

# A Framework for Patient-Centered Communication in Cancer Care

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

- Simple enough to be generally understood and useful
- Complex enough to account for clinical reality
- Designed to involve all relevant players, including different types of patients, families, clinicians, and health care systems
- Applicable to the relationship between clinical communication and relevant patient health outcomes

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

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

- Fostering healing relationships
- Exchanging information
- Responding to emotions
- Managing uncertainty

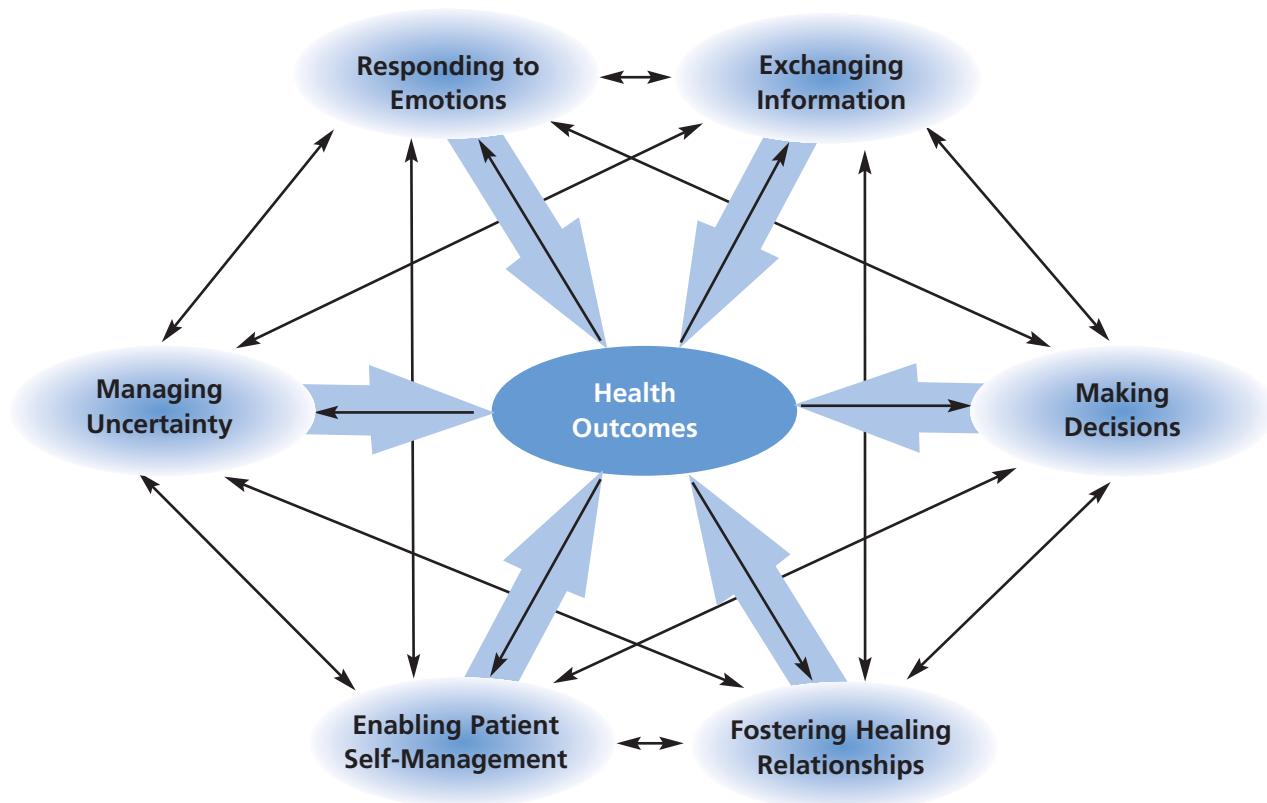
- Making decisions
- Enabling patient self-management

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

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



**Figure 2.1** The six core functions of patient-clinician communication overlap and interact to produce communication that can affect important health outcomes.



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

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

### 2.1 Fostering the Patient-Clinician Relationship

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

## 2.2 Exchanging Information

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

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

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

ing to the phase on the cancer care continuum:

- Prevention: discussing risks and benefits of screening with asymptomatic patients
- Diagnosis or recurrence: sharing bad news and explaining test results
- Treatment: Interpreting results of clinical trials for making decisions

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

### 2.2.1 Patients' information needs

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

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

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

information needs by providing the following:

- Audio recordings of clinical consultations to help patients with cancer recall and assimilate information<sup>85</sup>
- Multimedia resources that help explain complex features of disease and treatment options<sup>29</sup>
- Educational resources that provide instructions for patients and their family members on how to use the Internet to get the most useful information<sup>86</sup>

### ***2.2.2 Understanding what patients know and believe about health***

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

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

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

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

### ***2.2.3 Communicating clinical information***

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

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

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

- Use everyday language as much as possible
- Repeat and summarize
- Ask patients to restate information as a way to ensure they understand
- Encourage patients to ask questions
- Engage in active listening
- Allow adequate time for discussion with the patient
- Be honest

#### ***2.2.4 Sharing bad news and prognostic information***

Although patients and clinicians in the United States and other English-speaking countries overwhelmingly endorse honest disclosure of a cancer diagnosis,<sup>99</sup> the delivery of bad news continues to be stressful for clinicians and ineffective and/or traumatic for patients and their families.<sup>100</sup> Patients report feeling upset or overwhelmed after they hear the devastating news of a cancer diagnosis; such anxiety makes assimilation and recall of further information difficult.

Although no communication intervention can eliminate the life-changing impact of a cancer diagnosis, the effective delivery of bad news can at least help patients become the following:

- Better informed
- More motivated to follow through with further evaluation and treatment
- Less emotionally distressed
- Better able to ask questions and participate in the clinical encounter
- Better prepared to make treatment decisions
- Better able to navigate the health care system
- Clear about the level of uncertainty of the diagnosis

The difficulty in managing bad news may be further compounded by a patient’s psychological and emotional factors, cognitive impairment, and low health literacy.<sup>94</sup>

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

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

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

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

### 2.3 Responding to Emotions

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

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

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

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

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

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



- Legitimation: “It’s only natural to feel that...”
- Validation: “Yes, this is a very anxiety-provoking time for you.”
- Empathy: “This is making you both worried and sad, is that right?”
- Tangible help: “I think I can help by....”

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

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

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

## 2.4 Managing Uncertainty

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

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

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

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

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

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

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

## 2.5 Making Decisions

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

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

- Patients have not necessarily considered all of the options prior to the medical visit
- Patients and clinicians often hold different beliefs about health
- Patients are often not familiar with the clinical reasoning supporting a preferred option

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

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

- *Paternalistic*: clinician decides treatment
- *Shared*: clinician and patient together decide treatment

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

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

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

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

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

- Perspectives of both clinician and patients were voiced and understood
- Differences were reconciled satisfactorily
- Mutual agreement was achieved regarding the best course of action

- Decision was supported by current clinical evidence

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

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

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

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

- Setting an explicit agenda
- Listening actively
- Checking understanding
- Offering opportunities for involvement
- Endorsing patient participation in discussions and the decision
- Accommodating patients’ preferences
- Communicating empathy and warmth both verbally and nonverbally

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

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

## 2.6 Enabling Patient Self-Management

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

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

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

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

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

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

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

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

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

- Help patients obtain confirmatory testing for suspected cancer in a timely fashion
- Tell patients how to get to a specialist's office
- Explain clearly about when and with whom to follow up
- Arrange referrals for psychotherapy, support groups, and/or social work
- Coordinate care among specialists for hospitalized patients
- Provide palliative/end-of-life care or direct patients to resources for such care, as appropriate

### **2.6.2 Supporting patient autonomy**

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

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

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

- Find their way through the health care system
- Obtain access to the best clinicians for their particular condition
- Recognize gaps and lapses in care and bring them to clinicians' attention
- Improve adherence to treatment
- Become educated consumers of health care

### 2.6.3 Providing guidance, skills, and access to resources

By providing access to resources, clinicians can help patients directly or help patients help themselves. In addition to motivation and confidence (self-efficacy), patients also need the knowledge, skills, and resources to be able to follow through. Clinicians still need to provide recommendations, instruction, advocacy, and support. Even if a patient feels empowered and enabled, situations with regard to the patient's illness change over time. *Recommendations* should be clear, with nontechnical language and simple sentence structure. Recommendations should be accompanied by recall-promoting behaviors such as repetition, summarization, categorization, and asking the patient to repeat complex recommendations so that it is clear that they understand.<sup>193-199</sup>

*Instruction* helps patients do things for themselves. Instructions should include clear explanations on ways the patient should manage pain and other symptoms and how to follow through with a mutually agreed upon plan that might include scheduling medications, having an x-ray done, or talking to a social worker. Instruction also can include telling the patient and the family how and when to contact the clinician, how to make sure that the right people are present during family meetings, and what websites will provide relevant information.

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

- Use of lay health educators<sup>200</sup> and interactive media<sup>201</sup> to help patients be more proactive in controlling pain and other cancer-related symptoms
- Training patients how to use the Internet more effectively to access health information<sup>202</sup>
- Sponsoring of community-based programs for the management of cancer-related symptoms<sup>203</sup>
- Assistance for patients regarding the use of complementary and alternative medicine<sup>204</sup>
- Toolkits for learning self-advocacy<sup>205</sup>

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

## 2.7 Conclusion

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

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

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

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

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

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

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

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