A Patient-Centered Approach to Cancer Communication Research

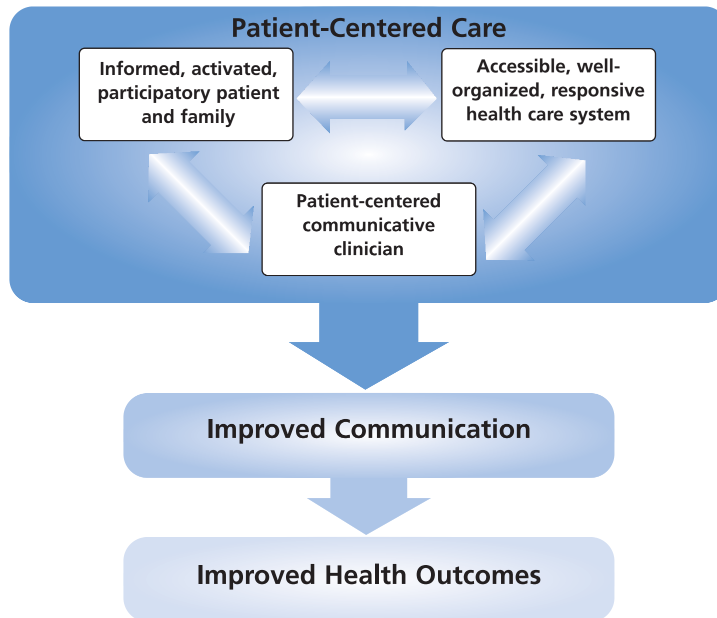
Although cancer communication has much in common with communication in other health contexts, several unique elements of cancer care make cancer communication research important. Among the distinct features of cancer care that affect communication are that few other illnesses are both life-threatening 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, feelings, 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 relationships (e.g., shared control vs. physician control),[60] gender,[61] and personality.[62]

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

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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