decision aids can help facilitate patient-clinician communication about treatment preferences, which, in turn, contributes to greater patient satisfaction and less decisional conflict.[34,35]

The relationship between patient involvement in the decision-making process and outcomes may in part be mediated by clinicians' efforts to encourage greater patient participation. For example, in studies that have involved the use of observational and self-report measures, patients with cancer were more active participants when their clinicians used partnership-building to encourage patient involvement.[36,37] In turn, clinician support of patient participation can foster a sense of having a choice of treatment and greater satisfaction with care.[38]

Correlates of patients' decision preferences

The quality of patient-clinician communication can affect patients' decisions and decision preferences, and some research has examined other factors affecting patients'

decisions about treatment. Patient preferences for decisions may in part be influenced by their perception of their physicians' preferences.[39] Patients' decisions to forego traditional therapies for alternative and nonconventional treatments are influenced by a host of factors, such as having a close friend or relative who has died from cancer when receiving conventional treatments, beliefs, need for control, side effects of conventional treatments, poor communication with physicians, and expected benefits of treatment.[40] Media hype about remarkable cures can also predispose individuals with cancer to choose experimental and nontested treatment.[41] Regardless of the source of influence, clinicians often have little understanding of patients' reasons to forego traditional therapy and/or choose alternative approaches.

There is a large body of literature on decision aids for assessing patients' decision preferences in general, and in the setting of cancer care specifically. The vast majority of studies on decision aids do not address their impact on patient-clinician communication. Research that has investigated their impact on communication will be reviewed later, in the discussion of patient activation interventions. In reviews of nearly 200 decision aids pertaining to health care decisions of all types, O'Connor et al. reported that most of the aids were provided before the consultation to make decisions, included an emphasis on information about treatment options and

relative advantages and disadvantages of options and were generally free of conflict of interest.[35] However, many of these aids were not fully evaluated. Decision aids generally increased knowledge about options, lowered decisional conflict, and reduced the proportion of people remaining undecided about the treatment. Importantly, simple decision aids seemed to be more effective than complex ones with respect to knowledge gained, more realistic expectations, and greater concordance between values and preferences. Contributions of decision aids to health outcomes and cost of implementing such interventions require further study. A follow-up to that review highlighted the fact that many of the decision aids described in the literature lack clear conceptual explanations of processes by which they are expected to achieve their goals, fail to recognize or acknowledge the values embraced by the decision aid itself, and are not thoroughly evaluated.[35,42]

In cancer care, resources to support decision-making should take into account not only patient values but also patient competencies; patients with cancer often want as much information as possible but can be overwhelmed with the information available and the complexity of decisions. Continued development and evaluation of decision aids, especially ones that use interactive technology, may be resources for optimizing patient involvement in decision-making in a progressive, iterative fashion.[43]

Implications for future study

Collectively, the findings of the studies on decision-making indicate that the quality of the patient-clinician interaction, and not patient involvement in treatment decision-making per se, is the most important factor affecting cancer outcomes. For example, in a study of patients with colorectal cancer, the perception that their clinicians explained treatment options in a clear and unhurried manner was especially important to most patients, regardless of their preferences for decision-making roles.[22] This finding is very similar to that of a qualitative study[44] in which women with a variety of cancers differed in their preferences for involvement in decision-making but were similar in that most reported that judgments about whether the right decision was reached was related to a feeling of being listened to, inclusion in the decision-making process (regardless of who made the final decision), and trust in the physician. Specific communication strategies that may facilitate patient-clinician communication about treatment include explicit agenda setting, active listening, checking understanding, offering opportunities for involvement, endorsing participation, and using nonverbal behaviors that convey empathy and warmth.[45] It remains unclear how often the patient-clinician conflict about the treatment and screening decisions occurs.

D.3 Decision-Making in the End-of-Life Phase

Palliation should occur at all phases of the cancer care continuum, but end-of-life care refers to the point at which relief of pain and other symptoms takes precedence over prolonging survival. There are no clear landmarks for the transition to end-of-life care, complicating both the communication challenges and their study. Much of the literature on decision-making at the end of life is based on individual case reports, qualitative interviews and focus groups, attitudinal surveys, and expert opinion rather than on observation of interactions and surveys addressing specific communication tasks.[46] Older studies from the hospice literature are not easy to access with use of standard search strategies. The studies that do exist indicate gaps in communication that result in inadequate symptom management, lack of emotional support, excessive use of medical technology, and insufficient use of hospice care.[47]

In general, patients, families, and clinicians consider patient involvement in decisions during the end-of-life phase to be important,[48] and most patients want to participate in such decisions.[49] However, the results of studies have suggested that there is substantial variability in patients' wishes to be involved, that discussions about end-of-life issues are often inadequate, [50] and that clinicians usually underestimate patients' desires to participate in decisions.[9] Outcome measures have been developed to determine the quality of life for patients at the end of life. Although these measures correlate with symptom scores and family ratings of care after the patient's death, challenges remain in validating the measures prospectively in a variety of populations and settings.[51]

End-of-life decision-making focuses on four areas: discontinuing anticancer therapies, the settings for end-of-life care, advance directives, and assisted suicide. Decisions in each of these areas involve the patient as well as the family;[52-55] in fact, about half of all patients lose decision-making capacity before their deaths, so family-based decision-making is common.[56]

Discontinuing anticancer therapies

The decision to forego or cease anticancer therapies may occur at the point when gains in survival and functioning and reduction of symptoms may be offset by a decrease in the quality of life due to the treatment itself. However, studies suggest that consideration of quality of life has had little influence on clinicians' recommendations and subsequent decisions to continue or cease chemotherapy.[57] Clinicians who use third-line and fourth-line chemotherapy in the last months of life in the absence of clinical evidence of its effectiveness[58] tend to be less skilled in communicating.[59] Presumably, decisions on such treatment are based on clinicians' emotions (feelings of guilt, failure, and blame) rather than open discussions about alternatives and choices.[60,61] Case reports and anecdotal evidence suggest, however, that many patients and families view the stopping of disease-directed therapy as "giving up." They may confuse the failure of treatment with the failure of their clinician and prefer to continue even long-shot experimental therapy to transitioning to a hospice approach.[62,63] Correspondingly, many patients' decisions are based on personal and spiritual belief systems, advice from others, and fear.[64]

Accurate and complete information about options at the end of life are necessary for informed decision-making, but according to questionnaire surveys, most patients did not fully understand their rights to withdraw treatment once initiated or their rights to aggressive symptom management with medication doses that may unintentionally hasten death.[65] Less than half of patients were presented with treatment choices and information about quality of life.[66] However, patients who reported participating in decisions about end-of-life care had higher levels of anxiety for at least two weeks following the decision. In one intervention to facilitate patients' participation in care and decisions, question prompt lists were well received and reduced the level of anxiety, but the impact on the process of decision-making was unclear.[67]

Settings for end-of-life care

The decision about the setting in which end-of-life care will occur

is also important. Options for the setting include the patient's home, with or without hospice services; a nursing home; or a dedicated hospice unit. Despite a large body of literature about patient attitudes regarding the setting of end-of-life care, no studies have specifically addressed patient-clinician discussions about this topic.

Advance directives

Discussions about advance directives and substituted judgment about life-sustaining treatments should the patient lose the capacity to decide are contextualized by numerous sociological, psychological, legal, and ethical factors that are beyond the scope of this monograph. A self-determination model suggests that patients would want to use a principle of substituted judgment if they lose capacity, but this application of self-determination theory is increasingly being called into question.[68] There is empirical support that some patients (especially those who are older and sicker) are more comfortable delegating such decisions to family members and, under certain circumstances, letting surrogates override the patient's own living will, depending on the context, recognizing that decisions are unstable over time.[69,70] However, patients and their surrogates do not always make the same decisions when presented with hypothetical scenarios, nor are their advance care decisions completely stable over time. Yet, most patients still favor the decision-making authority of

their selected surrogate, should they lose capacity in the future.[71-73] Although patients and clinicians believe that frank discussions about end-of-life choices are important and necessary, clinicians should be aware that patients' ability to maintain a positive attitude is associated with increased survival and quality of life[74] and that clinician recommendations can have psychological benefit for patients.[75] Thus, presenting "just the facts" and expecting patients to take a primary decision-making role may not always be good for the patient's health and well-being. Clinicians also have an important role in fostering positive attitudes and hope. They must often share responsibility for the decision with the patient and his or her family. One qualitative study emphasized the importance of determining whether the patient was an "activist" or a "delegator" before approaching discussions of advance directives.[76]

The SUPPORT study was an important effort to promote discussions about end-of-life issues with seriously ill patients, some of whom had cancer. [77] However, the intervention—nurses informing teams about the patient's values and prognosis—produced no changes in the use of advance directives, and care was no more concordant with patients' values in the intervention group than in the control group.[77] Even when discussions occurred, physician understanding of patients' preferences were no better than when such discussions were reported not to have

occurred.[78] Tulsky et al.[79] and Fischer et al.[80] recorded consultations addressing advance directives and then surveyed both physicians and patients. The discussions included questions about preferences and surrogate decision-making but rarely addressed values or uncertainty. The researchers found that most patients had misconceptions about the process and outcomes of cardiopulmonary resuscitation. Although physicians accurately predicted who the patient would choose as a health care proxy 89% of the time, they were unable to predict patients' preferences in 18 of 20 scenarios involving advance directives.[79,80] Our knowledge about the content and process of discussions about advance directives or do-not-resuscitate orders with patients with incurable cancer is limited. Furthermore, traditional models of decision-making consider only two parties—the patient and the clinician. However, families are normally involved in end-of-life decisions, even in Anglo-Saxon cultures, and more so in Asian, African, Mediterranean, and native American cultures.[81,82] Models for communicating about end-of-life issues have only begun to take the family into account,[83] and family interventions have not been tested empirically.

Assisted suicide

Assisted suicide and euthanasia are also issues that arise during the end-of-life phase. Even in locations where assisted death is illegal, 12% of physicians report having received explicit requests for

this.[84] In one study, half of oncologists surveyed reported having received such requests and 13.5% complied with them.[85] Although there are several published guidelines on the use of assisted suicide,[86-88] their implementation has been studied with only qualitative interview techniques with clinicians[89] and patient/family units.[90] Clinicians' reports suggested that their initial responses to such requests are to ask the patient to clarify his or her reasons for the request, address the physical symptoms and psychological issues underlying the request, and identify and treat depression. However, clinicians' greatest difficulty in responding to such requests and reaching a decision was related to existential suffering—patients' loss of meaning, loss of role function, and feeling that they are burdensome to their families. Patients and their families reported on clinicians' qualities necessary to facilitate these discussions, including openness to discussing assisted suicide, expertise dealing with the dying process, and maintaining a trusting relationship despite potential disagreements.[90] These interactions, however, have not been recorded or observed directly, nor is there information about how clinical communication affects suffering and quality of life in these settings.

Implications for future study

Little known about the content and process of discussions between clinicians, patients at the end of life, and their families regarding treat-ment decisions, advance directives, do-not-resuscitate orders, hospice care, family involvement in decision-making, and assisted dying. Study of communication in this domain must take into account, more than in other domains of cancer communication, the patient's implicit model of self-determination, desire for autonomy versus delegation to family or friends, desire for physician recommendations and willingness to confront difficult circumstances, all of which exist with an undercurrent of prognostic uncertainty. Addressing patients' emotions and existential suffering appears to be a necessary first step in reaching decisions regarding end-of-life care.

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Interventions to Improve Communication between Patients with Cancer and Clinicians

Encounters between clinicians and patients with cancer are complex. Such experiences are often emotion-laden, and the participants must discuss a complex array of diagnostic and treatment information. As a result, many clinicians have expressed the need for communication skills training to help them, their patients, and their patients' families have more positive, productive encounters.[1,2] Research to date has focused on three issues: communication skills training for clinicians (mostly for physicians and nurses), cultural competency training, and communication skills training for patients. Very little research has been conducted to determine how interventions focused on changing the structure of clinical practices and health care systems may affect communication and related outcomes.

## E.1 Communication Skills Training for Clinicians

In cancer care, clinicians have a number of communication tasks that must be accomplished skillfully. According to Beckman and Frankel,[3] these include the following:

- Delivering bad news

- Helping patients make truly informed choices

- Effectively working with families

- Facilitating the transition to palliative care

- Ensuring that end-of-life care honors the patient's requests

- Working with grief

Clinicians generally feel more comfortable discussing diagnosis and treatment than emotional and psychological issues.[4] Even the management of information is challenging; patients with cancer typically report that they want to know all the available information about their type of cancer and its treatment[5] yet are often overwhelmed by the sheer amount of information provided by clinicians, the mass media, and the Internet.[6]

Various communication training programs for clinicians have been described and evaluated in several studies. Typically, clinicians report that they find these programs to be satisfying and meaningful and to result in more confidence in handling difficult communication issues with patients who have cancer.[7-11] For example, in one study, before beginning a communication skills training program, oncologists expressed difficulty with a number of communication issues, such as giving complex information, obtaining informed consent, and handling cultural differences. Three months after the three-day
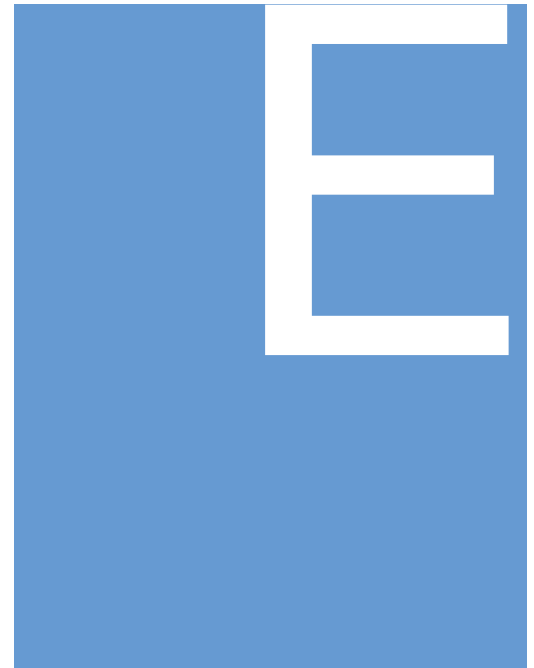
course, physicians reported having greater confidence in handling these matters, a more positive attitude toward patients' psychosocial needs, and a more patient-centered orientation.[12,13]

Other studies have focused on the effectiveness of interventions to teach clinicians emotion-management skills, such as expressing empathy, responding to patient cues, and handling psychological distress.[14] A recent review of randomized controlled trials and controlled before and after studies designed to assess the effectiveness of communication skill programs demonstrated that physicians and nurses improved on several patient-centered skills, including communicating empathy, using open-ended questions, and providing appropriate responsiveness to patient cues. These improvements were sustained over several weeks.[15] With the proper training, improvements in communication skills can be sustained over longer periods. In one study, 12 months following a physician intervention, there was no noticeable attrition in physicians' improvement in the use of open-ended questions and responsiveness to patient cues (although there was a decline in empathy).[16] The physicians also interrupted less and made more of an effort to summarize information for patients, skills that had not been observed immediately following training. In a Japanese study, oncologists' confidence in communicating with patients increased significantly after train-

ing, but the oncologists' emotional exhaustion worsened three months after the workshop.[17] This study raises the possibility that although communication training may increase clinicians' skills in patient-centered communication in cancer care, it may have the unintended consequence of adding to the clinician's stress.

Other interventions have specifically focused on the effects of training to uncover and discuss emotional distress in patients with cancer. In one study, nurses trained in ways to discuss and handle patients' emotions were indeed able to elicit more affective communication from patients than were untrained nurses.[18] In another study, nurses trained to address the emotional content of medical encounters used more words related to emotions immediately and three months after training compared with a control group.[19] Communication interventions for clinicians have also been linked to patients' perceptions of quality of care. Patients of trained physicians reported that they understood their disease better,[20] felt less depressed, and believed they were more in control than did patients whose physicians did not have training.[21] In the most recent study, physicians who participated in an intensive training program (a series of six three-hour workshops) used more open-ended questions and were more effective at eliciting and clarifying the psychological concerns of simulated patients than were physicians who participated in a less intensive training

program.[22] Moreover, patients (but not necessarily their relatives) were more satisfied with the physicians who received the more intensive training.

Although most studies have demonstrated improved communication skills following training, a few have had negative findings. A training program designed to increase physicians' ability to detect patients' distress led to no significant differences between those who participated in the workshops and the control group.[23] Instead, physicians' ability to assess patients' distress was negatively associated with patients' education level and self-reported distress both before and after the intervention. A study of nurses indicated that an intervention designed to help detect psychological difficulties in patients with cancer was successful in enhancing the detection of difficulties, but few of the patients were referred to psychological services. Unfortunately, there was no follow-up on patient health outcomes.[24] In another study, patient satisfaction associated with a physician communication training program was attenuated because of practical problems, such as waiting too long to see the physician.[25] These studies point to the possibility that system and organizational barriers can hinder the effectiveness of communication training programs.

It is also worth noting that the studies reviewed here generally focused on skills training for cancer consultations in general, but

other programs have been developed for more specific tasks and patient populations, including breaking bad news,[26-28] genetic counseling,[29] management of pain,[30] and communicating with patients with limited literacy.[31]

The most effective training programs for clinicians are those that[32,33]

- Are carried out over a long period of time

- Use multiple pedagogical methods

- Allow for rehearsal

- Provide timely feedback

- Allow clinicians to work in groups with skilled facilitators

Moreover, because clinicians develop routines for interacting with patients, communication training interventions should be introduced early in the medical school curriculum. Such interventions have been successful. In one program for students in which patients with cancer were enlisted as part of an educational program, students in the intervention group valued listening, trust, and showing concern for patients to a greater degree than did students who did not participate in the program. [34] Although three to five-day training courses can contribute to behavior and attitude change in students, these workshops may not be as effective as incorporating communication skills development throughout the medical and nursing curriculum.

E.2 Cultural Competency Training for Clinicians

We include cultural competence within this section on communication skills interventions because the construct has evolved beyond an awareness of language barriers and the ways cultures differ to the implementation of patient-centered communication (e.g., empathy and responsiveness to patients' values and preferences).[35,36] According to Paasche-Orlow,[37] the essential principles of cultural competence are the following:

- Acknowledgment of the importance of culture in people's daily lives

- Acceptance and respect for these differences

- Minimization of the negative effects of cultural differences

Clinicians and patients must adhere to these principles in order to communicate effectively. Cultural competency is important at all points across the cancer care continuum—during cancer screening, the informed consent process, decision-making about treatment after diagnosis, and palliative care.[38] Despite the need for programs in cultural competency,[39-41] very few of these programs have been developed or evaluated to date.

The challenges facing cultural competence training are manifold. Most medical students are not highly culturally competent with respect to understanding health disparities, stereotyping, and cultural differences in communication styles.[42] When patients and clini-

cians discuss cultural barriers in health care, each often has different conceptions of what cultural competence entails.[43] Nevertheless, a recent review of the published research on cultural competency training indicated that these programs generally increase clinicians' knowledge of cultural issues and their communication skills when interacting with diverse patients and that patients report greater satisfaction with such clinicians.[44] However, there has been little indication to date that this education contributes to greater patient adherence and improved health outcomes. We suspect that, like communication skills training, the most effective cultural competency education will be programs that provide intensive education before, during, and after clinical training[45] and that involve multiple pedagogical methods (role-playing, feedback, simulated patients, group discussion). Moreover, having culturally competent clinicians is but one requirement for a culturally responsive health care system. Patients and clinicians also must be supported with staff and practitioners who reflect the community served, with linguistically and culturally appropriate health education materials, and with access to interpreters when needed.[46]

E.3 Communication Skills Training for Patients

Patients, too, play an important role in the success of clinical encounters in cancer settings. The key premise underlying patient "activation" or communication

skills interventions is to increase patient participation in the consultation and, if they desire, to enhance their involvement in decision-making. The current research has shown that the most successful "patient activation" interventions are those that [47-49]

- Promote the legitimacy of the patient's participation in care

- Provide information about the patient's health condition and treatment options

- Provide specific communication strategies and behaviors for patients to use in their interactions with clinicians

- Deliver the intervention in a timely fashion so that the patient has an opportunity to act on behavioral intentions resulting from the program

Patients in gynecology clinics who were advised to write down specific questions and take the list into the consultation reported that they had asked more of the questions they wanted to, felt more in control, and were more satisfied with the information they had received.[50] With another intervention, patients were explicitly encouraged to be active information seekers and were advised to write down specific questions and concerns before the visit with their physician.[51] Patients who received the intervention asked significantly more questions and had better recall of the information provided by physicians than did patients not receiving the intervention. It has been shown that having patients watch video recordings of role models successfully asking questions and introducing topics for discussion also increases patient participation.[52] It is important to note that the effectiveness of these interventions may depend in part on providing patients with specific skills and goals for the encounter.[53-55] Simply encouraging patients to be more involved may not sufficiently help them overcome barriers to participation. In addition, interventions are more effective if the physician has a positive attitude toward patient participation.[56]

There is a large body of literature on the use of decision aids to inform patients about their type of disease and help them identify their treatment preferences,[57] and several studies have involved the evaluation of decision aids designed to enhance patient communication and participation in cancer consultations. The findings of many studies of aids to facilitate the involvement of patients with cancer in the decision-making process have demonstrated that patients receiving these interventions had greater knowledge about the surgical treatment of breast cancer, assumed a more active role in the process, had less decisional conflict, and were more satisfied with the decision-making process.[58,59] In contrast, some studies have indicated less success with interventions designed to help patients in the decision-making process. For example, Davison and Degner[60] reported that, paradoxically, women with breast cancer who used computer-assisted education designed to promote their involvement in decision-making actually participated less than the control group. Women in the control group completed measures of decision preference before their clinic appointments, whereas women in the intervention group were encouraged to use the information and decision preference profiles generated by the computer program at their clinic appointments. In general, the majority of women in both groups achieved their preferred roles in decision-making, but a higher proportion of women in the intervention group reported playing a more passive role than expected. One potentially moderating factor not examined in this study was the way in which physicians communicated with patients. In another study, women with newly diagnosed early-stage breast cancer[61] either received a multimedia program or an educational brochure; women in both groups achieved significant gains in knowledge about treatment and the two groups did not differ with respect to their rates of participation in decision-making. Rather, as with question prompt sheets, the degree to which patients asked questions, expressed concerns, and offered opinions was related to their age, education, and the extent to which physicians facilitated their involvement. This finding highlights the fact that the clinician's attitudes toward patient activation and behavior in the consultation likely moderate the effects of patient activation interventions and that the effectiveness of such interventions, in part, depends on physician endorsement.[61,62]

As noted by Parker et al.,[62] research on patient-based communication interventions show that a variety of methods (e.g., audio recordings, prompt sheets, coaching) generally work well at increasing patients' information-seeking and decision-making behavior. Yet, in cancer care, how patients manage their emotions and personal meaning of illness are also important. For example, in palliative care, patients' participation may be less focused on medical information and more focused on discussing their experiences and life circumstances.[63] Even when interventions are designed to facilitate patients' information-gathering and decision-making behavior, patients may be more interested in sharing their experiences with others rather than learning specific communication skills. In short, these results suggest that interventions designed to foster patient participation in cancer consultations should also focus on facilitating patients' emotional processing of the disease, particularly when it is incurable.

In summary, the research on activation and communication skills training for patients highlights the importance of providing specific communication strategies (e.g., through role models, prompt sheets, and writing down questions and concerns) when interacting with clinicians. Health information and encouragement also facilitate patient participation, but, to be most effective, patient activation interventions should provide resources to help patients select and enact specific communication tasks. Patients should be encouraged to express emotion and meaning. Providing the education immediately before the consultation is particularly effective because patients can use these communication strategies while they are salient and relevant. It is important to note that, when programs to enhance patient communication are well designed, they can be effective in a variety of media, including pamphlets or booklets,[50,55] prompt sheets,[59] video recordings,[52] multimedia programs,[61] coaching sessions,[64-66] or diaries.[67] However, it is not known how long the effects of the intervention persist or how to simultaneously augment physician endorsement and facilitation of patients' active involvement so that patients' values and experiences are thoroughly discussed and incorporated into actual decisions.

E.4 Interventions at the Team, Practice, and Health Care Systems Levels to Improve Communication between Patients with Cancer and Clinicians

There are very few studies of the effect of changes at the team, practice, and health care systems levels on communication between patients with cancer and clinicians.

Interventions at the team level

Patients normally encounter multiple clinicians during the cancer trajectory. Observational studies have indicated that clear and respectful communication is an essential quality of well-functioning teams[68,69] and that these qualities are not always present.[70] Many researchers have called for improved communication within health care teams,[71] but there are few interventions overall and even fewer in cancer contexts. Interventions in intensive care settings have had a positive impact on communication and leadership within health care teams,[68] however, the impact on patients is unknown. Interventions to provide structured written communication between primary care physicians and oncologists[70] and between general practitioners and oncology nurses [72] appeared to facilitate information transfer, but a subsequent study showed that a similar intervention had little impact on patient health care and information-seeking behavior.[73] The findings of one cohort study suggested that palliative care teams result in better patient insight into their illnesses than standard care,[74] but the results of a study of a team-building intervention indicated that interventions to improve team functioning may not be effective if there is understaffing.[75] Patient-held medical records have some promise in improving communication among team members and in facilitating patient understanding,[76] but effects on communication between clinicians and patients have not been reported. A shared-care intervention to promote teamwork between general practitioners and oncologists appear to influ-

ence patients' attitudes positively,[77] but, as with many of the studies cited, patient-clinician communication was not evaluated directly.

Interventions at the practice level

In a series of studies, Stange and colleagues[78-82] demonstrated that use of individualized interventions at the practice level could increase rates of cancer prevention and screening. These interventions involved research personnel trained in ethnographic and survey methods who would spend from several days to several weeks observing the organization, patient flow, and teamwork in primary care practices. These personnel would then meet regularly with the entire practice to propose changes in the structure of the practices tailored to the particular problems encountered. However, the impact of such interventions on communication between clinicians and patients, and the degree to which the effects of these interventions are mediated by changes in communication, is unknown.

Interventions at the health care systems level

One randomized trial identified problems in the physical layout of a cancer outpatient clinic and developed an intervention to make changes in that layout and to educate staff on communication techniques.[83] Patients in the intervention group were more likely to report higher satisfaction with communication, better privacy, fewer interruptions, clearer language, suffi-

cient time, and greater understanding. However, it is not clear whether the change in physical layout or the communication training was responsible for the results.

Systems interventions to facilitate transfer of information between patients and physicians include care diaries in which patients and all members of the health care team could share information,[67] patient-held medical records,[76] and direct access by patients to electronic medical records. In one study, patients expressed satisfaction with the care diary approach,[67] but no other randomized trials have been conducted to assess the effects of these approaches on communication, quality of life, and other outcomes. These interventions present compelling areas for future research.

E.5 Implications for Future Study

The evidence to date suggests that communication training interventions are generally effective for enhancing clinicians' patient-centered behaviors and patients' information-seeking and decision-making skills. In cancer care settings, more attention should be directed at developing programs designed to enhance clinicians' cultural competency and to help patients discuss and manage their emotions and feelings. Despite the promising results of these interventions, such programs have not been implemented system-wide within cancer care settings. Moreover, there is a paucity of research on how changes in the structure of

teams, clinical practices, and health care institutions, as well as use of other system resources—such as Web-based resources, multimedia programs, and electronic medical records—can be used to improve cancer care consultations. Interventions generally have not involved family members and friends, nor have the effects of the intervention on caregivers' well-being been assessed. Interventions have very rarely combined clinician and patient training, despite evidence that lack of physician endorsement can undermine patient interventions that are otherwise successful. Very few interventions incorporate means for reinforcing the effects of the intervention over time. These robust technologies hold much promise for improving patient-clinician communication.[84]

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Survey Instruments Used to Measure Patient and Clinician Communication Behavior in Cancer Settings

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured†
Ajaj A, et al. *BMJ*. 2001; 323:1160	—	Patient preference for level of information desired if diagnosed with cancer[1]
Argyris C. *Knowledge for Action: A Guide to Overcoming Barriers to Organization Change*. San Francisco, CA: Jossey-Bass; 1993 **Argyris C (ed)**. *On Organizational Learning*. Cambridge, UK: Blackwell; 1992	—	Patient report of why the appointment was scheduled, what he/she intends to say or do in the appointment, and what thoughts or feelings he or she intends to share with the physician[2]
Ashworth CD, et al. *Soc Sci Med.* 1984;19:1235-1238	Physician Psychosocial Beliefs Scale (PPBS)	Physician beliefs about psychosocial aspects of patient care[3,4]
Baile WF, et al. *J Cancer Educ*. 1997;12:166-173	—	Physician self-appraisal of communication skills[5]
Baile WF, et al. *J Clin Oncol*. 2002;20:2189-2196	—	Physician attitudes and practices in disclosing information to patients with advanced disease[6]

*Author given only if different from first author of citation for instrument (in left column).

†References indicate studies in which the survey instrument was used in the cancer setting.

Citation for Survey Instrument	Title/ of Survey Instrument (Author)[*]	Communication Behavior Measured[†]
Barnett M, McMichael H. *J Cancer Care*. 1992;1:145-149	Words Emotionally Related to Dying (WERD) (adapted from Henbest and Stewart)	Clinician rating of difficult or bad news scenarios as being centered on the disease, physician, or patient[3]
Berlin L. *Brainstorming Sessions Summary Report*. Palo Alto, CA, Community Breast Health Project; 1994 (www-med.stanford.edu/ CBHP/Brainstorming. html)	Community Breast Health Project Scale of Communication Barriers	Patient perceptions of communication barriers with physician[2]
Blanchard CG, et al. *Soc Sci Med*. 1988;27:1139-1145	—	Patient preferences for types of information[7]
Butow P, et al. *J Clin Oncol*. 2004;22: 4401-4409	—	Patient and physician satisfaction with decision-making process[8]
Butow PN, et al. *Support Care Cancer*. 2002;10:161-168 **Gattellari M, et al**. *J Clin Oncol*. 2002;20:503-513 **Leighl N, et al**. *J Clin Oncol*. 2001;19:1768-1778	—	Patient preferences for the content and format of prognostic discussion[9]
Caffo O, Amichetti M. *Br J Urol Internat*. 1999;83:462-468 **Weijmar Schultz WCM, et al**. *J Psychosom Obstet Gynecol*. 1986;5:119-127	—	Patient self assessment of information and support for cancer care[10]

Citation for Survey Instrument	Title/ of Survey Instrument (Author)[*]	Communication Behavior Measured[†]
Cancer Rehabilitation Evaluation System (CARES): Manual. Los Angeles, CA: CARES Consultants	Cancer Rehabilitation Evaluation System (CARES): Medical Interaction subscale (adapted from Schag and Heinrich)	Patient problems with interactions and communication with their physicians and nurses[11]
Cassileth BR, et al. *Ann Intern Med*. 1980;92:832-836	Information Styles Questionnaire	Patient preferences for level of information and involvement in consultation[8,12-14]
Curtis JR, et al. *Pain Symptom Manage*. 2002;24:17-31	—	Family satisfaction with family-clinician communication[15]
Curtis JR, Patrick DL. *J Gen Intern Med*. 1997;12:736-741	—	Patient and physician perceptions of barriers and facilitators to patient-physician communication about end-of-life care[16]
Degner LF, Sloane JA. *J Clin Epidemiol*. 1992;45:941-948	—	Patient preference for level of involvement in decision-making[8,13]
Delvaux N, et al. *Br J Cancer*. 2004;90:106-144	Satisfaction with the Interview Scale	Patient and nurse satisfaction with consultation[17]
Delvaux N. Dissertation, Universite Libre de Bruxelles; 1999 **Razavi D, et al**. *J Clin Oncol*. 2003;16:3141-3149	Perception of the Interview Questionnaire (Delvaux)	Physician satisfaction with the interview Patient and family perceptions of physician behaviors in the interview[18,19]
Detmar SB, et al. *J Clin Oncol*. 2000;18:3295-3301	—	Patient and physician preferences for discussing health-related quality-of-life issues[20]

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured[†]
Detmar SB, et al. *JAMA. 2002*; 288:3027-3034	Post Intervention Questionnaire	Patient and physician evaluation of intervention[21]
Dunn SM, et al. *J Clin Oncol*. 1993;11:2279-2285	—	Patient recall of aspects of consultation[14]
Fogarty LA, et al. *J Clin Oncol*. 1999;17:371-379	—	Patient perception of the effect of physician compassion on participants' anxiety, information recall, treatment decisions, and assessment of physician characteristics[22]
Hagerty RG, et al. *J Clin Oncol*. 2004;22:1721-1730	—	Patient preference regarding:[23] • Presentation ofl survival statistics • Specific prognostic information • When to discuss prognosis and who should initiate the discussion • Prognostic information, timing, and manner of presentation
Hagerty RG, et al. *J Clin Oncol*. 2005;23:1278-1288	—	Patient preferences for content and format of prognostic discussion[23]

Citation for Survey Instrument	Title/ of Survey Instrument (Author)[*]	Communication Behavior Measured[†]
Hays RD, et al. Scoring the medical outcomes study patient satisfaction questionnaire: PSQI-II.MOS memorandum. Santa Monica, CA: Rand Corporation, 1987 (unpublished)	Patient Satisfaction Questionnaire	Patient satisfaction with interview (needs addressed, active involvement in the interaction, interaction in general, information received, and emotional support received)[24]
Higginson I, McCarthy M. *Palliat Med*. 1994;8:282-290 **Higginson IJ, McCarthy M**. *Palliat Med.* 1993;7:219-228 Support Team Assessment Schedule	Support Team Assessment Schedule (STAS)	Palliative care team assessment of information-giving and empathic approach of physician communication between patients and family about end of life[25,26]
Jenkins V, Fallowfield L. *J Clin Oncol*. 2002;20:765-769	Physician Psychosocial Belief Scale	Physician perception of practice change after a communication intervention[4]
Kidd J, et al. *Patient Educ Couns*. 2004;52:107-112	—	Patient satisfaction with consultation and perceptions of self-efficacy in asking questions[27]
Krantz DS, et al. *J Pers Soc Psychol*. 1980;39:977-990	Krantz Health Opinion Survey	Patient preferences for information-seeking and for involvement in care[8,23]
Krupat E, et al. *Patient Educ Couns*. 2000;39:49-59	Patient-Practitioner Orientation Scale (PPOS)	Clinician and patient orientations toward control in their relationship[28]

Citation for Survey Instrument	Title/ of Survey Instrument (Author)[*]	Communication Behavior Measured[†]
Langewitz W. *Psychother Psychosom Med Psychol*. 1995;45:351-357 [transl]	—	Patient satisfaction with physician and consultation[29]
Lerman CE, et al. *J Gen Intern Med*. 1990;5:29-33	Perceived Involvement in Care Scale	Patient self-report of patient—and surgeon-initiated communication[30]
Lobb EA, et al. *Health Expect*. 2001;4: 48-57 **Sardell AN, Trierweiler SJ**. *Cancer*. 1993;72:3355-3365	—	Patient preferences, clinician views, and current practice regarding the communication of disease prognosis[23]
Matsumura S, et al. *J Gen Intern Med*. 2002;17:531-539	—	Physicians' attitudes about making prognostic disclosures[31]
Nayak S, et al. *J Clin Oncol*. 2005;23:4771-4775	—	Patient satisfaction with physician communication after a communication improvement strategy[32]
O'Connor AM. *Med Decis Making*. 1995;15:25-30	Decisional Conflict Scale	Patient and physician perceptions of potential benefit and harm from treatment (experimental and standard), relative value of quality and length of life, and perceived content of patient-physician consultations[33]

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured†
Ong LML, et al. *Psycho-oncology*. 1998;8:155-166 **van Zuuren FJ, Hanewald GJFP**. *Gedragstherapie*. 1993;26:33-48 [transl] **van Zuuren FJ, et al**. *Pers Indiv Diff*. 1996;21:21-31	Threatening Medical Situations Inventory (van Zuuren and Hanewald)	Patient self-assessment of monitoring (cognitive confrontation) and blunting (cognitive avoidance) coping styles[24]
Parker PA, et al. *J Clin Oncol*. 2001;19:2049-2056	Measure of Patients' Preferences (MPP)	Patient preference for social support[34]
Parle M, et al. *Soc Sci Med*. 1997;44:231-40	Confidence in Interviewing Skills Questionnaire (Maguire)	Physician confidence in interview skills[5]
Roberts C, et al. *J Cancer Educ*. 2005;20:113-118	Health Care Professional (HCP) Survey	Clinician attitudes regarding communication with patients Clinician perceptions of effectiveness of their personal communication skills; self-ratings of communication skills in difficult situations; and perceptions of challenges to professional satisfaction[35]
Sardell AN, Trierweiler SJ. *Cancer*. 1993;72:3355-3365 **Butow PN, et al**. *Support Care Cancer*. 2002;10:161-168	(Sardell and Trierweiler)	Patient perceptions of what kinds of communication convey hope[23]

Citation for Survey Instrument	Title/ of Survey Instrument (Author)[*]	Communication Behavior Measured[†]
Schmid Mast M, et al. *Patient Educ Couns*. 2005;58:244-251	—	Patient perception of disclosure of bad news, regarding:[29] • Appropriateness of information provided by clinician • Availability of physician • Physician dominance • Physician emotionality • Physician expression of hope
Sepucha KR, et al. *J Clin Oncol*. 2002;20:2695-2700	Physician Satisfaction Scale Patient Satisfaction with Interview Scale	Physician satisfaction with interview and patient satisfaction with preparation interview prior to consultation[2]
Shilling V, et al. *Psycho-oncology*. 2003;12:599-611	—	Physician satisfaction with interview[36]
Silberfarb PM, Levine PM. *Gen Hosp Psychiatr*. 1980;3:192-197	Semantic Differential Attitude Questionnaire	Nurses' attitudes about psychosocial aspects of cancer[17]
Smith JK, et al. *Eval Health Prof*. 1984;7:77-94 **Bowman MA, et al**. *Patient Educ Couns*. 1992;19:75-80	Patient-Doctor Interaction Scale (Smith)	Patient satisfaction with interview[2]
Sneeuw KC, et al. *J Clin Oncol*. 1997;15:1206-1217	—	Patient and physician preferences for discussing health-related quality-of-life issues[20]

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured[†]
Takayama K, et al. *Soc Sci Med* 2001;53:1335-1350	—	Patient perception of participation in patient-physician interactions[37]
Ware JE, Snyder MK. *Med Care*. 1975;13:669-682 **Ware JE, Davies AR**. *Eval Program Plan*. 1983;6:247-263	Patient Satisfaction with Communication Questionnaire (PSCQ) (adaptation)	Patient and physician satisfaction with communication during patient-physician consultation[36]
Wolf MH, et al. *J Behav Med*. 1978;1:391-401 **Baker R**. *Br J Gen Pract*. 1990;40:487-490	—	Patient satisfaction with medical interview[38]
Wolf MS, et al. *Patient Educ Couns*. 2005;57:333-341	Communication and Attitudinal Self-Efficacy (CASE) Scale	Patient report of self-efficacy[39]

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Observation-based Instruments for Coding and Rating Patient-Clinician Communication

Citation for Observation-based Instrument	Title of Observation Instrument (Author)*	Communication Behavior Measured†
Adelman RD, et al. *Gerontologist*. 987;27:729-734	—	Whether the utterance was addressed to patient, relative, or both[1]
Beach WA, et al. *Soc Sci Med*. 2005;60:893-910	(no title)	Participants' methods for organizing and accomplishing social actions[4]
Booth C, Maguire P. *Report to Cancer Research Campaign*, London; 1991 **Razavi D**. *Eur J Cancer*. 1993;29A:1858-1863 [transl]	Cancer Research Campaign Workshop Evaluation Manual (CRCWEM) (Booth and Maguire)	Form, function, and emotional level of each utterance[1,5-10]
Brown RF, et al. *Br J Cancer*. 2001;85:1273-1279	Coding manual developed for this study	Patient request for information or guidance[11]
Butow PN, et al. *Br J Cancer*. 1995; 71:1115-1121	Cancer-specific Interaction Analysis System (CN-LOGIT)	Comprehensive measure of patient-physician consultation[12]
Carcuff RR, Pierce RM. *Interviewing Strategies for Helpers —Fundamental Skills and Cognitive Behavioral Interventions*. Brooks/Cole Publishing: Pacific Grove, CA; 1975: 36-41	—	Physicians' verbal responses to emotional cues[13]

*Author given only if different from first author of citation for instrument (in left column).

†References indicate studies in which the observation-based instrument was used in the cancer setting.

Citation for Observation-based Instrument	Title of Observation Instrument (Author)[*]	Communication Behavior Measured[†]
Dent E, et al. *Patient Educ Couns*. 2005;56:35-44	Cancode Interaction Analysis System	Comprehensive view of the interaction; coding within four categories: source, content, function, and emotion[14]
Del Piccolo L, et al. *Eppidemiol Psichiat Soc*. 1999;8:56-67 [transl]	Verona Medical Interview Classification System (VR-MICS)	Information and instructions on illness management and information and instructions on psychosocial aspects[15]
Detmar SB, et al. *JAMA*. 2001;285:1351-1357	—	Whether tumor response was discussed in the context of palliative care consultations[16]
Detmar SB, et al. *JAMA*. 2002;288:3027-3034	—	Checklist to determine which health-related quality-of-life topics were discussed[17]
Ford S, et al. *Soc Sci Med*. 2000;50:553-566	Medical Interaction Process System (MIPS)	Classifies all utterances by patient and physician into content categories[18,19]
Beach WA, Dixson CN. *Soc Sci Med*. 2001;52:25-45 **Beach WA**. *Conversations about Ilness: Family Preoccupations with Bulimia*. Mahwah, NJ: Lawrence Erlbaum Associates; 1996	—	Patient-initiated actions (PIAs), and doctor-responsive actions (DRAs)[20]

Citation for Observation-based Instrument	Title of Observation Instrument (Author)[*]	Communication Behavior Measured[†]
Kidd J, et al. *Patient Educ Couns*. 2004;52:107-112	—	Number of questions asked by the patient[21]
Mays N, Pope C. *BMJ*. 1995;311:182-184	—	Factors in communication that contribute to false optimism[22]
Noldus LP, et al. *Behav Res Methods Instrum Comput*. 2000;32:197-206	The Observer System	Comprehensive collection and analysis of communication[2,3]
Ong LM, et al. *J Clin Oncol*. 2000;18:3052-3060	—	Patient recall of information[23]
Roter DL. *Health Educ Monogr*. 1977;5:281-315 **Roter DL**. In *RIAS Manual*. Baltimore: Johns Hopkins University; 1995	Roter Interactional Analysis System (RIAS)	Comprehensive utterance-based categories within three conceptual clusters: process, affective, and content[3,16,24-27]
Siminoff LA, et al. *Psycho-Oncology*. (in press)	—	Discord between patient and family members in treatment decision-making[28]
Stead ML, et al. *Br J Cancer*. 2003;88:666-671	—	Whether patient received information about sexual issues[29]

Citation for Observation-based Instrument	Title of Observation Instrument (Author)[*]	Communication Behavior Measured[†]
Street RL. *Health Communication* 2001;13:61-73 **Street RL, et al**. *Diabetes Care.* 1993;16:714-721 **Street RL**. *Soc Sci Med*. 1992;34:1155-1163 **Street RL**. *Soc Sci Med.* 1991;32:541-548	—	Patient participation, physician partnership building, and supportive talk[30,31]
Tulsky JA et al. *Ann Intern Med*. 1998;129:441-449	—	How physicians communicate about advance directives[32]
Zandbelt LC, et al. *Soc Sci Med*. 2005;61:661-671	Patient-Centered Behaviour Coding Instrument (PBCI)	Physician facilitating and inhibiting behaviors[33]

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NCI's Communication Resources

Program Planning

Health Communication and Informatics Research Branch	http://cancercontrol.cancer.gov/hcirb	NCI branch that supports basic and translational research across the cancer continuum on communication practices and infrastructure
Outcomes Research Branch	http://outcomes.cancer.gov/	NCI branch that supports research to measure, evaluate, and improve the outcomes of cancer care
Cancer.gov	http://www.cancer.gov	Main NCI Web page with links to information, tools, and resources on cancer
ClinicalTrials.gov	http://www.clinicaltrials.gov/	Searchable database of NIH and industry-sponsored clinical trials
Cancer Control P.L.A.N.E.T. (Plan, Link, Act, Network with Evidence-based tools)	http://cancercontrol-planet.cancer.gov/	Portal providing access to data and research-tested resources to design, implement, and evaluate evidence-based cancer control programs
Designing Print Materials: A Communications Guide for Breast Cancer Screening	http://appliedresearch.cancer.gov/icsn/publications/guide.html	Document developed to improve the quality of information provided by breast cancer screening programs to consumers

Physician Data Query	http://www.cancer.gov/cancertopics/pdq	Searchable database of cancer topics, clinical trials, and professional directories
Pink Book—Making Communications Programs Work	http://www.cancer.gov/pinkbook	Guide to communication program planning
Research Tested Intervention Programs	http://rtips.cancer.gov/rtips/index.do	Database of programs and products that can be adapted for individualized use
Risk Communication	http://riskfactor.cancer.gov/publications	Cancer risk prediction resources for clinicians and researchers
Understanding Cancer Series	http://www.cancer.gov/cancertopics/understandingcancer	Tutorials on cancer topics; some modules available in Spanish

Additional Tools for Researchers

Behavioral Risk Factor Surveillance System (BRFSS)	http://www.cdc.gov/brfss/	Annual telephone health survey instituted in 1984 to track health conditions and risk behaviors in the United States
Computer Retrieval of Information on Scientific Projects (CRISP)	http://crisp.cit.nih.gov	Searchable database of federally funded biomedical research projects
Current Population Survey	http://www.census.gov/cps/	Monthly survey of households conducted by the Bureau of the Census for the Bureau of Labor Statistics

Additional Tools for Researchers

Health Information National Trends Survey (HINTS)	http://hints.cancer.gov	National data about how adults gather information on cancer
National Health Interview Survey	http://www.cdc.gov/nchs/nhis.htm	Source of information on the health of the civilian noninstitutionalized population of the United States; one of the data collection programs of the National Center for Health Statistics
Surveillance, Epidemiology, and End Results (SEER) Program	http://seer.cancer.gov	Source of information on cancer incidence and survival in the United States
SEER-Medicare	http://healthservices.cancer.gov/seer-medicare/overview/	Provides population-based data on individuals from the Medicare population with cancer, identified through the linkage of Surveillance, Epidemiology and End Results (SEER) data and Medicare claims data

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