

Key Communication Tasks and Outcomes: The Cancer Care Continuum

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

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

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

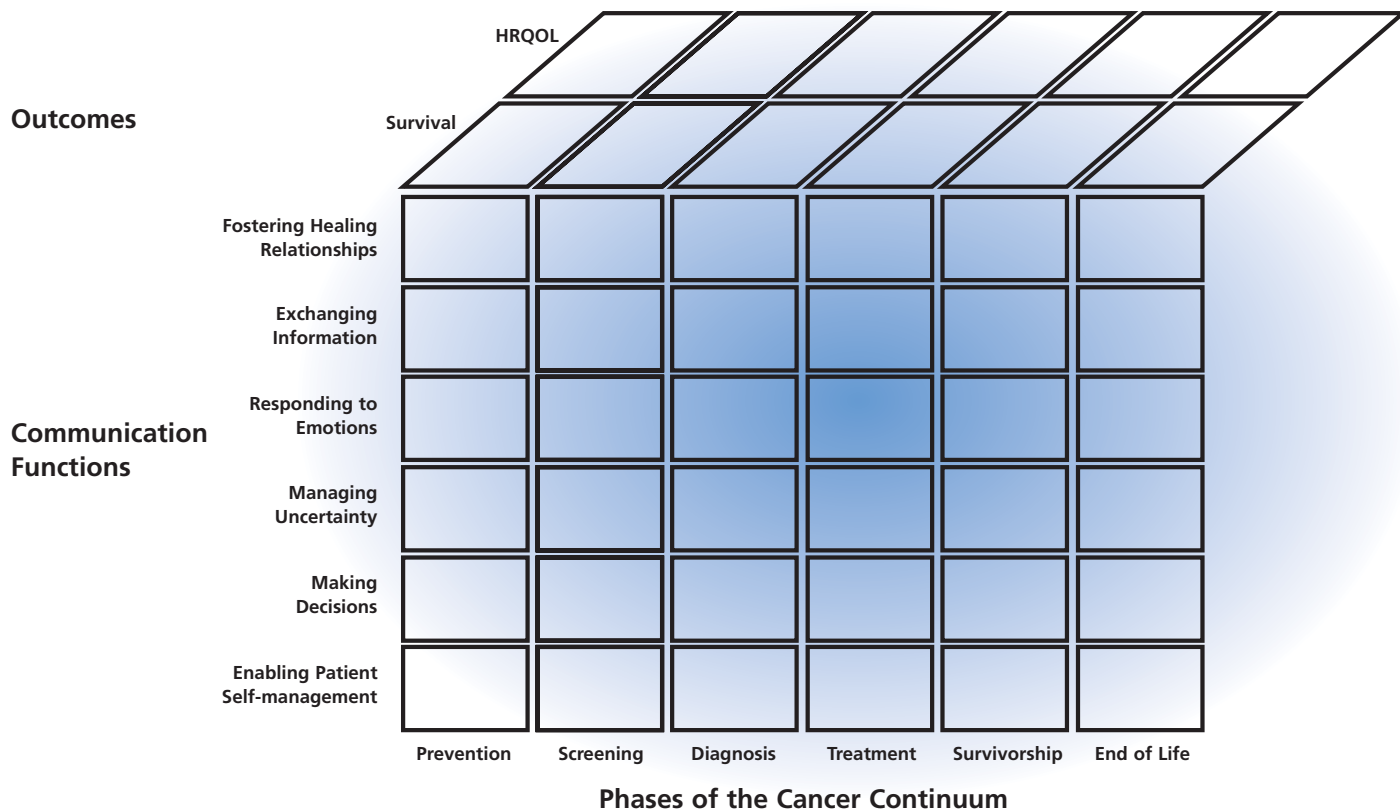
- Fostering healing relationships
- Exchanging information
- Responding to emotions
- Managing uncertainty
- Making decisions
- Enabling patient self-management

six phases of the cancer care continuum.

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



Figure 4.1 The six communication functions can help to improve survival and health-related quality of life (HRQOL) in each of the phases of the cancer care continuum.



such as adherence to treatment, often are necessary steps to achieve desired health outcomes at some phases, communication itself may have a more direct effect on well-being at other phases.

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

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

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

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

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

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

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

cont'd on p 70

Table 4.2 cont'd from p 69

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

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

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

4.1 Prevention Phase

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

4.1.1 Desirable outcomes

Effective cancer prevention should ideally result in a lower risk of cancer, as well as a reduction in racial, ethnic, educational, and

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

4.1.2 Communication tasks and functions

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

Patients must make decisions regarding prevention, the most important of which is whether to try to change a behavior at all. In addition, patients encounter decisions regarding immunizations. For example, now that two human papillomavirus vaccines are available, many parents must confront

the decision of whether to immunize their preadolescent children and, if so, with which of the vaccines. Clinicians have a role in making choices explicit for patients and helping them decide to adopt healthy behaviors.

Clinicians also should actively help patients adopt healthy behaviors. One method for enabling patients through a behavior change process;^{6,7} the process includes the following:

- Asking about the behavior
- Advising the patient to change
- Assessing facilitators and barriers to change
- Assisting (actively) the patient
- Arranging for further interventions and follow-up

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

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

4.2 Screening Phase

4.2.1 *Desirable outcomes*

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

4.2.2 *Communication tasks and functions*

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

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

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

Barriers to screening disproportionately affect disadvantaged,

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

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

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

4.3 Diagnosis Phase

4.3.1 *Desirable outcomes*

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

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

4.3.2 *Communication tasks and functions*

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

- Assess symptoms that raised suspicion of cancer
- Address patients' anxiety, fear, and sometimes terror at the anticipation of a cancer diagnosis, even before communicating bad news
- Communicate bad news clearly and compassionately
- Involve family members in discussions and decisions to the degree that it will be helpful and desired by patients
- Help patients recall important information
- Assist patients with navigating their way through the health

care system to gain access to procedures and consultations

- Discuss probabilistic data in ways that patients understand so that they can participate in discussions and decisions about treatment
- Assess patients' desire to participate in decisions
- Communicate prognosis while maintaining hope
- Help patients make decisions about anticancer treatments and advance directives
- Provide support to the patient, family, caregivers, and friends

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

The first major communication task at the diagnosis phase is either assessing symptoms that have raised the suspicion of cancer or notifying patients of results of a positive screening test. Some cancers, such as cancers of the cervix, breast, and colon are increasingly being diagnosed by routine or targeted screening, whereas other common cancers, such as cancers of the lung and ovary and hematological malignancies, usually are diagnosed in response to patients' reporting of symptoms. The initial

process of clinical evaluation involves gathering information from the patient. In later phases, clinicians provide information, but this information often is changing rapidly and is incomplete until the full diagnostic picture is clear. The entire process of diagnosis may take a day or less, but more often, it takes place over the course of several days or weeks. Furthermore, patients may need to choose which (if any) diagnostic procedures to pursue. The choice can be more difficult if the diagnostic procedures are uncomfortable. Patients experience chaos, terror, and anxiety during this phase, which, in turn, affects their ability to assimilate information and make rational decisions. Thus, eliciting and validating emotions may become more important and also more difficult during the advancement toward a definitive diagnosis.

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

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

The second task at the diagnosis phase is delivering bad news. Although almost all patients in Western industrialized countries wish to know their diagnosis, patients vary in their desire for information about treatment and prognosis at the time of the initial cancer diagnosis. Clinicians must assess how much detail patients want. Particularly important is asking patients what role they would like their families to play: what information should be shared, with whom, and when. Ideally, patient preferences should be discussed before diagnostic testing, but in actual clinical practice, that is often not the case. Because recall of such information is typically poor, providing information in small chunks, repeating key points, categorizing, summarizing, and checking patient understanding are key communication skills.¹⁵⁻¹⁹ Audio recordings of consultations²⁰⁻²² and written materials²³ may be helpful.

Managing the strong patient emotions associated with hearing bad news for the first time requires skillful clinician use of empathy. Patients' emotional well-being after a diagnosis is enhanced by adequate preparation for the news before diagnostic testing, presence of friends or family members at the consultation, discussion of the patient's feelings, and clear information presented in oral and written formats.^{24,25} Patients fear that they will face these challenges

alone; they need reassurance that their physicians and other health professionals will be there for them when they need them.²⁶

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

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

The third major communication task during the diagnosis phase is making decisions about the initial anticancer treatment. In some cases of slow-growing cancers, patients choose to forgo anticancer treatment entirely or opt for watchful waiting if it is possible that the risk of treatment-related complications will exceed the therapeutic

benefit. In trying to measure what constitutes a "good decision," researchers have considered whether the

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

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

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

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

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

Information is necessary but not sufficient for decision-making;³² patients and clinicians need to

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

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

4.4 Treatment Phase

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

4.4.1 Desirable outcomes

Effective communication can encourage patients to complete surgical treatment and/or receive adequate doses of chemotherapy agents or radiation. Better communication can lead to lower levels of anxiety and depression, fewer side effects, greater social support, and success in finding meaning.⁴⁷ Completion of adequate treatment and attention to psychosocial issues are both associated with improved survival and health-related quality of life. Conversely, poor communication may be partially responsible for the inadequate treatment more commonly seen in minority populations⁴⁸ and patients with low health literacy.¹⁰ Patient factors that influence communication include access to care, expectations, trust, and level of activation.

4.4.2 Communication tasks and functions

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

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

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

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

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

- Lack of understanding of clinical evidence suggesting that the treatment is effective
- Lack of understanding that lower doses may be equivalent to no treatment at all
- Lack of understanding that side effects may be transient and reversible
- Distrust of the clinician, or feeling "experimental"
- Distrust of the evidence on which treatment decisions are based
- Information and recommendations from other sources (particularly the Internet)
- Not feeling understood by the clinician

4.5 Survivorship Phase

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

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

4.5.1 Desirable outcomes

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

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

4.5.2 Communication tasks and functions

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

cer treatment, such as secondary cancers, obesity, sexual dysfunction, infertility, and birth complications, which are more common than previously thought.⁶¹ Other consequences of cancer are lower earning potential⁶² and difficulty in obtaining health insurance.

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

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

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

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

4.6 End-of-Life Phase

4.6.1 Desirable outcomes

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

4.6.2 Communication tasks and functions

In reviews of the communication tasks in end-of-life care, de Haes and Teunissen⁶⁴ and Tattersall et al.,⁴⁷ noted that the following tasks are important:

- Eliciting information from patients about pain and other symptoms
- Providing accurate prognostic information while maintaining hope
- Managing strong emotions in patients and clinicians
- Making numerous decisions about initiation and cessation of palliative chemotherapy,

radiation therapy, and life-sustaining treatments

- Deciding where the patient will live and who will care for him or her
- Dealing with patients' fears of abandonment
- Handling requests from the patient and family to use futile therapies, to set unrealistic goals, or to hasten death

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

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

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

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

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

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

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

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

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

4.7 The Real World of Cancer Care

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

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

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

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

Textbox 4.1 Case of Gloria Rodriguez*

Patient’s Cancer Experience

Communication Tasks

Screening phase

Gloria Rodriguez is a 48-year-old Mexican American factory worker who had a follow-up mammogram one year after she had discovered a lump in the right breast. The right breast was aspirated at that time, and the findings were benign. On the follow-up mammogram, a suspicious two-centimeter lesion was found in the left breast.

Exchanging information: Explaining the difference between a positive screening test and actual disease

Managing uncertainty: Interpreting test results

Neither she nor her primary care physician had detected the mass by palpation.

Fostering healing relationships: Establishing trust, understanding clinicians’ limitations

Ms. Rodriguez was referred to a large inner-city hospital that did not have a regional cancer center and had a lower percentage of Board-certified physicians on staff compared with other hospitals in the region.

Enabling patient self-management: Eliminating disparities in access to and quality of care

Diagnosis phase

The radiologist made an appointment for an ultrasound the next day, but the patient did not understand why an ultrasound was necessary and why she did not have an aspiration, as she had previously. When the radiologist said “suspicious,” Ms. Rodriguez thought he was being evasive. She missed the ultrasound appointment because of a lack of transportation. She attempted to call the radiology department to reschedule but was unsuccessful.

Making decisions: Involving patients in decision-making.

Exchanging information: Improving patient knowledge about the diagnostic process

Enabling patient self-management: Guiding the patient through the health care system

After a two-week delay, Ms. Rodriguez had an ultrasound that suggested a solid mass, and she was referred to a surgeon for needle biopsy later that week. Although the ultrasonographer mentioned that the mass was “solid,” Ms. Rodriguez did not know that the term meant that the mass was more likely to be malignant, nor did she realize that it was more appropriate for the diagnostic information to be conveyed by the physician, not a technician.

Enabling patient self-management: Communicating within the health care system

Coordinating involvement of multiple clinicians for the patient’s care

Exchanging information: Using electronic communication technology

Responding to emotions: Conveying empathy and taking action

Ms. Rodriguez returned to her primary care physician for a routine follow-up visit, but the reports from the ultrasound were not immediately available. Seeing that Ms. Rodriguez was distraught, the physician called the radiologist to obtain the findings.

The primary care physician explained the need for biopsy and probable surgery.

Exchanging information: Using lay language

cont’d on p 81

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

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

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

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

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

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

Enabling patient self-management: Promoting continuity of care

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

Fostering healing relationships: Considering family and social factors in communication

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

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

Enabling patient self-management: Coordinating involvement of multiple clinicians

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

Responding to emotions: Eliciting and addressing patient fears

Making decisions: Facilitating informed decision-making

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

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

Treatment phase

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

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

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

Exchanging information: Dealing with adverse outcomes

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

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

cont'd on p 82

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

Pathological findings indicated a 1.8 cm tumor and no evidence of disease in the lymph nodes. Because of the size of the tumor, Ms. Rodriguez was referred to a medical oncologist to discuss chemotherapy. She was puzzled because she thought that they “got it all.” No one had mentioned chemotherapy previously.

Fostering healing relationships: Optimizing communication among multiple clinicians and the patient

Ms. Rodriguez discussed the advantages and risks of chemotherapy with the oncologist. The oncologist also discussed other alternatives such as oophorectomy and hormone therapy and mentioned that research still is being done to determine the best option. She was given an informational booklet and asked to call once she had decided on the therapeutic option and whether she wanted to proceed. The list of side effects seemed frightening, so she did not make a follow-up appointment. She was also worried by the word “experimental”; she thought that she would be used as a guinea pig. Also, she did not understand the statistics on effectiveness in preventing recurrence.

Exchanging information: Offering both information and the skills to process the information
Communicating with patients with low health literacy

Responding to emotions

Making decisions: Communicating evidence

Fostering healing relationships: Establishing and maintaining trust

The radiation oncologist explained the course of radiation therapy and its risks, and, after Ms. Rodriguez provided consent, a five-week course of radiation therapy was begun. She came to know and trust the radiation oncology technician, and her brief conversations with her each day provided some comfort.

Fostering healing relationships: Lowering the level of patient anxiety

Survivorship phase

Ms. Rodriguez completed treatment and returned to her surgeon, radiation oncologist, and primary care physician for follow-up visits several times in the first year, with no indication of recurrence. Nonetheless, having not received chemotherapy put her at a 5% to 10% higher absolute risk for recurrence. Although she is afraid of recurrence, she and her family never spoke of these fears, and she did not initiate discussions of these issues with her physicians. If the cancer were to recur, she might blame herself, however, for not deciding to receive chemotherapy.

Fostering healing relationships: Coordinating communication with multiple clinicians

Responding to emotions: Addressing fears of recurrence

Managing uncertainty: Interpreting survival estimates

Judging the degree of numerical detail that would be meaningful for the patient

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

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

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

4.8 Conclusion

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

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

Textbox 4.2 Case of Randall Groves***Patient's Cancer Experience****Communication Tasks****Diagnosis phase**

Randall Groves is a 73-year-old semiretired, divorced professor of economics. His energy has been diminishing over several months and a sense of fullness and bloating developed in the upper left quadrant of the abdomen. On the physical examination, there was tenderness in that area but no mass was palpated. The findings of fecal occult blood testing were negative, as were the results of upper endoscopy and colonoscopy. Blood chemistry levels and cell counts were normal. He began to lose weight. His physician suspected cancer, which he communicated to the patient. He did not communicate that he considered pancreatic cancer most likely.

Exchanging information: Deciding how to share information and clinical impressions at different points in the diagnostic process

Responding to emotions, managing uncertainty: Dealing with anxiety until the diagnosis is clarified

Computerized tomography (CT) of the abdomen showed a large tumor involving the head of the pancreas. The radiologist suggested that it likely was inoperable. This information was communicated to the patient by the primary care physician. Mr. Groves was not surprised by the news. The patient wanted a surgical opinion. He indicated that symptom control was more important than life-extending procedures.

Exchanging information, managing uncertainty: Communicating bad news
Eliciting patient values and wishes

The surgeon suggested that a Whipple procedure might be possible, but whether it could be done would be known only after the abdomen had been opened. He estimated that the best-case scenario represented a 20% chance of long-term survival and a 30% chance of improved quality of life. Mr. Groves was devastated and terrified. He had not realized that the prognosis was so poor.

Exchanging information, making decisions: Framing choices to help patients decide among options
Communicating prognosis both accurately and sensitively
Responding to emotions: Managing terror

Mr. Groves preferred to talk it over with his primary care physician. The patient searched the Internet and found data indicating the prognosis was worse than the surgeon suggested. The primary care physician contacted the surgeon directly, who communicated a more pessimistic picture to the physician than he had to the patient.

Fostering healing relationships: Maintaining trust
Exchanging information, managing uncertainty: Dealing with complex ambiguous medical information

Mr. Groves and his primary care physician discussed and updated his health care proxy and living will. His primary care physician offered to help clarify the patient's choices.

Managing uncertainty: Discussing advance care planning and end-of-life issues

Both Mr. Groves and his primary care physician found information about a variety of chemotherapy regimens. A further Internet search by the patient led to 15 recently published reports, each supporting different regimens of palliative chemotherapy. Mr. Groves tried to reconcile the multiple conflicting sources of information about treatment effectiveness and prognosis. Although he was highly educated, he could not always distinguish between terms such as "treatment response," "clinical remission," "radiographic remission," and "quality of life improvement." He felt increasingly confused and anxious; the more he searched, the less sure and more anxious he became.

Exchanging information, managing uncertainty: Effectively using information that patients bring to the consultation
Enabling patient self-management: Using electronic media
Responding to emotions: Managing anxiety related to uncertainty and cognitive overload

When Mr. Groves consulted with a local oncologist, he was offered one of the palliative chemotherapy options; other treatments were available only through clinical trials in other cities. Mr. Groves opted not to have surgery but chose to go to a major cancer center in another city to discuss experimental options. He would stay with relatives there.

Enabling patient self-management: Facilitating family involvement in care;
Reducing disparities in access to care

cont'd on p 83

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

Treatment phase

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

Mr. Groves never spontaneously complained of pain and only described a sensation of abdominal “fullness.” However, when a daughter visited from out of town, she noted that he seemed uncomfortable and woke frequently at night. His primary care physician consulted the palliative care team, who made a home visit. They suggested a trial of long-acting opioid pain medication, which improved the patient’s quality of life and sense of well-being.

Exchanging information: Gathering information about the patient from family members and friends

Making decisions: Discussing palliation while still in the active treatment phase

Forgotten by the physician, but addressed by the home care nurses and clergy, were discussions about the meaning of the illness to the patient, the process of dying, and the role of the family.

Fostering healing relationships, responding to emotions: Introducing psychosocial dimensions into discussions

End-of-life phase

Mr. Groves completed three courses of chemotherapy, two weeks apart, but worsened clinically. Jaundice and ascites developed, requiring paracentesis for comfort. He postponed the fourth and final course of chemotherapy, intending to return in a couple of weeks. His appetite and energy waned. He required increasing doses of oral opioids to control his abdominal discomfort. Mr. Groves and his primary care physician discussed hospice care and suspension of further anticancer treatment.

Exchanging information: Discussing treatment failure and transition to palliative care

Managing uncertainty: Helping the patient articulate end-of-life wishes

Previously active in making decisions regarding his care, Mr. Groves relegated these and subsequent decisions to his girlfriend, who also was his health care proxy. He moved to another city (where she lived) and received hospice care in the home.

Fostering healing relationships: Accommodating patients’ changing wishes for involvement in decision-making, and increased family involvement

Mr. Groves died two weeks later, more rapidly than anyone expected. The day after Mr. Groves’ death, the oncologist called Mr. Groves’ girlfriend to tell her that he had admired how Mr. Groves coped with his illness and recognized the girlfriend’s role in caring for him.

Fostering healing relationships, responding to emotions: Communicating with the patient’s family and friends after the patient’s death

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

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

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

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

References

- (1) Howie JG, Heaney DJ, Maxwell M, et al. Quality at general practice consultations: cross sectional survey. *BMJ*. 1999;319:738-743.
- (2) Little P, Everitt H, Williamson I, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *BMJ*. 2001;323:908-911.
- (3) Williams GC, Rodin GC, Ryan RM, Grolnick WS, Deci EL. Autonomous regulation and long-term medication adherence in adult outpatients. *Health Psychol*. 1998;17:269-276.
- (4) Williams GC, Freedman Z, Deci EL. Promoting motivation for diabetics' self-regulation of HgbA1c. *Diabetes*. 1997;45:13A.
- (5) Carroll J, Epstein R, Fiscella K, et al. Health promotion and preventive services for African refugee women. *Health Care Women Internat*. (in press)
- (6) Glynn TJ, Manley MW. *How to Help Your Patients Stop Smoking: A Manual for Physicians*. Bethesda, MD: National Cancer Institute, NIH Publication 89-3064; 1989.
- (7) Whitlock EP, Orleans CT, Pender N, Allan J. Evaluating primary care behavioral counseling interventions: an evidence-based approach. *Am J Prev Med*. 2002;22:267-284.
- (8) Goodwin MA, Zyzanski SJ, Zronek S, et al. A clinical trial of tailored office systems for preventive service delivery. The Study to Enhance Prevention by Understanding Practice (STEP-UP). *Am J Prev Med*. 2001;21:20-28.
- (9) Swan J, Breen N, Coates RJ, Rimer BK, Lee NC. Progress in cancer screening practices in the United States: results from the 2000 National Health Interview Survey. *Cancer*. 2003;97:1528-1540.
- (10) Davis TC, Williams MV, Marin E, Parker RM, Glass J. Health literacy and cancer communication. *CA Cancer J Clin*. 2002;52:134-149.
- (11) Doak CC, Doak LG, Friedell GH, Meade CD. Improving comprehension for cancer patients with low literacy skills: strategies for clinicians. *CA Cancer J Clin*. 1998;48:151-162.
- (12) Balsa AI, McGuire TG. Statistical discrimination in health care. *J Health Econ*. 2001;20:881-907.
- (13) Balsa AI, McGuire TG. Prejudice, clinical uncertainty and stereotyping as sources of health disparities. *J Health Econ*. 2003;22:89-116.
- (14) van Ryn M. Research on the provider contribution to race/ethnicity disparities in medical care. *Med Care*. 2002;40:1140-1151.
- (15) Back AL, Arnold RM, Baile WF, Tulskey JA, Fryer-Edwards K. Approaching difficult communication tasks in oncology. *CA Cancer J Clin*. 2005;55:164-177.
- (16) Ley P, Bradshaw PW, Eaves D, Walker CM. A method for increasing patients' recall of information presented by doctors. *Psychol Med*. 1973;3:217-220.
- (17) Bertakis KD. The communication of information from physician to patient: a method for increasing patient retention and satisfaction. *J Fam Pract*. 1977;5:217-222.
- (18) Kupst MJ, Dresser K, Schulman JL, Paul MH. Evaluation of methods to improve communication in the physician-patient relationship. *Am J Orthopsychiatry*. 1975;45:420-429.
- (19) Ley P. Memory for medical information. *Br J Soc Clin Psychol*. 1979;18:245-255.
- (20) Hogbin B, Jenkins VA, Parkin AJ. Remembering the 'bad news' consultations: An evaluation of tape-recorded consultations. *Psychooncology*. 1992;1:147-154.
- (21) Scott JT, Harmsen M, Prictor MJ, et al. Recordings or summaries of consultations for people with cancer. *Cochrane Database of Systematic Reviews*. 2005.
- (22) Ford S, Fallowfield L, Hall A, Lewis S. The influence of audiotapes on patient participation in the cancer consultation. *Eur J Cancer*. 1995;31A:2264-2269.
- (23) Ellis DA, Hopkin JM, Leitch AG, Crofton J. "Doctors' orders": controlled trial of supplementary, written information for patients. *Br Med J*. 1979;1:456.
- (24) Roberts CS, Cox CE, Reintgen DS, Baile WF, Gibertini M. Influence of physician communication on newly diagnosed breast patients' psychologic adjustment and decision-making. *Cancer*. 1994;74:336-341.
- (25) Schofield PE, Butow PN, Thompson JF, et al. Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol*. 2003;14:48-56.
- (26) Quill TE, Cassel CK. Nonabandonment: a central obligation for physicians. *Ann Intern Med*. 1995;122:368-374.
- (27) Fallowfield L, Jenkins V, Farewell V, et al. Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *Lancet*. 2002;359:650-656.
- (28) Jenkins V, Fallowfield L. Can communication skills training alter physicians' beliefs and behavior in clinics? *J Clin Oncol*. 2002;20:765-769.

- (29) Fallowfield L, Jenkins V, Farewell V, Solis-Trapala I. Enduring impact of communication skills training: results of a 12-month follow-up. *Br J Cancer*. 2003;89(8):1445-1449.
- (30) Lantz PM, Janz NK, Fagerlin A, et al. Satisfaction with surgery outcomes and the decision process in a population-based sample of women with breast cancer. *Health Serv Res*. 2005;40:745-767.
- (31) Fallowfield LJ, Hall A, Maguire GP, Baum M. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *BMJ*. 1990;301:575-580.
- (32) Woolf SH, Chan EC, Harris R, et al. Promoting informed choice: transforming health care to dispense knowledge for decision making. *Ann Intern Med*. 2005; 143:293-300.
- (33) Street RL Jr. Information-giving in medical consultations: the influence of patients' communicative styles and personal characteristics. *Soc Sci Med*. 1991;32(5):541-548.
- (34) Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Arch Intern Med*. 2005;165:2618-2624.
- (35) Hoffman J. Awash in information, patients face a lonely, uncertain road. *The New York Times*. August 14, 2005.
- (36) Epstein RM, Alper BS, Quill TE. Communicating evidence for participatory decision making. *JAMA*. 2004;291:2359-2366.
- (37) Peele PB, Siminoff LA, Xu Y, Ravdin PM. Decreased use of adjuvant breast cancer therapy in a randomized controlled trial of a decision aid with individualized risk information. *Med Decis Making*. 2005;25:301-307.
- (38) O'Connor AM, Stacey D, Entwistle V, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*. 2005.
- (39) Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med*. 1999;49:651-661.
- (40) Mallinger JB, Shields CG, Griggs JJ, et al. Stability of decisional role preference over the course of cancer therapy. *Psychooncology*. 2006; 15(4):297-305.
- (41) Brown RF, Butow PN, Henman M, et al. Responding to the active and passive patient: flexibility is the key. *Health Expect*. 2002;5:236-245.
- (42) Henman MJ, Butow PN, Brown RF, Boyle F, Tattersall MH. Lay constructions of decision-making in cancer. *Psychooncology*. 2002;11:295-306.
- (43) Wright EB, Holcombe C, Salmon P. Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *BMJ*. 2004;328:864.
- (44) Merckaert I, Libert Y, Razavi D. Being known: patients' perspectives of the dynamics of human connection in cancer care. *Psychooncology*. 2005;14:899-900.
- (45) McWilliam CL, Brown JB, Stewart M. Breast cancer patients' experiences of patient-doctor communication: a working relationship. *Patient Educ Couns*. 2000;39:191-204.
- (46) Howie JG, Heaney DJ, Maxwell M, Walker JJ. A comparison of a Patient Enablement Instrument (PEI) against two established satisfaction scales as an outcome measure of primary care consultations. *Fam Pract*. 1998;15:165-171.
- (47) Tattersall MH, Butow PN, Clayton JM. Insights from cancer patient communication research. *Hematol Oncol Clin North Am*. 2002;16:731-743.
- (48) Griggs JJ, Sorbero ME, Stark AT, Heininger SE, Dick AW. Racial disparity in the dose and dose intensity of breast cancer adjuvant chemotherapy. *Breast Cancer Res Treat*. 2003;81:21-31.
- (49) Maguire P. Improving the detection of psychiatric problems in cancer patients. *Soc Sci Med*. 1985;20:819-823.
- (50) Lang F, Floyd MR, Beine KL. Clues to patients' explanations and concerns about their illnesses. A call for active listening. *Arch Fam Med*. 2000;9:222-227.
- (51) Levinson W, Gorawara-Bhat R, Lamb J. A study of patient clues and physician responses in primary care and surgical settings. *JAMA*. 2000;284:1021-1027.
- (52) Butow PN, Lobb EA, Meiser B, Barratt A, Tucker KM. Psychological outcomes and risk perception after genetic testing and counselling in breast cancer: a systematic review. *Med J Aust*. 2003;178: 77-81.
- (53) Maguire P, Faulkner A, Booth K, Elliott C, Hillier V. Helping cancer patients disclose their concerns. *Eur J Cancer*. 1996;32A:78-81.
- (54) Goldberg DP, Jenkins L, Millar T, Faragher EB. The ability of trainee general practitioners to identify psychological distress among their patients. *Psychol Med*. 1993;23:185-193.
- (55) Fallowfield LJ, Hall A, Maguire P, Baum M, A'Hern RP. Psychological effects of being offered choice of surgery for breast cancer. *BMJ*. 1994;309:448.

(56) National Cancer Institute, Cancer Control and Population Sciences. Available at: http://progressreport.cancer.gov/doc_detail.asp?pid=1&did=2005&chid=25&ccoid=227&mid=. 2006. Accessed April 20, 2007.

(57) National Coalition for Cancer Survivorship (NCCS). Available at: <http://www.canceradvocacy.org/> Accessed March 22, 2007.

(58) Leigh SA. Defining our destiny. In: Hoffman B, ed. *A Cancer Survivor's Almanac: Charting the Journey*. Minneapolis, MN: Chronimed Publishing; 1996:261-71.

(59) Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med*. 1985;313:270-273.

(60) Aziz NM. Cancer survivorship research: challenge and opportunity. *J Nutr*. 2002;132:3494S-3503S.

(61) Aziz NM, Rowland JH. Trends and advances in cancer survivorship research: challenge and opportunity. *Semin Radiat Oncol*. 2003;13:248-266.

(62) Committee on Cancer Survivorship, Institute of Medicine. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: National Academies Press; 2006.

(63) Frank AW. *The Wounded Storyteller*. Chicago, IL: University of Chicago Press; 1995.

(64) de Haes H, Teunissen S. Communication in palliative care: a review of recent literature. *Curr Opin Oncol*. 2005;17:345-350.

(65) Potter J, Higginson IJ. Pain experienced by lung cancer patients: a review of prevalence, causes and pathophysiology. *Lung Cancer*. 2004;43:247-257.

(66) Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *JAMA*. 2002;288(23):3027-3034.

(67) Shanafelt TD, Novotny P, Johnson ME, et al. The well-being and personal wellness promotion strategies of medical oncologists in the North Central Cancer Treatment Group. *Oncology*. 2005;68:23-32.

(68) Shanafelt TD, Bradley KA, Wipf JE, Back AL. Burnout and self-reported patient care in an internal medicine residency program. *Ann Intern Med*. 2002;136:358-367.

(69) Shanafelt TD, West C, Zhao X, et al. Relationship between increased personal well-being and enhanced empathy among internal medicine residents. *J Gen Intern Med*. 2005;20:559-564.

(70) Feudtner C. Hope and the prospects of healing at the end of life. *J Altern Complement Med*. 2005;11 Suppl 1:S23-S30.

(71) Delvecchio-Good M, Good BJ, Schaffer C, Lind SE. American oncology and the discourse on hope. *Culture, Med Psychiatry*. 1990;14:59-79.

(72) Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. *JAMA*. 1995;274:820-825.

(73) Benzein E, Norberg A, Saveman BI. The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliat Med*. 2001;15:117-126.

(74) Koedoot CG, Oort FJ, de Haan RJ, et al. The content and amount of information given by medical oncologists when telling patients with advanced cancer what

their treatment options are. palliative chemotherapy and watchful-waiting. *Eur J Cancer*. 2004;40:225-235.

(75) Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Ann Intern Med*. 2001;134:1096-1105.

(76) The AM, Hak T, Koeter G, van der WG. Collusion in doctor-patient communication about imminent death: an ethnographic study. *West J Med*. 2001;174(4):247-253.

(77) Maguire P. The stress of communicating with seriously ill patients. *Nursing (Lond)*. 1988;3:25-27.

(78) Back AL, Arnold RM, Quill TE. Hope for the best, and prepare for the worst. *Ann Intern Med*. 2003;138:439-443.

(79) Shields CG, Epstein RM, Fiscella K, et al. Influence of accompanied encounters on patient-centeredness with older patients. *J Am Board Fam Pract*. 2005;18:344-354.

