

# 3

## Pathways from Communication to Health Outcomes: Mediators and Moderators

The relationship between patient-clinician communication and outcomes of care is, from a conceptual standpoint, one of the least developed areas of communication research. Much of the current literature on cancer communication focuses on immediate, proximal outcomes of com-

munication, such as whether patients recall clinician recommendations, and intermediate outcomes, such as whether patients follow through with treatment (Table 3.1). The outcomes of greatest relevance to patients and their families, however, are health, survival, and quality of life. Survival

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

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

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

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

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

informed, concordant with patient values, and mutually endorsed)

- Patient agency (self-efficacy, empowerment, and enablement) leading to improved treatment adherence, health habits, and self-care

**Health outcomes**

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

**Societal outcomes**

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

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

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

The construct of health-related quality of life (HRQOL) is increasingly being used to measure subjective outcomes of care (Table 3.2). HRQOL refers to the impact of an individual’s health on his or her ability to function and on his or her perceived well-being, in physical, mental, and social domains of life. The functioning aspect of HRQOL includes basic activities, such as self-care, cognitive ability, and abil-

**Table 3.2 Domains of Health-Related Quality of Life**

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

\*Items in parentheses are encountered less frequently.

ity to perform at work, and the extent to which one is able to interact with family and friends. The well-being component of HRQOL relies almost exclusively on the perceptions of the patient and is therefore more subjective than the functioning aspect. Included in the well-being component is the degree to which the person has symptoms (physical well-being); feels happy, sad, depressed, or anxious (emotional well-being); and feels energetic or lethargic. Comprehensive HRQOL measures address multiple domains of function and well-being. Cancer can affect non-HRQOL domains as well, such as earning potential and standard of living, but the impact of communication on these domains is more

speculative.<sup>2,3</sup> Elements of HRQOL that have been assessed in communication studies in cancer and non-cancer settings include emotional and social well-being, and in some cases, symptoms and physical functioning.<sup>4,5</sup> Very few cancer communication studies have focused on the effects of communication on societal outcomes such as costs and health care disparities.

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

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

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

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

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

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

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

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

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

care that has intrinsic value regardless of other outcomes. Krupat et al.<sup>9</sup> reported that most patients endorse this latter viewpoint.

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

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

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

### 3.2 A Conceptual Model of Communication and Outcomes

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

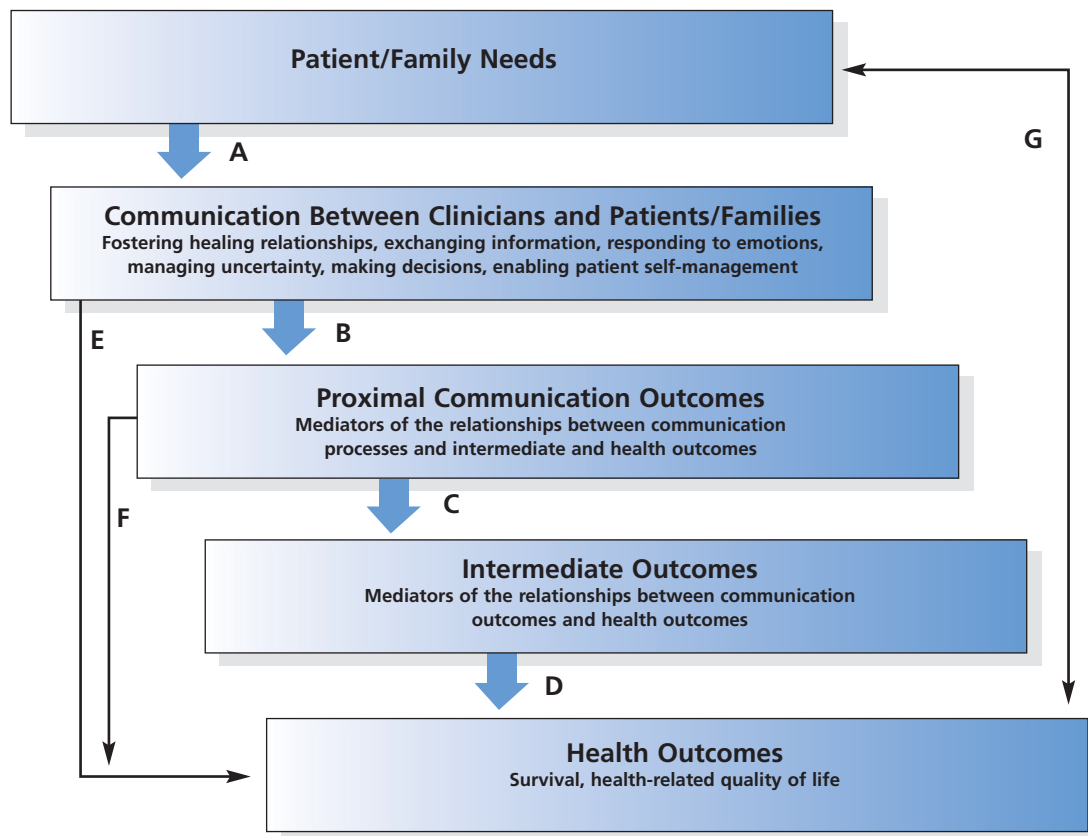
*diate outcomes* (Table 3.1) become mediators only when they are proved to be important steps along the pathway from communication to more distal outcomes. *Links*, indicated by the letters B through G in Figure 3.1, are components of larger pathways that start with communication and end with the most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

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

- Development of a trusting relationship
- Access to disease-related information
- Response to their emotions
- Help with decision-making and management of uncertainty
- Being empowered and capable of self-care

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

**Figure 3.1** Our conceptual model includes several mediating pathways that link the effects of communication with health outcomes. Links (B through G) are components of larger pathways that start with communication and end with the most distal outcome.



Link E suggests that sometimes communication can have a direct therapeutic effect on patients and families. For example, by providing information that a test result is normal, a clinician may directly reduce anxiety and thus contribute to improved HRQOL. In contrast, links B through F suggest that the pathway between communication and outcomes is mediated by a more complex series of steps. For example, a patient with breast cancer who is reluctant to take tamoxifen may first need to feel empowered to ask questions during a clinical consultation (a communication

behavior). In response to the patient's questions, the clinician is more likely to provide information about the overall benefits compared with the risks in a way the patient understands. The clinician's provision of information leads to greater trust (a proximal outcome) and a greater willingness of the patient to follow through with recommended therapy (an intermediate outcome), which, in turn, may affect survival. However, development of the patient's trust in the clinician and the health care system may involve not only the provision of information but also other kinds of commu-

nication behaviors, such as empathy and asking for the patient's perspective.<sup>15</sup> Furthermore, the establishment of trust may facilitate future communication about different topics in different contexts; thus, the effects of communication are both recursive (link G, Figure 3.1) and cumulative across time.

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



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

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

- Access to care
- Patient knowledge and shared understanding
- Therapeutic alliances (i.e., patient and clinician commitment to the relationship)
- Emotional self-management
- Family/social support and advocacy
- Quality of medical decisions (e.g., informed, clinically sound, concordant with patient values, and mutually endorsed)

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

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

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

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

### 3.2.1 Improving access to care

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

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

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

### ***3.2.2 Improving patient knowledge and shared understanding***

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

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

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

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

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

### ***3.2.3 Enhancing therapeutic alliances***

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

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

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

### ***3.2.4 Enhancing patients’ ability to manage emotions***

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

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

### ***3.2.5 Improving family/social support and advocacy***

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

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

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



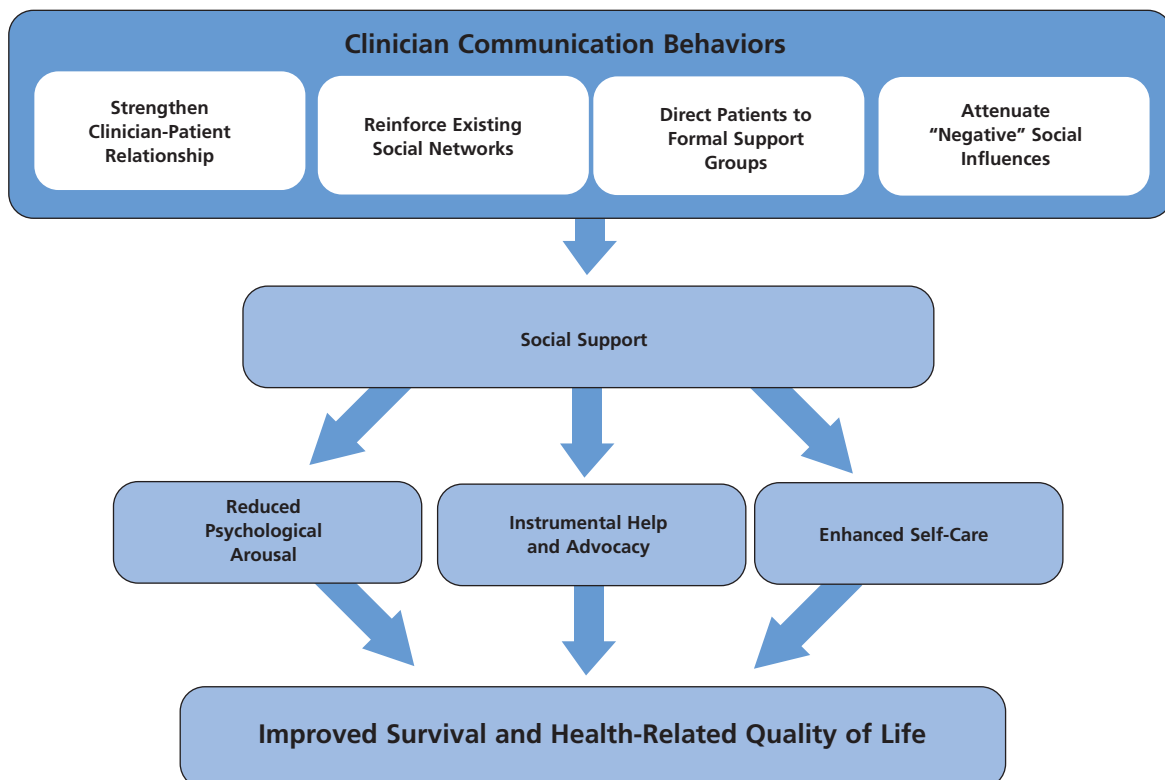
designed to simultaneously examine these multiple mechanisms of social support, to explore which aspects are linked to specific health outcomes, and to understand which features are more important in different settings;<sup>42</sup> rather, studies have tended to be designed to examine individual aspects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

Patient-clinician communication can contribute to improved health through the social support pathway in several ways. First, patient-clinician communication itself is a form of social support that decreases social isolation and pro-

vides encouragement and facilitation. Health care facilities can significantly help patients take advantage of social support resources by providing access to social workers, family therapists, and support groups. Second, clinicians and patients can discuss ways of reinforcing patients' social environments and the resources available within these networks (e.g., transportation, emotional support). Third, because cancer survivors with close supportive relationships often adjust better to the disease, clinicians can help direct patients to support groups and other resources, especially when a patient's networks have failed to provide needed support.<sup>59</sup> Face-to-

face support groups are inconvenient for many cancer survivors because of the time needed to travel, physical incapacity, or scheduling conflicts, and health care facilities can help overcome these barriers by directing patients to online support groups, which have much greater reach and often produce benefits that are comparable to those of face-to-face groups.<sup>60</sup> Lastly, because some forms of social support may be "negative" (promoting unhealthy behaviors such as smoking or well-intentioned nagging that creates more stress),<sup>61</sup> clinicians can discuss with patients the nature of negative support and ways to manage these problems or can even

**Figure 3.2** Several clinician communication behaviors can enhance social support, which improves health outcomes through several mechanisms.



talk directly to family members about how best to support a patient's needs.

### 3.2.6 Improving the quality of medical decisions

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

- Elicits the patient's needs
- Presents relevant clinical evidence in a way that the patient understands
- Effectively addresses the emotional aspects of decision-making
- Aligns clinician and patient perspectives so that the decision reached is concordant with the patient's values and with clinical evidence (link B in Figure 3.1)

High-quality decisions ideally improve both survival and multiple dimensions of quality of life.<sup>65</sup>

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

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

Measurable indicators of better medical decisions include the following:

- Consensus on treatment
- Clinician and patient/family satisfaction with their respective involvement in the decision-making process
- Concordance of the decision with the patient's values

- Adherence to evidence-based guidelines
- Feasibility of implementing the decision, given the available resources and the patient's means and capabilities

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

### 3.2.7 Enhancing patient empowerment and agency

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

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

O’Hair et al. describe a three-stage process through which communication can enhance patients’ sense of agency.<sup>77</sup> At the first stage, patients are confronted with uncertainty as they try to find their paths through unfamiliar and often terrifying circumstances. By managing uncertainty, the problems acquire a structure; they appear manageable rather than chaotic and random. The second stage involves empowerment, which requires advocacy on the part of others (clinicians, family members, support groups, etc.), as well as patients finding and having a voice in the clinical environment, whether that involves seeking information, participating

in decisions, or simply expressing feelings. The third stage, agency, involves action, self-determination,<sup>78</sup> self-efficacy in managing one’s health,<sup>79</sup> enablement,<sup>80-82</sup> a sense of control, and assertion of one’s perspective in both clinical and nonclinical settings.<sup>83</sup> Patients and families who are enabled have the ability to solve problems and cope with health-related complications and to seek and interpret health-related information. They also have the ability and volition to follow through with appropriate treatment recommendations.

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

- Supporting patient autonomy<sup>84,85</sup>
- Building partnerships<sup>83</sup>
- Managing uncertainty<sup>86</sup>
- Facilitating information exchange
- Providing access to educational and problem-solving resources
- Assisting with effective navigation of the health care system

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

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

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

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

**Table 3.3 Agency**

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

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

We have noted that the research on communication and outcomes in cancer settings is limited, and even fewer studies have been conducted on moderators of these relationships. Moreover, much of the research has been superficial at best, focusing most often on individual differences among clinicians and patients rather than on theoretical reasons explaining *why* these individual differences have a moderating effect. As a case in point, suppose an investigation found that the relationship between a clinician's advice and the patient's subsequent commitment to chemotherapy was moderated by whether the clinician and patient were of the same race.

Although racial concordance moderated the effect of communication on adherence in this study, it is not clear why. The patient may have perceived a clinician of the same race to be more trustworthy or empathic and/or similar with regard to language use; each of these factors could account for the moderating influence of racial concordance. Importantly, one could easily identify other variables that may render racial concordance insignificant,<sup>89</sup> such as the duration of the patient-clinician relationship, similarity in age or religion, or clinician skill at finding common ground with the patient.

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

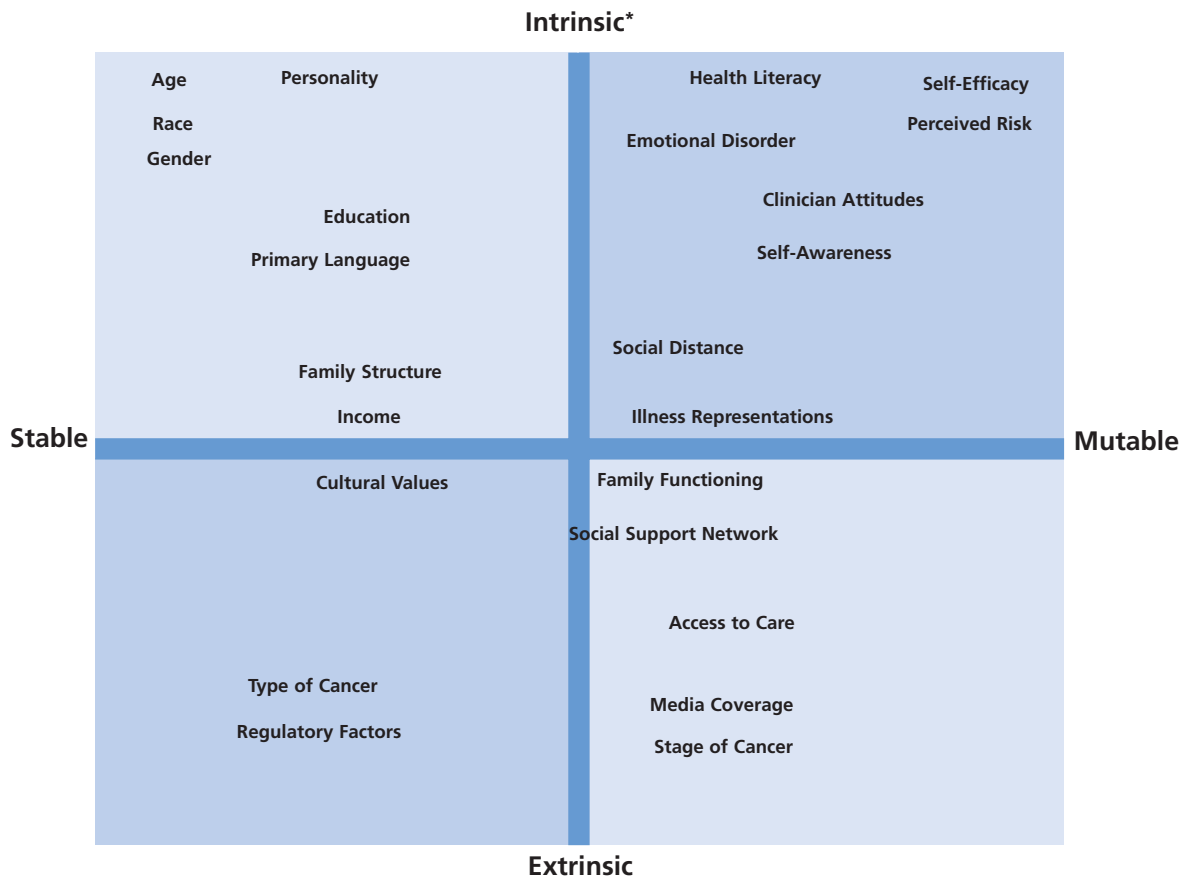
An important challenge for researchers is to uncover the cognitive, emotional, and behavioral processes accounting for the effects of variables moderating the relationship between communication and outcomes, as well as to identify the reasons some moderators are more important than others in certain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

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

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

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

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



\*Intrinsic to clinicians, patients, and other relationships

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

desired outcomes. Factors that are more stable (i.e., less modifiable) impose constraints or opportunities that must be taken into account.

For example, health literacy (discussed later) is apt to be an important moderator of the relationship between patient involvement in decision-making and adherence to treatment. Patients who have a better understanding of the disease, their options for treatment, and the risks and benefits of different treatments will probably participate more effectively in the decision-making process. Because health

literacy is to some degree mutable, clinicians providing patient education interventions prior to decision-making<sup>92</sup> can optimize the patient's capacity to participate effectively. This enhanced participation could lead to a greater likelihood of completing treatment and thus, longer survival.

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



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

**Factors intrinsic to the clinician-patient/family relationship**

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

**Relationship factors: Patients, multiple clinicians, and family members**

- Mutual influence and accommodation
- Family structure and functioning

- Mutual knowledge, duration of relationship, trust

**Contextual factors affecting clinician-patient/family communications**

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

the reasons they are moderators are often due to potentially mutable factors. Consider, for example, the common research finding that older patients prefer to be less involved in decision-making than younger patients.<sup>93-97</sup> It is unclear whether the relationship between age and preferences for involvement is due

to expectations based on previous experience (a modifiable factor), traditional beliefs about control in the patient-clinician relationship (a potentially modifiable factor), or cognitive impairment (a stable factor). It would be important to discover the reason for an older patient's preferences in order to

determine whether the clinician should take control of decision-making (if the preference was firmly held) or offer the patient an educational intervention that, in addition to providing information about treatment options, legitimized the patient's involvement and encouraged the patient to par-

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

### 3.3.1 *Intrinsic moderators of patient-clinician communication and outcomes*

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

#### *Health literacy*

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

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

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

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

#### *Social distance*

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

Social distance is an important moderator of the relationship

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

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

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

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

#### *Clinicians' attitudes toward patients*

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

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

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

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

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

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

#### *Patients' preferences for clinician and patient roles*

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

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

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

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

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



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

### ***3.3.2 Context as an important source of extrinsic moderators***

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

Several contextual elements have the potential to influence health

care, but six require further consideration in cancer contexts:

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

#### *Disease-related factors*

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

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

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

#### *Family and social environment*

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

Clinicians must conceptualize cancer care as a family issue regardless



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

#### *Cultural context*

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

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

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

#### *Media environment*

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

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

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

### *Health care system*

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

### *Societal factors*

Although the subject of little research, societal factors, including the regulatory and legal environ-

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

### **3.4 Multilevel Modeling**

Given the complexities of factors affecting patient-clinician communication processes, the pathways through which communication achieves desired outcomes, and the moderators of these relationships,

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

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

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

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

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

### 3.5 Conclusion

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

outcomes. We described seven pathways through which effective communication leads to intermediate and distal outcomes, providing improvements in the following:

- Patient knowledge and shared understanding
- Access to care
- Therapeutic alliances
- Emotional self-management
- Family/social support and advocacy
- Quality of medical decisions
- Patient agency (self-efficacy, empowerment, and enablement)

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

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

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