Summary, Conclusions, and Future Directions

6

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 psychology.

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 facilitators.[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

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 contin-

uum, 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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