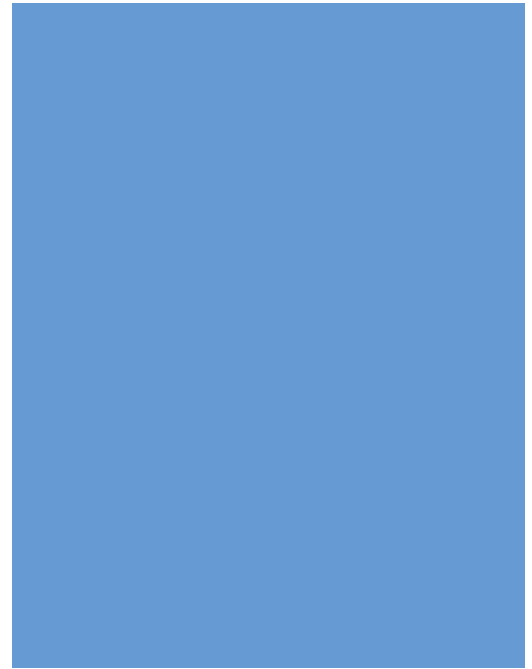


Appendices



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Communication and Healing Relationships in Cancer Settings



The literature on how patient-clinician *relationships* affect patient-clinician *communication* (and vice versa) is sparse, and even less is known about the patient/*family*-clinician interactions in cancer care. What follows is a review of selected relevant articles from the cancer literature as well as the general communication literature.

A.1 Understanding the Patient-Clinician Relationship

Most quantitative studies of communication focus on the accomplishment of specific communication tasks (e.g., delivering bad news, sharing information, or making decisions), but qualitative studies of patients and families dealing with cancer have tended to characterize the ways that these behaviors occur within relationships with clinicians. Clinicians are more than sources of information and expertise; they provide emotional support, guidance, and understanding.¹⁻³ The findings of several studies have suggested that patients with cancer value clinicians' enduring characteristics more than specific communication techniques.⁴⁻⁶ For example, Butow et al.⁷ reported that the most important factors in communication of prognosis to patients with metastatic cancer was that the communication be within a caring,

trusting, long-term relationship and that there be open and repeated negotiations for patient preferences. Salander and Henriksson⁸ found that patients reported that being "connected to health care" and "acknowledged as a person" by their clinicians' as the most important features of their care, more so than the provision of information. Patients' perceptions of their clinicians' overall interpersonal style can be quite nuanced. Some patients, for example, distinguished among "inexperienced messengers," "emotionally burdened," "rough-and-ready experts," "benevolent but tactless experts," "distanced doctors," and "empathic professionals" when discussing transitions to palliative care.⁹ These perceptions may partially account for patients' tendency to rate clinicians according to an underlying global sense of the clinician rather than according to specific behaviors, even when those behaviors are explicitly listed as items on a survey.¹⁰

Therapeutic relationships with clinicians can help patients adjust better to their illnesses.^{3,5,11,12} However, the mechanisms by which an enduring, strong relationship is formed and how a trusting relationship facilitates communication and helps patients adjust to their illnesses, is poorly understood. Some clues to the interactions between communication and

relationships have been explored qualitatively. For example, communication may lead to a patient's greater sense of "being known"¹³ by his or her clinician. Warmth, caring, and confidence may be communicated more through non-verbal channels than through verbal ones. Physicians' tone of voice may affect patients' confidence in them and has even been correlated with the likelihood that a physician was sued.¹⁴ Effective communication presumably is a key to strengthening relationships and providing patients with a greater sense of support.¹ Conversely, a global sense of trust, warmth, and caring also may allow for forgiveness for, and repair of miscommunications and medical errors.

A.2 Patient Participation in Care

Regardless of their preferred roles in making medical decisions, patients generally want to be involved in the process of care, be informed of all their treatment options, feel as if they were listened to, and feel as if their physicians know them as people not simply diseases.¹⁵⁻¹⁷ In order to be involved and feel understood, patients must be able to effectively and actively communicate their needs, concerns, and perspectives.

From a communication perspective, active patient participation may be defined as the extent to which patients produce verbal responses that have the potential to significantly influence the content and structure of the interaction, as well as the clinicians' beliefs and

behaviors.^{18,19} Particularly powerful linguistic behaviors include asking questions, being assertive (e.g., offering opinions, introducing topics, making requests), expressing concerns and feelings, and telling one's health story (i.e., discussing health within the context of daily living). In general, compared with less assertive (passive) patients, patients who use these behaviors more often²⁰⁻²⁴

- Have increased satisfaction with care
- Receive more information and support from clinicians
- Are more committed to treatment plans
- Have a better understanding of treatment options
- Experience greater improvement in health

Although clinicians sometimes complain about overly talkative and controlling patients, many clinicians believe patients' communicative openness is desirable.²⁵ Clinicians report that active communication reveals valuable information about patients' health needs and beliefs^{26,27} and contributes to treatment recommendations better suited to an individual patient's life circumstances.²⁸

In order to be more active communicators, patients need to have sufficient cognitive and linguistic resources and skills, believe in the legitimacy of their participation, and interact with clinicians who support their involvement.¹⁸ In studies that have included use of

observational and self-report measures, cancer care and cancer prevention settings, patients are more active participants when their clinicians use more partnership-building and supportive talk (e.g., reassurance, encouragement).²⁹⁻³² Other communication strategies of clinicians that encourage greater patient involvement include explicit agenda-setting, active listening, checking of understanding, and nonverbal behaviors conveying empathy and warmth.³³ Even if they wish to be actively involved, patients with low health literacy may lack sufficient knowledge to adequately understand treatment information³⁴ and lack the linguistic repertoire to produce elaborated, fluent conversational contributions.³⁵ This fact may explain why the findings of one study indicated that educated patients with breast cancer were more actively communicative in their cancer consultations than were less educated patients.³⁰ Patients' communicative self-efficacy is also related to their perceptions of greater participation in cancer care consultations.²⁹ Some patients, especially older patients³⁶ and patients from Mediterranean and Asian cultures,³⁷ are more likely to prefer passive roles and paternalistic relationships with clinicians. However, there is substantial variability among members of these groups, and it is not clear how fixed their preferences actually are.

The quality of the patient-clinician relationship and the degree of patient participation in cancer consultations are inter-related. As an

example, a patient's greater trust and rapport with his or her clinician lead to more openness and a willingness to discuss personal and sensitive topics.³⁸ This assertion is supported by observations that black patients often have less trust in physicians and the health care system, which in turn, may be one reason black patients may be more cautious and less engaged in their interactions with clinicians compared with white patients.³⁹ On the other hand, trust may create less of a need for information.⁴

A.3 Clinician Self-Awareness and Well-Being

Communication requires clinicians' ongoing capacity for self-monitoring.^{40,41} Identification of patients' concerns,⁴² recognition of changes in clinical status, exploration of patients' emotions⁴³ and early recognition of errors^{44,45} in care all likely depend on clinicians' ability to be attentive, curious, and perceptive.

Clinicians' ability to be attentive and perceptive is 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.⁴⁶⁻⁵⁵ Correspondingly, clinicians' ability to self-monitor, their availability of means to improve personal well-being and job satisfaction, and their ability to derive greater satisfaction from the patient-clinician relationship have all been noted as possible avenues for improving the quality of care, including commu-

nication with patients. A 1990 survey of physicians identified several means to reduce stress and improve well-being:⁵⁶

- Self-awareness
- Sharing of feelings and responsibilities
- Self-care
- Development of a personal philosophy
- Balancing of work and home life

However, few of these approaches have been studied formally.

Some studies have shown benefit of education and training in self-awareness, communication skills, and ways to promote well-being. Multiday workshops for oncologists that included self-awareness sessions and communication training had a positive impact on burnout and self-rated communication skills.^{57,58} A descriptive study of workshops for residents suggested that previously unrecognized negative attitudes interfered with learning communication skills, and consciously addressing those attitudes facilitated future learning of communication skills.⁵⁹ A before-and-after study of an eight-week workshop on stress reduction through the use of meditation techniques showed increase in the capacity for empathy in a group of nursing trainees.⁵² In qualitative studies, mindfulness and self-monitoring were linked to better conflict-resolution skills⁶⁰ and more compassionate hospice care.⁶¹ Personal wellness strategies

among oncologists were associated with better job satisfaction and a lower rate of burnout.⁴⁷ In the only study of patients' reports of physicians' mindful actions, a survey of 5,000 patients suggested that patient-perceived physician mindfulness is highly correlated with satisfaction, patient trust in their physicians, and physicians' respect for patients' autonomy.⁶² It is clear that research in this area is quite preliminary and in need of further attention.

A.4 Implications for Future Study

Qualitative data have pointed the way to future quantitative and epidemiological studies of the patient-clinician relationship. Effective communication and relationships are generally mutually reinforcing. Nevertheless, a strong relationship does not ensure that difficult and emotionally charged issues are managed effectively. The effects of conversation on control of chronic diseases^{63,64} have not been studied in cancer settings. In some cases, the perceived qualities of that relationship may be more important to outcomes than the specific communication techniques used. Conversely, communication may serve to strengthen the patient-clinician relationship, which, in turn, may have a direct effect on quality of life, adherence to treatment, and control of disease. These mediating and recursive influences of patient-clinician relationships on communication warrant further study.

References

- (1) Rose JH. Social support and cancer: adult patients' desire for support from family, friends, and health professionals. *Am J Community Psychol.* 1990;18:439-464.
- (2) Takayama T, Yamazaki Y, Katsumata N. Relationship between outpatients' perceptions of physicians' communication styles and patients' anxiety levels in a Japanese oncology setting. *Soc Sci Med.* 2001;53:1335-1350.
- (3) McWilliam CL, Brown JB, Stewart M. Breast cancer patients' experiences of patient-doctor communication: a working relationship. *Patient Educ Couns.* 2000;39:191-204.
- (4) Wright EB, Holcombe C, Salmon P. Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *BMJ.* 2004;328:864.
- (5) Bakker DA, Fitch MI, Gray R, Reed E, Bennett J. Patient-health care provider communication during chemotherapy treatment: the perspectives of women with breast cancer. *Patient Educ Couns.* 2001;43:61-71.
- (6) Bensing JM, Dronkers J. Instrumental and affective aspects of physician behavior. *Med Care.* 1992;30:283-298.
- (7) Butow PN, Dowsett S, Hagerty R, Tattersall MH. Communicating prognosis to patients with metastatic disease: what do they really want to know? *Support Care Cancer.* 2002 March;10(2):161-168.
- (8) Salander P, Henriksson R. Severely diseased lung cancer patients narrate the importance of being included in a helping relationship. *Lung Cancer.* 2005;50:155-162.
- (9) Friedrichsen MJ, Strang PM, Carlsson ME. Breaking bad news in the transition from curative to palliative cancer care—patient's view of the doctor giving the information. *Supp Care Cancer.* 2000;8(6):472-478.
- (10) Franks P, Fiscella K, Shields CG, et al. Are patients' ratings of their physicians related to health outcomes? *Ann Fam Med.* 2005;3:229-234.
- (11) Finset A, Smedstad LM, Ogar B. Physician-patient interaction and coping with cancer: the doctor as informer or supporter? *J Cancer Educ.* 1997;12:174-178.
- (12) Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 seconds of compassion reduce patient anxiety? *J Clin Oncol.* 1999;17:371-379.
- (13) Merckaert I, Libert Y, Razavi D. Being known: patients' perspectives of the dynamics of human connection in cancer care. *Psychooncology.* 2005;14:899-900.
- (14) Ambady N, LaPlante D, Nguyen T, et al. Surgeons' tone of voice: A clue to malpractice history. *Surgery.* 2002;132:5-9.
- (15) Henman MJ, Butow PN, Brown RF, Boyle F, Tattersall MH. Lay constructions of decision-making in cancer. *Psychooncology.* 2002;11:295-306.
- (16) Thorne SE, Bultz BD, Baile WF. Is there a cost to poor communication in cancer care?: a critical review of the literature. *Psychooncology.* 2005;14:875-884.
- (17) Liang W, Burnett CB, Rowland JH, et al. Communication between physicians and older women with localized breast cancer: implications for treatment and patient satisfaction. *J Clin Oncol.* 2002;20:1008-1016.
- (18) Street RL Jr. Active patients as powerful communicators. In: Robinson WP, Giles H, eds. *The New Handbook of Language and Social Psychology.* New York, NY: John Wiley & Sons; 2001:541-560.
- (19) Street RL Jr, Millay B. Analyzing patient participation in medical encounters. *Health Communication.* 2001;13:61-73.
- (20) Stewart M. Effective physician-patient communication and health outcomes: a review. *CMAJ.* 1995;152:1423-1433.
- (21) Ward MM, Sundaramurthy S, Lotstein D, et al. Participatory patient-physician communication and morbidity in patients with systemic lupus erythematosus. *Arthritis Rheum.* 2003;49:810-818.
- (22) Gordon HS, Street RL Jr, Adam KP, Soucek J, Wray NP. Physician-patient communication following invasive procedures: an analysis of post-angiogram consultations. *Soc Sci Med.* 2005;61:1015-1025.
- (23) Heszen-Klemens I, Lapinska E. Doctor-patient interaction, patients' health behavior and effects of treatment. *Soc Sci Med.* 1984;19:9-18.
- (24) Street RL Jr. Information-giving in medical consultations: the influence of patients' communicative styles and personal characteristics. *Soc Sci Med.* 1991;32:541-548.
- (25) Sleath B, Roter D, Chewning B, Svarstad B. Asking questions about medication: analysis of physician-patient interactions and physician perceptions. *Med Care.* 1999;37:1169-1173.
- (26) Sharf BF, Street RL Jr. The patient as a central construct: shifting the emphasis. *Health Communication.* 1997;9:1-11.
- (27) Langewitz W, Denz M, Keller A, et al. Spontaneous talking time at start of consultation in outpatient clinic: cohort study. *BMJ.* 2002;325:682-683.

- (28) Henbest RJ, Stewart MA. Patient centeredness in the consultation. 2. Does it really make a difference? *Fam Pract.* 1990;7:28-33.
- (29) Maly RC, Umezawa Y, Leake B, Silliman RA. Determinants of participation in treatment decision-making by older breast cancer patients. *Breast Cancer Res Treat.* 2004;85:201-209.
- (30) Street RL Jr, Voigt B, Geyer C, Jr, Manning T, Swanson GP. Increasing patient involvement in choosing treatment for early breast cancer. *Cancer.* 1995;76:2275-2285.
- (31) Street RL Jr, Gordon HS, Ward MM, Krupat E, Kravitz RL. Patient participation in medical consultations: why some patients are more involved than others. *Med Care.* 2005;43:960-969.
- (32) Williams GC, Deci EL. Activating patients for smoking cessation through physician autonomy support. *Med Care.* 2001;39:813-823.
- (33) 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.
- (34) Kim SP, Knight SJ, Tomori C, et al. Health literacy and shared decision making for prostate cancer patients with low socioeconomic status. *Cancer Invest.* 2001;19:684-691.
- (35) Davis TC, Williams MV, Marin E, Parker RM, Glass J. Health literacy and cancer communication. *CA Cancer J Clin.* 2002;52:134-149.
- (36) Pinquart M, Duberstein PR. Information needs and decision-making processes in older cancer patients. *Crit Rev Oncol Hematol.* 2004;51:69-80.
- (37) Pronzato P, Bertelli G, Losardo P, Landucci M. What do advanced cancer patients know of their disease? A report from Italy. *Support Care Cancer.* 1994;2:242-244.
- (38) Street RL Jr, Cauthen D, Buchwald E, Wiprud R. Patients' predispositions to discuss health issues affecting quality of life. *Fam Med.* 1995;27(10):663-670.
- (39) Gordon HS, Street RL Jr, Sharf BF, Kelly PA, Soucek J. Racial differences in trust and lung cancer patients' perceptions of physician communication. *J Clin Oncol.* 2006;24:904-909.
- (40) Novack DH, Epstein RM, Paulsen RH. Toward creating physician-healers: fostering medical students' self-awareness, personal growth, and well-being. *Acad Med.* 1999;74:516-520.
- (41) Novack DH, Suchman AL, Clark W, et al. Calibrating the physician. Personal awareness and effective patient care. *JAMA.* 1997;278:502-509.
- (42) Marvel MK, Epstein RM, Flowers K, Beckman HB. Soliciting the patient's agenda: have we improved? *JAMA.* 1999;281:283-287.
- (43) Epstein RM, Morse DS, Frankel RM, et al. Awkward moments in patient-physician communication about HIV risk. *Ann Intern Med.* 1998;128:435-442.
- (44) Epstein RM, Hundert EM. Defining and assessing professional competence. *JAMA.* 2002;287:226-235.
- (45) Borrell-Carrio F, Epstein RM. Preventing errors in clinical practice: a call for self-awareness. *Ann Fam Med.* 2004;2:310-316.
- (46) 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.
- (47) 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.
- (48) Shanafelt T, Adjei A, Meyskens FL. When your favorite patient relapses: physician grief and well-being in the practice of oncology. *J Clin Oncol.* 2003;21:2616-2619.
- (49) 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.
- (50) Lemkau JP, Purdy RR, Rafferty JP, Rudisill JR. Correlates of burnout among family practice residents. *J Med Educ.* 1988;63:682-691.
- (51) Firth-Cozens J, Greenhalgh J. Doctors' perceptions of the links between stress and lowered clinical care. *Soc Sci Med.* 1997;44:1017-1022.
- (52) Beddoe AE, Murphy SO. Does mindfulness decrease stress and foster empathy among nursing students? *J Nurs Educ.* 2004;43:305-312.
- (53) Meier DE, Back AL, Morrison RS. The inner life of physicians and care of the seriously ill. *JAMA.* 2001;286:3007-3014.
- (54) Kash KM, Holland JC, Breitbart W, et al. Stress and burnout in oncology. *Oncology (Williston Park).* 2000;14:1621-1633.
- (55) Shanafelt TD, Sloan JA, Habermann TM. The well-being of physicians. *Am J Med.* 2003;114:513-519.
- (56) Quill TE, Williamson PR. Healthy approaches to physician stress. *Arch Intern Med.* 1990;150:1857-1861.

(57) Baile WF, Lenzi R, Kudelka AP, et al. Improving physician-patient communication in cancer care: outcome of a workshop for oncologists. *J Cancer Educ.* 1997;12:166-173.

(58) Fallowfield LJ. How to improve the communication skills of oncologists. *Ann Oncol.* 2000;11 (Suppl 3):63-66.

(59) Smith RC, Dorsey AM, Lyles JS, Frankel RM. Teaching self-awareness enhances learning about patient-centered interviewing. *Acad Med.* 1999;74:1242-1248.

(60) Horton-Deutsch SL, Horton JM. Mindfulness: overcoming intractable conflict. *Arch Psychiatr Nurs.* 2003;17:186-193.

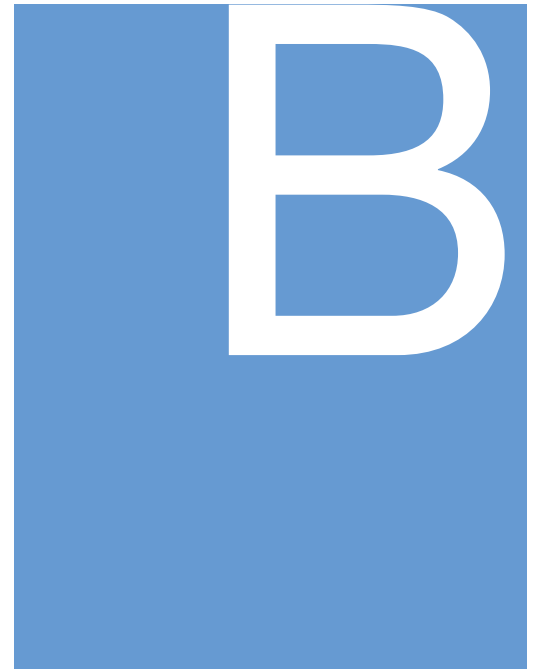
(61) Bruce A, Davies B. Mindfulness in hospice care: practicing meditation-in-action. *Qual Health Res.* 2005;15:1329-1344.

(62) Epstein RM, Shields CG, Franks P, et al. Exploring and validating patient concerns: relation to appropriateness of prescribing in depression. *Ann Fam Med.* 2007;5(1):21-28.

(63) Greenfield S, Kaplan S, Ware JE Jr. Expanding patient involvement in care. Effects on patient outcomes. *Ann Intern Med.* 1985;102:520-528.

(64) Greenfield S, Kaplan SH, Ware JE Jr, Yano EM, Frank HJL. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med.* 1988;3:448-457.

Information Exchange in Cancer Care*



Information exchange accounts for a large percentage of the time in clinical consultations. The first part of this appendix is a review of selected recent literature regarding the way information is managed in general, centering on four themes: patients' information needs, patients' sources of information, information exchange, and patient recall and understanding. The second part of the appendix addresses two specific areas in which there has been more intense research: communicating bad news and discussing prognosis.

B.1 Patients' Information Needs

Patients with cancer seek information about the cause, diagnosis, treatment, prognosis, and psychosocial aspects of their illness, but these needs vary among patients and change over time.^{1,2} Although most research has focused on delivery of information at or shortly after initial diagnosis, patients' information and education needs persist throughout the cancer care continuum.³ Attending to patients' information needs is important not only in conveying the facts of the illness to the patient but also in developing a strong patient-clinician relationship and improving patients' psychosocial well-being and coping abilities.^{4,5} Information given

to patients with cancer should be tailored to the type and stage of cancer that they have and should also consider personal characteristics such as age, sex, and cultural identification.⁶ The availability of information has increased over the past decades, but many patients and family members remain dissatisfied with the information they are given and when they are given it.⁷

Researchers have measured the information needs of patients with cancer through the use of self-report surveys, individual interviews, and descriptive narratives in qualitative studies. Specific instruments have been developed to identify the general and diagnosis-specific information needs of patients with cancer. Some, but not all, of the instruments have been validated. The information needs of patients with breast and prostate cancer have been well described, whereas the information needs of patients with head and neck, lung, colorectal, gynecological, and testicular cancers have been less well described. In particular, the information needs of patients with breast cancer have been high.^{8,9}

Younger patients and those with breast, prostate, gynecological, or testicular cancer reported needing more information regarding sexuality, sexual functioning, fertility,

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and self-esteem than patients with primary cancers at other sites.^{8,10-14} Many patients report that sexuality has not been adequately addressed¹⁵ and cannot recall any information regarding sexuality given to them by clinicians.¹⁶ About two-thirds of patients with prostate cancer surveyed desired more information pertaining to the effects of brachytherapy on sexual function and on treatment options for erectile dysfunction.¹⁷ Younger patients with prostate cancer have had greater general information needs than their older counterparts.¹⁸ In general, sexuality was often addressed later in the course of the illness than patients would have preferred.

During the treatment phase, patients have valued detailed information about their treatment plan, potential side effects, and the potential impact of these on their quality of life.¹⁹⁻²² Patients with cancer frequently arrive at the consultation with expectations of side effects from treatment,^{23,24} and such expectations actually increase the likelihood of experiencing those side effects.²⁴ Accurate information may help to decrease patients' negative experiences and increase their participation in consultations.^{23,25} Information on pain management also is often lacking from discussions with patients,^{26,27} as is information regarding possible emotional reactions, alternative treatments, and the long-term effects of cancer treatment.¹⁶

Patients with cancer have used information not only to address their physical needs but to their

psychological needs as well.²⁸ Patients have indicated that their psychosocial information needs are not always adequately addressed by clinicians; if these needs were met, patients may be better able to cope with their illnesses.²⁹⁻³³

In general, the benefits of providing patients with information include increased satisfaction with and participation in the consultation, decreased anxiety, and increased ability to cope.³⁴

Patients with cancer often use their information resources not only to understand their disease but to find hope as well.^{35,36} When surveyed, more than 80% of patients with cancer said they wanted as much information as possible regarding their cancer diagnosis and treatment options.^{16,37} The more information patients received, the more satisfied they were.^{38,39} However, some patients with cancer avoid information as a coping mechanism.⁴⁰ Although information-seekers should be given larger amounts of information, doing the same may overwhelm information-avoiding patients.⁴¹ Interestingly, the greater the information needs of patients with cancer, the more anxiety, depression, and psychosocial concerns that they tended to have.⁴² Patients who were more dissatisfied with the information they received tended to have more information-avoiding behaviors.⁴³

Information needs change over time.⁴⁴ At the time of diagnosis, patients may want full disclosure

but they may need some time to absorb the details and implications. During the period between diagnosis and treatment, patients often want more detailed information in discussions of their prognosis, treatment options, side effects, and changes to their daily living. After patients have had treatment, the amount of information they need may be less but the topics—psychosocial issues, rehabilitation, recovery, and recurrence—are no less important to them.

Barriers to information-gathering have been the source of some frustration for patients with cancer.⁴⁵ Patients with breast cancer who experienced barriers to accessing information had decreased sense of functional, emotional, social, and family well-being.⁴⁶ Patients encountered problems if they were unable to access the information, if they had communication difficulties with their clinicians, if they experienced information overload, if they had difficulties with information retention, or if the information they were given was inaccurate.

Patients' recall of information is variable. Patients especially may not recall discussing psychosocial issues, sexuality, or sexual dysfunction.¹⁶ Patients' ability to understand and retain information may vary depending on the format of the information and how easy it is for them to extract it.⁴⁷ Written materials and audio recordings of consultations tend to improve recall and are discussed in detail later.⁴⁸⁻⁵¹

B.2 Patients' Information Sources

The findings of recent reviews and studies suggest that patients most often used information they received from their clinician and preferred information from this source.^{52,53} Generally speaking, patients with cancer continue to believe that their physician is the most highly trusted information source, even though 48% consulted the Internet before seeing their physician.⁵³ Print resources are also commonly used,⁵⁴ but use of this type of material has decreased since the availability of online access to health information. Although information-seeking behavior in general decreases with age,⁵⁵ most patients with cancer are particularly interested in information regarding treatment and side effects.^{21,56,57}

Whether or not patients are satisfied with the information that has been presented to them by clinicians, they often use the Internet to confirm or expand on that information.^{58,59} Some cancer centers have created their own educational programs to instruct patients and their family members on how to use the Internet.⁶⁰ Although there is concern about the quality of information found on the Internet,^{61,62} there is little evidence of adverse outcomes related to inaccurate information from the Internet. Patients with cancer use the Internet not only to obtain general information on a cancer diagnosis and its treatment but to also gain access to other patients with cancer and support groups where they

can share their experiences through electronic mail, blogs, and chat rooms.^{63,64} Mass media have played a role in influencing information-gathering, patient-clinician interactions, and decision-making roles of patients.^{65,66} Also, advertisements have increased the use of the National Cancer Institute Cancer Information Service by patients with cancer, their families, and the general public.^{67,68}

Until recently, print information resources have been second only to information obtained from clinicians. Although the findings of some studies suggest that print materials can have a positive effect on patient recall and satisfaction,⁴⁷ others have found that patients with cancer may be satisfied with this information source but it does not appear to have a significant impact on recall.⁶⁹ The format of information sheets may affect the usefulness of these materials for patients.⁷⁰ Literacy limits the usefulness of written materials for large portions of the population.⁷¹⁻⁷³ Low-literacy print materials or videos help increase patients' knowledge.⁷⁴

Telephone help lines can be a useful source of information and emotional support for patients with cancer.^{75,76} The National Cancer Institute Cancer Information Service (CIS) telephone help line has provided cancer information support services^{68,77,78} and outreach services for patients with cancer and their families.^{79,80} Individuals with a recent cancer diagnosis often use the service to obtain treatment

information to prepare for speaking with their clinician.^{81,82}

B.3 Information Exchange

The goal of information exchange is for patients to understand and to be understood. Clinicians often have a flawed understanding of patients' information needs and consequently do not provide enough information or the kind of information patients find useful.⁸³⁻⁹⁰ Correspondingly, patients do not always immediately disclose substantive information about their symptoms or concerns; clinicians play a key role in helping patients to self-disclose.¹ Clinicians do not always appreciate the complexity of concerns that patients have^{91,92} and thus may not explore areas important to their patients.⁹³

Clinicians overestimate their own informativeness⁹⁴ as well as the level of understanding of their patients with cancer.^{94,95} While imparting information, clinicians often use medical terms that patients do not understand, and they do not check patient understanding.^{96,97} Clinicians also may not be aware of their patients' information-seeking and information-avoiding coping styles and thus may not tailor the manner of information delivery accordingly.

The breast cancer literature, in particular, includes descriptions of the importance of the flow of information among clinicians, patients,⁹⁸⁻¹⁰¹ and patients' spouses.¹⁰² Patients have viewed sharing information as an attempt to share power and control in the interaction.¹⁰³ The

literature is sparse about information-sharing in the setting of other types of cancer. Patients with prostate cancer have appreciated obtaining as many facts as they could from their clinicians.¹⁰⁴

Among patients with lung cancer, many did not understand their situation well enough to make independent decisions and physicians were not aware of the information gap.¹⁰⁵ Not only do patients with lung cancer express greater satisfaction with physicians who are informative, they also trust these physicians more than do patients who perceive their physicians as less informative.¹⁰⁶

Given that patients with cancer with more concerns are also more likely to have poorer quality of life,^{107,108} clinicians need to engage in behaviors that encourage patients' disclosure of these concerns. Patient-centered communication is characterized by effective efforts by clinicians to elicit patients' fears and concerns¹⁰⁹ and encourage more active patient participation in the consultation.¹¹⁰ Patient-centered communication has been associated with higher patient satisfaction with the clinician, and better coping, adherence to treatment, and quality of life in populations with and without cancer.¹¹¹⁻¹¹³ Poor patient-clinician communication has sometimes led to patients' poor understanding of their disease and the process and intent of staging and treatment; as such, they may lose confidence in their medical care team.¹¹⁴ In one study, patients and family members generally preferred a patient-

centered approach when presented with recordings of different consultation styles.¹¹⁵

B.4 Patient Recall and Understanding

Interventions to improve communication are discussed in Appendix E, but mentioned here are prompt sheets, audio recorded consultations, and patient-held records. Prompt sheets used by patients with cancer can improve their ability to gather information during the consultation.¹¹⁶⁻¹¹⁹ When physicians addressed concerns on patients' prompt sheets, patients' anxiety decreased and their recall improved.¹²⁰ Physicians also said that they thought that prompt sheets stimulated useful discussion.¹²¹

Audio recordings of clinical consultations have been helpful for patients' recall and assimilation of information.^{48,122,123} Such recordings also increase patient satisfaction⁵¹ and may increase their participation at later consultations.¹²⁴ Recordings, however, have had inconsistent effects on anxiety and psychological distress in patients.^{50,125} Most of the studies on audio recordings were done with initial consultations only; the findings of some studies have suggested that using audio recordings would be beneficial for all consult visits.¹²² Physicians have become more accepting of audio recorded consults,^{126,127} and although it is unclear if audio recordings can improve physician-patient relationships,¹²⁸ one study demonstrated

that they led to increased patient participation in the clinical encounter.¹²⁴

Giving patients access to their own medical information (in the form of patient-held records, patient information files, or log books) has helped patients and clinicians communicate more efficiently with one another.¹²⁹⁻¹³¹

B.5 Implications for Future Study

Information needs, information resources, patient recall, and patient-clinician information exchange are all areas that require further study. The limitations of many of the studies to date have been that they have involved small sample sizes; patients with a limited number of types of cancer; few minority, non-English speaking, and low-literacy patients; and a focus on the initial phases of the illness. The information needs of patients with forms of cancer other than breast, colorectal, or prostate cancer warrant additional exploration. Further longitudinal studies may help track patients' information needs over time and patients' recall and understanding of the information provided to them. Lastly, cancer survivors will need better sources of information about rehabilitation, surveillance for recurrence, and late effects.

B.6 Communicating Bad News

Communicating bad news has been the subject of some of the earliest cancer communication research. Although no communica-

tion intervention will take away the life-changing impact of a cancer diagnosis, effective delivery of bad news can result in patients who are 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

However, the authors of a recent review concluded that despite a large body of literature with seemingly sensible recommendations for delivering bad news and an increasing number of courses to train students and residents, the delivery of bad news continues to be stressful for clinicians and ineffective and/or traumatic for patients.¹³²

Clinician-related factors in communicating bad news

Beginning physicians, residents, and medical students often deliver diagnostic information without having had training or support in the task.^{133,134} Most physicians were untrained in communicating bad news at the time they were first required to deliver it, and many

report having felt overwhelmed and traumatized by their early experiences.¹³⁴ Clinicians may know how they should deliver bad news but do not follow through because of their own discomfort, fear and anxiety,^{135,136} and lack of forums to deal with their own feelings. Correspondingly, it is not surprising that patient reports of cold, impersonal, blunt, evasive, tactless, indirect, jargon-laden, and poorly timed delivery of news still appear in the popular press and the medical literature. Clinicians' actions may favor their needs to reduce their own anxiety and uncertainty and bring the visit to closure rather than address the needs of patients.¹³⁷

Patient-related factors in communicating bad news

Communication at the bad news visit is affected by patient-related psychological factors, cognitive functioning, and health literacy. Patients report that they felt upset or overwhelmed anticipating devastating news or after hearing it, making assimilation and recall of additional information difficult. Patients may function at a much lower cognitive level when they are critically ill than when they are well.¹³⁸ Low health literacy may lead to confusion; for example, the word "positive" may connote something good to a patient unfamiliar with the reporting of test results.⁷²

Social, cultural, and family-related factors in communicating bad news

Culture, social distance between clinician and patient, and relationships between the patient and family members play important roles in the communication of bad news and prognoses. In many Mediterranean, Latin American, black African, and Asian cultures, it is still common for clinicians to disclose cancer diagnoses to family members and not the patient.¹³⁹⁻¹⁴² Although younger patients increasingly say that they want information, it is also common for even these patients to relinquish some control to family members. There is controversy about how to reconcile views about patient rights and autonomy as articulated in mainstream Anglo-Saxon culture with the views and values of individuals from other cultures. It is often recommended that the patient should initially be given the choice about what they wish to know; the consequences of this approach have not been studied.

The diagnosis of cancer is often delayed in racial and ethnic minorities and individuals of low socioeconomic status.¹⁴³⁻¹⁴⁹ One factor affecting this delay is a relative lack of trust and therefore less open communication between black patients and white clinicians compared with racially concordant pairs.¹⁵⁰ Further research can clarify whether providing easily understood information in the context of a trusting relationship when cancer is first suspected

will lead to earlier completion of diagnostic testing and initiation of treatment.

Health care system-related factors in communicating bad news

Health care system-related barriers to timely and confidential provision of bad news include discontinuity of care, lack of access, lack of a private space, and environmental noise. Scheduling of same-day face-to-face meetings is difficult within most health care systems. Because of this, when patients want to know test results as soon as possible, it is often necessary for clinicians to communicate with patients by telephone—a method that both agree is suboptimal. When bad news is communicated by phone, other members of the health care team may be unaware of what has already been discussed with the patient.¹⁵¹ Team-related issues have rarely been the subject of empirical studies.

Effect of poor delivery of bad news on patients

Poor delivery of bad news appears to have important effects on patients' subsequent coping and anxiety.¹³² However, it is unclear whether following recommended methods for delivering bad news affects satisfaction, knowledge, ability to make decisions, or follow-through with care. Further research can determine the optimal balance and degree of flexibility needed in the elicitation of patient perspectives, provision of information, and reassurance that the

patient is receiving the best care and emotional support. Few longitudinal studies of patient satisfaction with the delivery of bad news have been conducted; clearly, the immediate impact of bad news and later reflection may be different.

Training for clinicians

The curriculum at many medical schools in the United States now includes sessions on giving bad news. Intensive training courses of several days' length designed to help residents and clinicians improve their skills in communicating bad news have a lasting impact on skills,^{152,153} but the majority of less intensive courses have been evaluated only in terms of satisfaction of participants and intention to use the learned skills.¹³² The exploration of clinicians' emotions is a key feature of effective training courses. Future research can identify other key elements, with the hope of accomplishing training using less intensive and more cost-effective interventions.

Training for patients

In medical encounters not involving cancer, training, guidance, or information for patients in anticipation of a clinician visit has shown promise in improving the outcomes of the consultation.^{154,155} Patient interventions, including decision aids and prompt sheets, have been used to help patients decide about cancer screening.¹⁵⁶ However, there have been no studies about interventions for patients undergoing diagnostic testing for

cancer with the possibility of bad news. In planning future research, the AIDS literature may be instructive. Guidelines for counseling before HIV testing include suggestions for anticipating and managing anxiety, discussing how the diagnosis might affect the patient's life, legal ramifications, and social support.¹⁵⁷

Implications for future study of communicating bad news

Although there is a substantial body of descriptive, attitudinal, and intervention literature on the delivery of bad news, several issues remain unstudied, including the following:

- Long-term impact of different types of delivery
- Patient satisfaction with the timing and manner of communication
- Management of patients' anxiety following the initial disclosure of bad news
- Role of family members in such discussions
- Means of reducing physicians' anxiety so that such discussions can flow more openly.

Studies of delivery of news of tumor progression after remission and treatment failure are also needed. The impact of communication among clinicians caring for the same patients and health care system factors on the delivery of consistent information are poorly understood.

B.7 Communicating Prognosis

Delivery of bad news is closely linked with the discussion of prognosis. Information on prognosis helps patients make choices among treatment options, plan their lives, and receive optimal palliative care. Communicating prognosis, thus, depends on the physician's ability to estimate the expected lifespan of patients with cancer, the patients' desire to know the prognosis, and the physician's willingness to disclose the true prognosis. Considering the goals of information exchange, clinicians discussing prognosis with patients and families must choose what to disclose, when disclosure should occur, how to disclose prognostic information, and to whom the information should be disclosed.

Much of what follows here is a summary of the review by Hagerty et al.¹⁵⁸ of studies published before 2004, in which those authors suggested important themes in discussing prognosis with patients. Most of the studies reviewed had involved patients with early stage cancer and focused on the initial diagnosis and treatment decisions. The largest number of studies has been conducted in Australia, with the United States, the United Kingdom, Japan, and continental Europe also represented. Given large cultural differences among English-speaking, Mediterranean, and Asian cultures in discussing prognosis, and perhaps differences within the English-speaking world, many of these findings

need further investigation to determine their generalizability.

Frequency of discussion

Data on the frequency of discussions of prognosis is mixed and difficult to compare across populations.¹⁵⁸ In one study, most patients with breast cancer knew their prognosis,¹⁵⁹ but more recent studies of patients with melanoma and advanced cancer indicate otherwise,^{137,160,161} suggesting that uncertain or serious prognoses are withheld more often. There appears to be both a norm of silence¹⁶¹ and a norm of vagueness¹⁶² among physicians, patients, and caregivers in which euphemisms and discussions of treatment plans overshadow more frank discussions of difficult topics. When discussions of prognosis do occur, they are usually initiated by physicians.¹⁶³

What patients want to know

In responding to surveys, patients tend to endorse wanting information about prognosis^{44,97,137,164-168} and value clear and straightforward presentations of data. However, in a study in the United States in which additional details about patients' preferences were sought, many patients expressed reservations and qualifications about universal disclosure of quantitative survival estimates and many preferred qualitative rather than quantitative estimates;^{168,169} surveys of patients in Australia have shown no preference.¹⁷⁰ Patients' views may be ambivalent and inconsistent. They may reinforce physician

avoidance by suggesting that they want full information but did not want to know about a "bad prognosis."¹⁶⁹ Even among patients receiving palliative care only 55% of patients in the United States wished to have discussed life expectancy with their physicians,¹⁶⁹ and only 59% of patients in Australia wanted to know their prognosis at the time of diagnosis of metastatic disease.¹⁷⁰ Many patients preferred to be asked what information they wanted before it was disclosed and also wanted to be asked when the disclosure should take place.¹⁷⁰ Patients with depression appeared more interested in knowing the most dire possibilities, whereas patients who were not depressed were more likely to want information about the maximal possible survival or wanted no information at all.¹⁷⁰ Anxious patients, however, generally avoided discussions about prognosis and were more likely to prefer that clinicians disclose that information to family members.^{168,171} The findings of studies involving convenience samples suggest that women tend to want more information than men do,¹⁶⁶ but these findings were not adjusted for actual expected prognosis. Most studies were conducted considering preferences without necessarily considering the context and nature of the patient-clinician relationship. It may be that the nature of the communication process also influences patients' preferences and responses and should be studied in greater depth.

What physicians believe that patients should know

While physicians usually provide accurate, complete information to patients about their diagnosis and treatment options, physicians still commonly have difficulty providing prognostic information for several reasons. First, physicians' prospective estimates of prognosis are usually more favorable than indicated by the actual course of the disease.¹⁷² Second, although the vast majority of physicians favor truth-telling, many feel uncomfortable about discussing dire prognoses¹⁷³ and intentionally exaggerate prognoses when communicating with patients and families.¹⁷⁴ Correspondingly, patients frequently report not knowing their prognosis^{95,175} or overestimate their prognosis, even when provided accurate information.^{95,105,176-182} In these studies, higher educational level, lower levels of depression, and higher patient ratings of their physician were associated with better understanding, but further research is needed to examine causal relationships among these factors.

Participants in discussions of prognosis

Some literature exists on family involvement in cancer care, but little has been written explicitly about sharing of prognostic information.¹⁷⁰ Although most patients prefer to have a family member present during discussions of prognosis,^{164,171} patients do want control over the information that family

members receive.¹⁶⁹ Moreover, when caregivers have prognostic information first, they may be reluctant to share it with patients.¹⁸³ One study found that disclosure of prognosis to family members first and using euphemisms diminished a patient's hope.³⁵ Disparities in provision of prognostic information has been a concern. Although most studies suggest that white patients of higher socioeconomic status tend to get more information than poor black patients, one qualitative study suggested the opposite outcome with regard to prognosis; poorer and nonwhite populations reported having more discussions of prognosis.¹⁸⁴

The results of several studies suggest that patients get information about prognosis from several members of the health care team, and that such information may be complementary or sometimes haphazard¹⁵¹ and contradictory. In one study, an organized team approach, in which the patient presumably received well-coordinated information increased patients' understanding of their illness, including prognosis.¹⁸⁵ Our understanding of specifically how teams can improve understanding and recall of prognostic information is limited, however.

Elements of effective discussions of prognosis

Although most studies focus on the content of discussions of prognosis, patients frequently suggest that the manner of presenting the

information and the relationship with their clinicians is equally important. In qualitative studies, patients reported that they valued communication of information within clinical contexts in which they felt known, connected, and acknowledged.¹⁸⁶

Communicating clinical evidence is challenging, raising questions about framing, use of visual aids, and communication of risk.¹⁸⁷ Patient and clinician understanding of statistics may be limited, and misunderstandings about median or mean survival may lead to overly concrete interpretations.^{97,167} Graphical displays are increasingly used to improve patient understanding of statistical data, but the findings of at least one survey suggested that patients preferred words to pictures.¹⁷⁰ In that study, however, health literacy was not assessed. Patients tended to favor framing estimates in positive terms (survival) rather than in terms of mortality. Use of a mix of positive (survival) and negative (mortality) language may enhance understanding. Other recommendations from the literature conform to principles of general patient-centered communication skills and have few elements specific to cancer communication or prognosis: summarizing and checking understanding, active listening, privacy, adequate time, and honesty.³⁵

Increasingly, the Internet and patient advocacy organizations provide more ready access to prognostic information. Until recently, no studies have been conducted on reconciling physicians

as a source of prognostic information with other sources. Patients, however, choose to discuss this information with their physicians on the basis of trust and need to resolve uncertainty.¹⁸⁸ Although most patients thought that contradictory information would not undermine their trust in their physicians, a significant minority felt that it might. Those patients also tended to express that there was one correct answer to the question and reported discomfort with uncertain or contradictory primary data. Patient access to primary data on prognosis and ways to discuss this data effectively with health professionals is an important area for future research.

The communication of hope is frequently encountered in the context of the discussion of prognosis.¹⁸⁹ However, patients' experience of hope is related both to the process of communication as well as to the content of communication. Providing up-to-date information, answering questions, and offering emotional support are often seen as engendering hope, whereas a cold, impersonal clinical style appear to diminish hope.¹⁹⁰ This finding implies that frank and honest discussion of prognosis need not diminish hope if it is conducted in a patient-centered manner. In some situations, the dialogue on hope appears detrimental to the discussion of prognosis.¹⁹¹ Some patients think that the burden of maintaining the appearance of a "fighting spirit" limits discussions of their fears and concerns, including about prognosis and quality of life.

Cultural factors

As with the disclosure of bad news, patients and physicians from Anglo-Saxon cultures favor disclosure, whereas individuals in other cultures do not.¹⁵⁸ However, there is significant change in some areas. Family members may take a more primary role in information exchange in Mediterranean and Asian cultures compared with Anglo-Saxons. In Spain,¹⁹² for example, over the past 10 years, there has been a radical shift from nondisclosure to disclosure. Relevant to settings in the United States, however, is recognition that several factors could contribute to patients' desires for information about prognosis, including culture of origin, health literacy, educational level, prior illness experiences, and degree of cultural assimilation. Generalizations can be made on population levels, but they may not apply to individual patients; clinicians must be prepared to inquire about individual beliefs and values. We have not encountered any published work suggesting how the level of a clinician's cultural awareness affects discussions of prognosis.

Outcomes of discussions of prognosis

Few outcome studies have separated discussions of prognosis from discussions of bad news or other aspects of cancer care. The results of studies that have been published suggest associations between recalled discussion of prognosis and increased satisfaction, as well

as lower levels of depression, anxiety, and hope. Compelling qualitative data suggest that toxic effects of intentional deceit can lead to heightened anxiety and distrust.¹⁹³ However, there is disagreement whether collusion should be broken down quickly¹⁹⁴ rather than maintaining "necessary collusion" temporarily¹⁹⁵ to soften the blow (by delaying disclosure until it can be more easily assimilated). The cross-sectional design and plausible bidirectional causality make it difficult to draw conclusions from the current literature. Future research on the relationship between discussions of prognosis and quality of life is needed.

We are aware of no interventions designed specifically to improve the delivery of prognostic information. However, inference might be drawn from intensive workshops to improve delivery of bad news, which have enhanced clinicians' communication skills for at least 12 months following the intervention.^{152,153} The most important intervention in the United States was a large randomized trial for patients with a prognosis of no more than six months.¹⁹⁶ Specially trained research nurses provided information about the disease, treatment, and prognosis, convened individual and family meetings, and discussed and documented patient and family preferences with the goal of improving communication about advance directives, improving pain control, and lessening the likelihood that patients would receive unwanted intensive care. The trial yielded completely nega-

tive results for all outcome measures, including communication. The large body of literature that has attempted to explain and learn from this trial indicates that interventions must focus on patient-clinician relationships and involve repeated contact and reinforcement in order to be effective.¹⁹⁷

Implications for future study of communicating prognosis

Physician optimism and reluctance to paint a grim picture, along with patients' highly variable desire to hear complete prognostic information, create a complex set of factors to consider in discussions of prognosis. Communicating statistical information is challenging especially with patients of low health literacy and low numeracy; there is very little empirical research to draw on in determining how best to communicate clinical evidence with these patients. Research should also address cultural values and beliefs and family issues. Patients need hope, but it is not known the degree to which skilled clinicians can provide hopeful messages without distorting prognostic information. Studies to date have addressed only parts of this complex picture, which may explain failure of even large innovative studies to improve communication about prognosis and advance care planning.

References

- (1) Arora NK. Interacting with cancer patients: the significance of physicians' communication behavior. *Soc Sci Med*. 2003;57:791-806.
- (2) Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Educ Couns*. 2005;57:250-261.
- (3) Harris KA. The informational needs of patients with cancer and their families. *Cancer Pract*. 1998;6:39-46.
- (4) Krasuska ME, Stanislawek A. Professional information, education and counselling as prerequisites for quality cancer care. *Ann Univ Mariae Curie Sklodowska [Med]*. 2003;58:179-184.
- (5) Sawyer H. Meeting the information needs of cancer patients. *Prof Nurse*. 2000;15:244-247.
- (6) Mossman J, Boudioni M, Slevin ML. Cancer information: a cost-effective intervention. *Eur J Cancer*. 1999;35:1587-1591.
- (7) Champman K, Rush K. Patient and family satisfaction with cancer-related information: a review of the literature. *Can Oncol Nurs J*. 2003;13:107-116.
- (8) Galloway S, Graydon J, Harrison D, et al. Informational needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. *J Adv Nurs*. 1997;25:1175-1183.
- (9) Raupach JC, Hiller JE. Information and support for women following the primary treatment of breast cancer. *Health Expect*. 2002;5:289-301.
- (10) Gray RE, Klotz LH, Iscoe NA, et al. Prostate cancer patients' satisfaction

with medical information. *Can J Urol*. 1997;4:83-87.

- (11) Thewes B, Meiser B, Rickard J, Friedlander M. The fertility- and menopause-related information needs of younger women with a diagnosis of breast cancer: a qualitative study. *Psychooncology*. 2003;12:500-511.
- (12) Gurevich M, Bishop S, Bower J, Malka M, Nyhof-Young J. (Dis)embodying gender and sexuality in testicular cancer. *Soc Sci Med*. 2004;58:1597-1607.
- (13) Perez MA, Skinner EC, Meyerowitz BE. Sexuality and intimacy following radical prostatectomy: patient and partner perspectives. *Health Psychol*. 2002;21:288-293.
- (14) Stead ML. Sexual dysfunction after treatment for gynaecologic and breast malignancies. *Curr Opin Obstet Gynecol*. 2003;15:57-61.
- (15) Bonevski B, Sanson-Fisher R, Girgis A, et al. Evaluation of an instrument to assess the needs of patients with cancer. Supportive Care Review Group. *Cancer*. 2000;88:217-225.
- (16) Cox A, Jenkins V, Catt S, Langridge C, Fallowfield L. Information needs and experiences: An audit of UK cancer patients. *Eur J Oncol Nurs*. 2005.
- (17) Davison BJ, Keyes M, Elliott S, Berkowitz J, Goldenberg SL. Preferences for sexual information resources in patients treated for early-stage prostate cancer with either radical prostatectomy or brachytherapy. *BJU Int*. 2004;93:965-969.
- (18) Dale J, Jatsch W, Hughes N, Pearce A, Meystre C. Information needs and prostate cancer: the development of a systematic means of identification. *BJU Int*. 2004;94:63-69.

- (19) Fitch MI, Johnson B, Gray R, Franssen E. Survivors' perspectives on the impact of prostate cancer: implications for oncology nurses. *Can Oncol Nurs J*. 1999;9:23-34.
- (20) Lock KK, Willson B. Information needs of cancer patients receiving chemotherapy in an ambulatory-care setting. *Can J Nurs Res*. 2002;34:83-93.
- (21) Nair MG, Hickok JT, Roscoe JA, Morrow GR. Sources of information used by patients to learn about chemotherapy side effects. *J Cancer Educ*. 2000;15:19-22.
- (22) Skalla KA, Bakitas M, Furstenberg CT, Ahles T, Henderson JV. Patients' need for information about cancer therapy. *Oncol Nurs Forum*. 2004;31:313-319.
- (23) Hofman M, Morrow GR, Roscoe JA, et al. Cancer patients' expectations of experiencing treatment-related side effects: a University of Rochester Cancer Center—Community Clinical Oncology Program study of 938 patients from community practices. *Cancer*. 2004;101:851-857.
- (24) Roscoe JA, Bushnow P, Morrow GR, et al. Patient expectation is a strong predictor of severe nausea after chemotherapy: a University of Rochester Community Clinical Oncology Program study of patients with breast carcinoma. *Cancer*. 2004;101:2701-2708.
- (25) Hinds C, Streater A, Mood D. Functions and preferred methods of receiving information related to radiotherapy. Perceptions of patients with cancer. *Cancer Nurs*. 1995;18:374-384.
- (26) Berry DL, Wilkie DJ, Thomas CRJ, Fortner P. Clinicians communicating with patients experiencing cancer pain. *Cancer Invest*. 2003;21:374-381.
- (27) Brandt B. Informational needs and selected variables in patients receiving brachytherapy. *Oncol Nurs Forum*. 1991;18:1221-1227.
- (28) Sainio C, Eriksson E. Keeping cancer patients informed: a challenge for nursing. *Eur J Oncol Nurs*. 2003;7:39-49.
- (29) Baum LD. Psychosocial needs of patients with cancer in the primary care setting. *Lippincott's Prim Care Pract*. 2000;4:417-425.
- (30) Bunston T, Mings D. Identifying the psychosocial needs of individuals with cancer. *Can J Nurs Res*. 1995;27:59-79.
- (31) Leydon GM, Boulton M, Moynihan C, et al. Cancer patients' information needs and information seeking behaviour: in depth interview study. *BMJ*. 2000;320:909-913.
- (32) Matthews BA, Baker F, Spillers RL. Oncology professionals and patient requests for cancer support services. *Support Care Cancer*. 2004;12:731-738.
- (33) van der Molen B. Relating information needs to the cancer experience: 1. Information as a key coping strategy. *Eur J Cancer Care (Engl)*. 1999;8:238-244.
- (34) Arraras JI, Wright S, Greimel E, et al. Development of a questionnaire to evaluate the information needs of cancer patients: the EORTC questionnaire. *Patient Educ Couns*. 2004;54:235-241.
- (35) Hagerty RG, Butow PN, Ellis PM, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol*. 2005;23:1278-1288.
- (36) Leydon GM, Boulton M, Moynihan C, et al. Faith, hope, and charity: an in-depth interview study of cancer patients' information needs and information-seeking behavior. *West J Med*. 2000;173:26-31.
- (37) Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. *Br J Cancer*. 2001;84:48-51.
- (38) Davidson R, Mills ME. Cancer patients' satisfaction with communication, information and quality of care in a UK region. *Eur J Cancer Care (Engl)*. 2005;14:83-90.
- (39) Jones R, Pearson J, McGregor S, et al. Cross sectional survey of patients' satisfaction with information about cancer. *BMJ*. 1999;319:1247-1248.
- (40) Case DO, Andrews JE, Johnson JD, Allard SL. Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *J Med Libr Assoc*. 2005;93:353-362.
- (41) Rees CE, Bath PA. Information-seeking behaviors of women with breast cancer. *Oncol Nurs Forum*. 2001;28:899-907.
- (42) Mesters I, van den Borne B, De Boer M, Pruyn J. Measuring information needs among cancer patients. *Patient Educ Couns*. 2001;43:253-262.
- (43) Elf M, Wikblad K. Satisfaction with information and quality of life in patients undergoing chemotherapy for cancer. The role of individual differences in information preference. *Cancer Nurs*. 2001;24:351-356.
- (44) Butow PN, Maclean M, Dunn SM, Tattersall MH, Boyer MJ. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann Oncol*. 1997;8:857-863.

- (45) Eakin EG, Strycker LA. Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: patient and provider perspectives. *Psychooncology*. 2001;10:103-113.
- (46) Arora NK, Johnson P, Gustafson DH, et al. Barriers to information access, perceived health competence, and psychosocial health outcomes: test of a mediation model in a breast cancer sample. *Patient Educ Couns*. 2002;47:37-46.
- (47) Butow P, Brindle E, McConnell D, Boakes R, Tattersall M. Information booklets about cancer: factors influencing patient satisfaction and utilization. *Patient Educ Couns*. 1998;33:129-141.
- (48) Bruera E, Pituskin E, Calder K, Neumann CM, Hanson J. The addition of an audiocassette recording of a consultation to written recommendations for patients with advanced cancer: A randomized, controlled trial. *Cancer*. 1999;86:2420-2425.
- (49) Hack TF, Pickles T, Bultz BD, et al. Impact of providing audiotapes of primary adjuvant treatment consultations to women with breast cancer: a multisite, randomized, controlled trial. *J Clin Oncol*. 2003;21:4138-4144.
- (50) McHugh P, Lewis S, Ford S, et al. The efficacy of audiotapes in promoting psychological well-being in cancer patients: a randomised, controlled trial. *Br J Cancer*. 1995;71:388-392.
- (51) Ong LM, Visser MR, Lammes FB, et al. Effect of providing cancer patients with the audiotaped initial consultation on satisfaction, recall, and quality of life: a randomized, double-blind study. *J Clin Oncol*. 2000;18:3052-3060.
- (52) Parker PA, Davison BJ, Tishelman C, Brundage MD. What do we know about facilitating patient communication in the cancer care setting? *Psychooncology*. 2005;14:848-858.
- (53) 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.
- (54) Basch EM, Thaler HT, Shi W, Yakren S, Schrag D. Use of information resources by patients with cancer and their companions. *Cancer*. 2004;100:2476-2483.
- (55) Turk-Charles S, Meyerowitz BE, Gatz M. Age differences in information-seeking among cancer patients. *Int J Aging Hum Dev*. 1997;45:85-98.
- (56) Edgar L, Remmer J, Rosberger Z, Fournier MA. Resource use in women completing treatment for breast cancer. *Psychooncology*. 2000;9:428-438.
- (57) Satterlund MJ, McCaul KD, Sandgren AK. Information gathering over time by breast cancer patients. *J Med Internet Res*. 2003;5(3):e15.
- (58) Lipp ER. Web resources for patients with prostate cancer: a starting point. *Semin Urol Oncol*. 2002;20:32-38.
- (59) London JW, Gomella LG. Overview of the Internet and prostate cancer resources. *Semin Urol Oncol*. 2000;18:245-253.
- (60) Edgar L, Greenberg A, Remmer J. Providing internet lessons to oncology patients and family members: a shared project. *Psychooncology*. 2002;11:439-446.
- (61) Al-Bahrani A, Plusa S. The quality of patient-orientated internet information on colorectal cancer. *Colorectal Dis*. 2004;6:323-326.
- (62) Crocco AG, Villasis-Keever M, Jadad AR. Analysis of cases of harm associated with use of health information on the internet. *JAMA*. 2002;287:2869-2871.
- (63) Leadbeater M. A nurse-led e-mail service for breast cancer information. *Nurs Times*. 2005;101:36-38.
- (64) Rimer BK, Lyons EJ, Ribisl KM, et al. How new subscribers use cancer-related online mailing lists. *J Med Internet Res*. 2005;7:e32.
- (65) Balmer C. The information requirements of people with cancer: where to go after the "patient information leaflet"? *Cancer Nurs*. 2005;28:36-44.
- (66) Chen X, Siu LL. Impact of the media and the internet on oncology: survey of cancer patients and oncologists in Canada. *J Clin Oncol*. 2001;19:4291-4297.
- (67) Arkin EB, Romano RM, Van Nevel JP, McKenna JW. Effect of the mass media in promoting calls to the Cancer Information Service. *J Natl Cancer Inst Monogr*. 1993;35-43.
- (68) Fleisher L, Kornfeld J, Ter MJ, et al. Building effective partnerships: a national evaluation of the Cancer Information Service outreach program. Part 2. *J Health Communication*. 1998;3(Suppl):21-35.
- (69) Hope S, Williams AE, Lunn D. Information provision to cancer patients: a practical example of identifying the need for changes in practice from the Dorset Cancer Centre. *Eur J Cancer Care (Engl)*. 2000;9:238-242.

(70) Frost MH, Thompson R, Thiemann KB. Importance of format and design in print patient information. *Cancer Pract.* 1999;7:22-27.

(71) Chelf JH, Deshler AM, Thiemann KM, et al. Learning and support preferences of adult patients with cancer at a comprehensive cancer center. *Oncol Nurs Forum.* 2002;29:863-867.

(72) Davis TC, Williams MV, Marin E, Parker RM, Glass J. Health literacy and cancer communication. *CA Cancer J Clin.* 2002;52:134-149.

(73) 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.

(74) Meade CD, McKinney WP, Barnas GP. Educating patients with limited literacy skills: the effectiveness of printed and videotaped materials about colon cancer. *Am J Public Health.* 1994;84:119-121.

(75) Carlsson ME, Strang PM, Lindblad L. Telephone help line for cancer counseling and cancer information. *Cancer Pract.* 1996;4:319-323.

(76) Jefford M, Black C, Grogan S, et al. Information and support needs of callers to the Cancer Helpline, the Cancer Council Victoria. *Eur J Cancer Care (Engl).* 2005;14:113-123.

(77) Darrow SL, Speyer J, Marcus AC, Ter MJ, Krome D. Coping with cancer: the impact of the Cancer Information Service on patients and significant others. Part 6. *J Health Communication.* 1998;3 (Suppl): 86-96.

(78) Muha C, Smith KS, Baum S, Ter MJ, Ward JA. The use and selection of sources in information seeking: the Cancer

Information Service experience. Part 8. *J Health Communication.* 1998;3 (Suppl): 109-120.

(79) Kornfeld J, Fleisher L, Ter MJ, et al. Reaching minority and underserved populations: the impact of the Cancer Information Service's outreach program. Part 3. *J Health Communication.* 1998;3(Suppl):36-49.

(80) Thomsen CA, Ter MJ. Evaluating the Cancer Information Service: a model for health communications. Part 1. *J Health Communication.* 1998;3(Suppl):1-13.

(81) Manfredi C, Czaja R, Price J, Buis M, Janiszewski R. Cancer patients' search for information. *J Natl Cancer Inst Monogr.* 1993;93-104.

(82) Manfredi C, Czaja R, Buis M, Derk D. Patient use of treatment-related information received from the Cancer Information Service. *Cancer.* 1993;71:1 326-1337.

(83) Drew A, Fawcett TN. Responding to the information needs of patients with cancer. *Prof Nurse.* 2002;17:443-446.

(84) Feldman-Stewart D, Capirci C, Brundage MD. Information for patients with early-stage prostate cancer: a comparison of professionals' attitudes in Canada and Italy. *Support Care Cancer.* 2003;11: 472-480.

(85) Hiranmanek N, McAvoy BR. Meeting the needs of patients with cancer—a GP guide to support services. *Aust Fam Physician.* 2005;34:365-367.

(86) Lampic C, Sjoden PO. Patient and staff perceptions of cancer patients' psychological concerns and needs. *Acta Oncol.* 2000;39:9-22.

(87) Lauer P, Murphy SP, Powers MJ. Learning needs of cancer patients: a comparison of nurse and patient perceptions. *Nurs Res.* 1982;31:11-16.

(88) Matthews BA, Baker F, Spillers RL. Healthcare professionals' awareness of cancer support services. *Cancer Pract.* 2002;10:36-44.

(89) Nylenna M. The general practitioner and information to cancer patients. *Scand J Prim Health Care.* 1985;3:35-38.

(90) Smith C. The role of health professionals in informing cancer patients: findings from The Teamwork Project (phase one). *Health Expect.* 2000;3:217-219.

(91) Burt J, Caelli K, Moore K, Anderson M. Radical prostatectomy: men's experiences and postoperative needs. *J Clin Nurs.* 2005;14:883-890.

(92) Butow PN, Brown RF, Cogar S, Tattersall MH, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. *Psychooncology.* 2002;11:47-58.

(93) Eide H, Quera V, Graugaard P, Finset A. Physician-patient dialogue surrounding patients' expression of concern: applying sequence analysis to RIAS. *Soc Sci Med.* 2004;59:145-155.

(94) Chaitchik S, Kreidler S, Shaked S, Schwartz I, Rosin R. Doctor-patient communication in a cancer ward. *J Cancer Educ.* 1992;7:41-54.

(95) Gattellari M, Butow PN, Tattersall MH, Dunn SM, MacLeod CA. Misunderstanding in cancer patients: why shoot the messenger? *Ann Oncol.* 1999;10:39-46.

(96) Lerman C, Daly M, Walsh WP, et al. Communication between patients with breast cancer and health care providers. Determinants and implications. *Cancer.* 1993;72:2612-2620.

- (97) Lobb EA, Butow PN, Kenny DT, Tattersall MHN. Communicating prognosis in early breast cancer: do women understand the language used? *Med J Aust.* 1999;171:290-294.
- (98) Harris SR, Templeton E. Who's listening? Experiences of women with breast cancer in communicating with physicians. *Breast J.* 2001;7:444-449.
- (99) Salminen E, Vire J, Poussa T, Knifssund S. Unmet needs in information flow between breast cancer patients, their spouses, and physicians. *Support Care Cancer.* 2004;12:663-668.
- (100) Schain WS. Physician-patient communication about breast cancer. A challenge for the 1990s. *Surg Clin North Am.* 1990;70:917-936.
- (101) Takayama T, Yamazaki Y. How breast cancer outpatients perceive mutual participation in patient-physician interactions. *Patient Educ Couns.* 2004;52:279-289.
- (102) Baker R, Wu AW, Teno JM, et al. Family satisfaction with end-of-life care in seriously ill hospitalized adults. *J Am Geriatr Soc.* 2000;48:S61-S69.
- (103) Bakker DA, Fitch MI, Gray R, Reed E, Bennett J. Patient-health care provider communication during chemotherapy treatment: the perspectives of women with breast cancer. *Patient Educ Couns.* 2001;43:61-71.
- (104) Davison BJ, Parker PA, Goldenberg SL. Patients' preferences for communicating a prostate cancer diagnosis and participating in medical decision-making. *BJU Int.* 2004;93:47-51.
- (105) Quirt CF, Mackillop WJ, Ginsburg AD, et al. Do doctors know when their patients don't? A survey of doctor-patient communication in lung cancer. *Lung Cancer.* 1997;18:1-20.
- (106) Gordon HS, Street RL Jr, Sharf BF, Kelly PA, Soucek J. Racial differences in trust and lung cancer patients' perceptions of physician communication. *J Clin Oncol.* 2006;24:904-909.
- (107) Maguire P. Improving communication with cancer patients. *Eur J Cancer.* 1999;35:1415-1422.
- (108) Parle M, Jones B, Maguire P. Maladaptive coping and affective disorders among cancer patients. *Psychol Med.* 1996;26:735-744.
- (109) Beach WA, Easter DW, Good JS, Pigeron E. Disclosing and responding to cancer "fears" during oncology interviews. *Soc Sci Med.* 2005;60:893-910.
- (110) Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered communication in patient-physician consultations: Theoretical and practical issues. *Soc Sci Med.* 2005;61:1516-1528.
- (111) Ong LM, Visser MR, van Zuuren FJ, et al. Cancer patients' coping styles and doctor-patient communication. *Psychooncology.* 1999;8:155-166.
- (112) Kahana E, Kahana B. Patient proactivity enhancing doctor-patient-family communication in cancer prevention and care among the aged. *Patient Educ Couns.* 2003;50:67-73.
- (113) Mallinger JB, Griggs JJ, Shields CG. Patient-centered care and breast cancer survivors' satisfaction with information. *Patient Educ Couns.* 2005;57:342-349.
- (114) Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. *Eur J Cancer.* 1999;35:1592-1597.
- (115) Dowsett SM, Saul JL, Butow PN, et al. Communication styles in the cancer consultation: preferences for a patient-centred approach. *Psychooncology.* 2000;9:147-156.
- (116) Bruera E, Sweeney C, Willey J, et al. Breast cancer patient perception of the helpfulness of a prompt sheet versus a general information sheet during outpatient consultation: a randomized, controlled trial. *J Pain Symptom Manage.* 2003;25:412-419.
- (117) Butow PN, Dunn SM, Tattersall MH, Jones QJ. Patient participation in the cancer consultation: evaluation of a question prompt sheet. *Ann Oncol.* 1994;5:199-204.
- (118) McJannett M, Butow P, Tattersall MH, Thompson JF. Asking questions can help: development of a question prompt list for cancer patients seeing a surgeon. *Eur J Cancer Prev.* 2003;12:397-405.
- (119) Wells T, Falk S, Dieppe P. The patients' written word: a simple communication aid. *Patient Educ Couns.* 2004;54:197-200.
- (120) Brown RF, Butow PN, Dunn SM, Tattersall MH. Promoting patient participation and shortening cancer consultations: a randomised trial. *Br J Cancer.* 2001;85:1273-1279.
- (121) Jones R, Pearson J, McGregor S, et al. Does writing a list help cancer patients ask relevant questions? *Patient Educ Couns.* 2002;47:369-371.
- (122) Knox R, Butow PN, Devine R, Tattersall MH. Audiotapes of oncology consultations: only for the first consultation? *Ann Oncol.* 2002;13:622-627.
- (123) Scott JT, Harmsen M, Prictor MJ, et al. . Recordings or summaries of consul-

tations for people with cancer. *Cochrane Database of Systematic Reviews*. 2005.

- (124) 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.
- (125) North N, Cornbleet MA, Knowles G, Leonard RC. Information giving in oncology: a preliminary study of tape-recorder use. *Br J Clin Psychol*. 1992;31 (Pt 3):357-359.
- (126) McConnell D, Butow PN, Tattersall MH. Audiotapes and letters to patients: the practice and views of oncologists, surgeons and general practitioners. *Br J Cancer*. 1999;79:1782-1788.
- (127) Stockler M, Butow PN, Tattersall MH. The take-home message: doctors' views on letters and tapes after a cancer consultation. *Ann Oncol*. 1993;4:549-552.
- (128) McClement SE, Hack TF. Audio-taping the oncology treatment consultation: a literature review. *Patient Educ Couns*. 1999;36:229-238.
- (129) Lecouturier J, Crack L, Mannix K, Hall RH, Bond S. Evaluation of a patient-held record for patients with cancer. *Eur J Cancer Care (Engl)*. 2002;11:114-121.
- (130) van Wersch A, de Boer MF, van der Does E, et al. Continuity of information in cancer care: evaluation of a logbook. *Patient Educ Couns*. 1997;31:223-236.
- (131) Whelan TJ, Rath D, Willan A, et al. Evaluation of a patient file folder to improve the dissemination of written information materials for cancer patients. *Cancer*. 1998;83:1620-1625.
- (132) Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet*. 2004;363:312-319.
- (133) Eggly S, Afonso N, Rojas G, et al. An assessment of residents' competence in the delivery of bad news to patients. *Acad Med*. 1997;72:397-399.
- (134) Orlander JD, Fincke BG, Hermanns D, Johnson GA. Medical residents' first clearly remembered experiences of giving bad news. *J Gen Intern Med*. 2002;17:825-831.
- (135) Ptacek JT, Ptacek JJ, Ellison NM. "I'm sorry to tell you ..." physicians' reports of breaking bad news. *J Behav Med*. 2001;24:205-217.
- (136) Clever SL, Tulsy JA. Dreaded conversations: moving beyond discomfort in patient-physician communication. *J Gen Intern Med*. 2002;17:884-885.
- (137) Schofield PE, Beeney LJ, Thompson JF, et al. Hearing the bad news of a cancer diagnosis: the Australian melanoma patient's perspective. *Ann Oncol*. 2001;12:365-371.
- (138) Cassell EJ, Leon AC, Kaufman SG. Preliminary evidence of impaired thinking in sick patients. *Ann Intern Med*. 2001;134:1120-1123.
- (139) Lazcano-Ponce E, Angeles-Llerenas A, Alvarez-del Rio A, et al. Ethics and communication between physicians and their patients with cancer, HIV/AIDS, and rheumatoid arthritis in Mexico. *Arch Med Res*. 2004;35:66-75.
- (140) Harris JJ, Shao J, Sugarman J. Disclosure of cancer diagnosis and prognosis in Northern Tanzania. *Soc Sci Med*. 2003;56(5):905-913.
- (141) Mosconi P, Meyerowitz BE, Liberati MC, Liberati A. Disclosure of breast cancer diagnosis: patient and physician reports. GIVIO (Interdisciplinary Group for Cancer Care Evaluation, Italy). *Ann Oncol*. 1991;2:273-280.
- (142) Elwyn TS, Fetters MD, Sasaki H, Tsuda T. Responsibility and cancer disclosure in Japan. *Soc Sci Med*. 2002;54(2):281-293.
- (143) 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.
- (144) Chang SW, Kerlikowske K, Napoles-Springer A, et al. Racial differences in timeliness of follow-up after abnormal screening mammography. *Cancer*. 1996;78:1395-1402.
- (145) Gwyn K, Bondy ML, Cohen DS, et al. Racial differences in diagnosis, treatment, and clinical delays in a population-based study of patients with newly diagnosed breast carcinoma. *Cancer*. 2004;100:1595-1604.
- (146) Hedeem AN, White E. Breast cancer size and stage in Hispanic American women, by birthplace: 1992-1995. *Am J Public Health*. 2001;91:122-125.
- (147) Lannin DR, Mathews HF, Mitchell J, et al. Influence of socioeconomic and cultural factors on racial differences in late-stage presentation of breast cancer. *JAMA*. 1998;279:1801-1807.
- (148) Madison T, Schottenfeld D, James SA, Schwartz AG, Gruber SB. Endometrial cancer: socioeconomic status and racial/ethnic differences in stage at diagnosis, treatment, and survival. *Am J Public Health*. 2004;94:2104-2111.
- (149) Schwartz KL, Crossley-May H, Vigneau FD, Brown K, Banerjee M. Race, socioeconomic status and stage at diagnosis for five common malignancies. *Cancer Causes Control*. 2003;14:761-766.

- (150) LaVeist TA, Nuru-Jeter A, Jones KE. The association of doctor-patient race concordance with health services utilization. *J Public Health Policy*. 2003;24:312-323.
- (151) Jenkins VA, Fallowfield LJ, Poole K. Are members of multidisciplinary teams in breast cancer aware of each other's informational roles? *Qual Health Care*. 2001;10:70-75.
- (152) 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.
- (153) 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;89:1445-1449.
- (154) Greenfield S, Kaplan S, Ware JE Jr. Expanding patient involvement in care. Effects on patient outcomes. *Ann Intern Med*. 1985;102:520-528.
- (155) Greenfield S, Kaplan SH, Ware JE Jr, Yano EM, Frank HJL. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med*. 1988;3:448-457.
- (156) 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.
- (157) Anderson TJ, Atkins D, Baker-Cirac C, et al. Revised guidelines for HIV counseling, testing, and referral: *Morbidity Mortality Weekly Rep*. 2001;50:1-58.
- (158) Hagerly RG, Butow PN, Ellis PM, Dimitry S, Tattersall MH. Communicating prognosis in cancer care: a systematic review of the literature. *Ann Oncol*. 2005;16:1005-1053.
- (159) Leighl N, Gattellari M, Butow P, Brown R, Tattersall MH. Discussing adjuvant cancer therapy. *J Clin Oncol*. 2001;19:1768-1778.
- (160) Chan A, Woodruff RK. Communicating with patients with advanced cancer. *J Palliat Care*. 1997;13:29-33.
- (161) Bradley EH, Hallemeier AG, Fried TR, et al. Documentation of discussions about prognosis with terminally ill patients. *Am J Med*. 2001;111(3):218-223.
- (162) Epstein RM, Morse DS, Frankel RM, et al. Awkward moments in patient-physician communication about HIV risk. *Ann Intern Med*. 1998;128:435-442.
- (163) Siminoff LA, Fetting JH, Abeloff MD. Doctor-patient communication about breast cancer adjuvant therapy. *J Clin Oncol*. 1989;7:1192-1200.
- (164) Lobb EA, Kenny DT, Butow PN, Tattersall MH. Women's preferences for discussion of prognosis in early breast cancer. *Health Expect*. 2001;4:48-57.
- (165) Butow PN, Kazemi JN, Beeney LJ, et al. When the diagnosis is cancer: patient communication experiences and preferences. *Cancer*. 1996;77:2630-2637.
- (166) Derdarian AK. Informational needs of recently diagnosed cancer patients. *Nurs Res*. 1986;35:276-281.
- (167) Davey HM, Butow PN, Armstrong BK. Cancer patients' preferences for written prognostic information provided outside the clinical context. *Br J Cancer*. 2003;89:1450-1456.
- (168) Kaplowitz SA, Campo S, Chiu WT. Cancer patients' desires for communication of prognosis information. *Health Communication*. 2002;14:221-241.
- (169) Benson J, Britten N. Respecting the autonomy of cancer patients when talking with their families: qualitative analysis of semistructured interviews with patients. *BMJ*. 1996;313:729-731.
- (170) Hagerly RG, Butow PN, Ellis PA, et al. Cancer patient preferences for communication of prognosis in the metastatic setting. *J Clin Oncol*. 2004;22:1721-1730.
- (171) Marwit SJ, Datson SL. Disclosure preferences about terminal illness: an examination of decision-related factors. *Death Stud*. 2002;26(1):1-20.
- (172) Glare P, Virik K, Jones M, et al. A systematic review of physicians' survival predictions in terminally ill cancer patients. *BMJ*. 2003;327:195.
- (173) Miyata H, Takahashi M, Saito T, Tachimori H, Kai I. Disclosure preferences regarding cancer diagnosis and prognosis: to tell or not to tell? *J Med Ethics*. 2005;31:447-451.
- (174) Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Ann Intern Med*. 2001;134:1096-1105.
- (175) Kim MK, Alvi A. Breaking the bad news of cancer: the patient's perspective. *Laryngoscope*. 1999;109:1064-1067.
- (176) Seale C. Communication and awareness about death: a study of a random sample of dying people. *Soc Sci Med*. 1991;32:943-952.
- (177) Johnston G, Abraham C. Managing awareness: negotiating and coping with a terminal prognosis. *Int J Palliat Nurs*. 2000;6:485-494.

- (178) Mackillop WJ, Stewart WE, Ginsburg AD, Stewart SS. Cancer patients' perceptions of their disease and its treatment. *Br J Cancer*. 1988;58:355-358.
- (179) Haidet P, Hamel MB, Davis RB, et al. Outcomes, preferences for resuscitation, and physician-patient communication among patients with metastatic colorectal cancer. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Am J Med*. 1998;105:222-229.
- (180) Pronzato P, Bertelli G, Losardo P, Landucci M. What do advanced cancer patients know of their disease? A report from Italy. *Support Care Cancer*. 1994;2:242-244.
- (181) Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA*. 1998;279:1709-1714.
- (182) Eidinger RN, Schapira DV. Cancer patients' insight into their treatment, prognosis, and unconventional therapies. *Cancer*. 1984;53:2736-2740.
- (183) Prigerson HG. Socialization to dying: social determinants of death acknowledgement and treatment among terminally ill geriatric patients. *J Health Soc Behav*. 1992;33:378-395.
- (184) Goldstein NE, Concato J, Bradley EH, O'Leary JR, Fried TR. Doctor-patient communication about prognosis: the influence of race and financial status. *J Palliat Med*. 2005;8(5):998-1004.
- (185) Jack B, Hillier V, Williams A, Oldham J. Hospital based palliative care teams improve the insight of cancer patients into their disease. *Palliat Med*. 2004;18:46-52.
- (186) Salander P, Henriksson R. Severely diseased lung cancer patients narrate the importance of being included in a helping relationship. *Lung Cancer*. 2005;50:155-162.
- (187) Epstein RM, Alper BS, Quill TE. Communicating evidence for participatory decision making. *JAMA*. 2004;291:2359-2366.
- (188) Davey HM, Armstrong BK, Butow PN. An exploratory study of cancer patients' views on doctor-provided and independent written prognostic information. *Patient Educ Couns*. 2005;56:349-355.
- (189) Delvecchio-Good M, Good BJ, Schaffer C, Lind SE. American oncology and the discourse on hope. *Cult Med Psychiatry*. 1990;14:59-79.
- (190) Sardell AN, Trierweiler SJ. Disclosing the cancer diagnosis. Procedures that influence patient hopefulness. *Cancer*. 1993;72:3355-3365.
- (191) Byrne A, Ellershaw J, Holcombe C, Salmon P. Patients' experience of cancer: evidence of the role of 'fighting' in collusive clinical communication. *Patient Educ Couns*. 2002;48:15-21.
- (192) Gracia D. Moral deliberation: the role of methodologies in clinical ethics. *Med Health Care Philos*. 2001;4:223-232.
- (193) Fallowfield LJ, Jenkins VA, Beveridge HA. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat Med*. 2002;16:297-303.
- (194) Kalemkerian GP. Is collusion necessary? A commentary on necessary collusion. *J Clin Oncol*. 2005 May 1; 23(13):3153-3154.
- (195) Helft PR. Necessary collusion: prognostic communication with advanced cancer patients. *J Clin Oncol*. 2005 May 1; 23(13):3146-3150.
- (196) The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA*. 1995;274:1591-1598.
- (197) Hanson LC, Tulskey JA, Danis M. Can clinical interventions change care at the end of life? *Ann Intern Med*. 1997;126:381-388.

Recognizing and Responding to Emotional Distress in Cancer Consultations



One of the most important features of patient-clinician communication and cancer care is affective communication, an arena of particular salience, as patients are confronting a life-threatening diagnosis, treatment of uncertain effectiveness with potentially debilitating side effects, and an uncertain future. Patients experience and often express a variety of emotions in their interactions with clinicians, including fear,¹ humor,^{2,3} nervousness, worry or sadness, or fatalistic thinking.^{4,5}

It is particularly important to understand the factors that lead to recognition of and response to patients' emotional states, given their potential effect on treatment outcomes. Depression, anxiety, and adjustment disorders have a major effect on quality of life.⁶⁻¹¹ In addition, depression has been found to influence responses to chemotherapy, risk of death,¹² and experience of pain.¹³ Anxiety has been shown to be a predictor of clinical response to treatment.¹² Early recognition of depression and anxiety is crucial for reducing the risk of suicide and social isolation and for initiating pharmacological and psychological treatments that improve quality of life. Most patients with cancer who have mental disorders have adjustment disorders and not major depression or severe anxiety disorders.⁹ Recognition of these disor-

ders may lead to mobilizing social support¹⁴ and psychotherapeutic interventions that could improve quality of life and perhaps increase the likelihood that cancer treatment would be completed.

However, the diagnosis of depressive and anxiety disorders is often missed in oncology practice. The findings of one large study demonstrated that emotional distress was recognized by physicians in 29% of affected patients,¹⁵ and results of another study showed that oncologists correctly identified 17% of patients who were found to be anxious and 6% of those who were found to be depressed on a standardized anxiety and depression scale.¹⁶ Communication barriers influence the diagnosis of mental illness,¹⁷⁻²¹ and some issues are particularly salient in the cancer setting. Many common symptoms of depression are also symptoms associated with cancer or its treatment, including fatigue, lack of energy, insomnia, and loss of appetite. Thus, clinicians must rely to a greater degree on elicitation of the patient's emotional state and maintain the possibility that these physical symptoms may also signify underlying depression.

Research to date on the role of emotion in cancer care primarily has focused on three issues: the psychological benefits of patient expression of emotion during the

consultation, how clinicians respond to patients' emotional state, and emotional well-being as an outcome of patient-clinician communication.

C.1 Benefits of Patients' Emotional Expression

Patients who share their emotions and feelings during medical consultations often experience therapeutic benefits. The use of humor has been found to decrease stress, increase comfort levels, and restore immune function.^{2,3} Patient narratives about their illness experience help to decrease emotional distress.²² Conversely, patients who restrain the expression of their negative emotions may become more anxious, depressed, and confused after receiving a cancer diagnosis.²³ Disclosing emotions may even contribute to improvements in physical symptoms.²⁴ The written disclosure of emotion can also buffer the negative effects of the inadequacy of social support.²⁵

Although emotional expression can have positive benefits, patients appear to vary in the kind and manner of emotions expressed. For example, humor in consultations can be either positive or negative. Patients with testicular cancer have reported that humor in the consultation can dispel tension and make them feel "normal," but, if such humor is managed poorly, it can be a source of humiliation or stigma.²⁶ Just as disclosing emotions may have cathartic effects, failing to disclose emotions may hurt emotional processing. Patients may fail

to disclose fears because of low social support, low emotional well-being, or the belief that the clinician is not responsible for helping with emotional concerns.^{11,27} Undisclosed fear can cause patients to underreport their difficulties with cancer to their clinicians.²⁸ In one study, the worry of appearing disrespectful to clinicians caused some patients to withhold their feelings about wanting to reconsider decisions about treatment.²⁹

C.2 Clinicians' Responsiveness to Patients' Emotional States

Most patients with cancer respond favorably when clinicians are receptive and interested in their emotional states and well-being. In one study of patients terminally ill with cancer, the patients perceived their clinicians more positively when they offered more emotional support.⁵ In another study, oncologists' affective tone and socioemotional behaviors were associated with greater patient satisfaction.³⁰ Facilitating patients' emotional processing helped them to participate more effectively in making decisions about palliative care.³¹ Because cancer also has a significant emotional impact on patients' family members, clinicians may need to help families address their own emotional distress and experiences.³²

Clinicians typically are not effective at recognizing patients' emotional cues or at uncovering their fears and concerns, although some clinicians may be minimally receptive to patients' emotional

expressions.^{1,33} Clinicians' difficulty in recognizing emotional cues may, in part, be related to Patients' tendency to articulate concerns that are informational rather than emotional in nature³⁴ and to disclose physical symptoms rather than psychological problems.³⁵ Adding to the difficulty is that the patients who are the most anxious or depressed are often the least likely to disclose their emotional concerns.³⁵ The findings of one study found that nurses were not accurate in identifying patients' concerns and most could not even identify the patient's three primary concerns.³⁶ Nurses were biased toward concerns about physical symptoms and medical treatment compared with emotional and other psychosocial issues.

The lack of communication skills, time, and a quiet private environment in hospital settings appear to be barriers to clinicians' validation of and responsiveness to patients' emotions.³⁷ With respect to skills, the findings of several studies demonstrate that educational interventions could help clinicians become more adept at addressing the patient's emotional needs.^{38,39} Clinicians can elicit the fears and concerns of patients with cancer more effectively with use of patient-centered communication tactics such as open-ended questions, focusing on and clarifying psychological issues, and empathic statements.¹⁸ In contrast, disclosure is less likely when clinicians use leading questions, focus on physical aspects of health, and prematurely move into giving advice and reassurance.

It is important to recognize that the relationship between patient-clinician communication and patients' emotional states can be quite complex. The body of literature in this area is small and most of the studies have focused on patient-clinician communication during the survivorship phase, with emphasis on the management of anxiety related to uncertainty and on the process of reassurance. Cancer survivors with disease in clinical remission are often anxious and present physical symptoms that clinicians interpret as requests for reassurance. However, in other settings, clinicians' expression of reassurance to patients without obvious disease can sometimes heighten the patients' anxiety.⁴⁰⁻⁴² In one of the few studies of reassurance, Stark et al.⁴³ reported, not surprisingly, that in more than 90% of posttreatment oncology visits, clinicians attempted to provide reassurance, either spontaneously, or, more commonly, in response to patient-reported physical symptoms. These attempts at reassurance often produced initial lowering of the anxiety level followed by paradoxical worsening of anxiety. Spontaneous reassurance ("you look well") increased anxiety in the most anxious patients before their next scheduled visit, and offering a treatment plan without explanation raised the level of anxiety in all patients within one week after the consultation, regardless of the baseline anxiety level. Moreover, providing reassurance may worsen outcomes if it appears to avoid the focus of the patient's

anxiety or is offered before the patient can express his or her concerns. The imperative to reduce anxiety may also drive diagnostic testing, some of which is not medically indicated, in an attempt to provide reassurance. If extrapolations from studies of populations without cancer hold,^{41,42,44} clinicians' reporting of normal test results may provide only temporary reduction of anxiety. In contrast, providing simple reassurance while offering clear explanations has a more neutral effect on anxiety.⁴³ Through effective communication, clinicians can contribute at least temporarily to a transient decrease of patient anxiety, but the long-term effects of communication on anxiety in cancer survivors are unknown.

C.3 Emotional Well-Being as an Outcome of Patient-Clinician Communication

In the previous sections, we examined patients' emotional expressions and clinicians' responsiveness to these cues, but other elements of patient-clinician communication can also influence the affective states of patients with cancer following the consultation. For example, the way clinicians manage information can have a significant effect on patient emotions. Research has shown that less anxiety and depression were experienced by children with cancer in the initial stages when clinicians were open about the diagnosis and prognosis.⁴⁵ Information about diagnosis may lead to greater hope, although the time between

diagnosis and disclosure may moderate that relationship.⁴⁶ These findings are consistent with those of other studies in which patients' perceptions of being told "everything" led to an increase in patient satisfaction.⁴⁷

Clinicians' communication style can directly influence patients' emotional well-being. For example, the degree to which patients perceive their clinicians' communication as patient-centered and facilitative may decrease postconsultation anxiety, although this relationship was weaker for patients with more advanced disease.⁴⁸ Communication that can help reduce anxiety included preparing the patient for diagnosis, giving the patient clear information, providing written information, discussing questions and feelings, encouraging the patient to be involved in decision-making, and being reassuring.⁴⁷ Additionally, compassionate communication and empathy from clinicians also may play a role in reducing patient anxiety and emotional distress.^{49,50}

Other variables that may affect patients' emotions after the consultation visit revolve around the patient's participation in decision-making. As patients participate in treatment decisions, they may feel more anxiety regarding their responsibility in the outcome of that treatment. However, if patients are more satisfied with their increased level of involvement, then increased patient participation is associated with reduced emotional distress.⁵⁰

C.4 Implications for Future Study

Eliciting, acknowledging, normalizing, and empathizing with patients' emotional expressions have positive effects on patients' subsequent functioning and quality of life. Yet, clinicians rarely engage patients in discussions about their fears and worries. Emotional dialogue is embedded in other communication activities such as exchanging information, making decisions, and providing access to care, yet the interface of instrumental and affective communication is poorly understood. For example, is patient involvement in decisions facilitated by emotional dialogue and understanding, not just the provision of information and choices? Interventions to improve emotional responsiveness in clinicians have been successful in small-scale studies, but future research should identify and overcome barriers to participation in these interventions and provide means for sustaining the positive effects.

References

- (1) Beach WA, Easter DW, Good JS, Pigeron E. Disclosing and responding to cancer "fears" during oncology interviews. *Soc Sci Med*. 2005;60:893-910.
- (2) Bennett MP, Zeller JM, Rosenberg L, McCann J. The effect of mirthful laughter on stress and natural killer cell activity. *Altern Ther Health Med*. 2003;9:38-45.
- (3) Christie W, Moore C. The impact of humor on patients with cancer. *Clin J Oncol Nurs*. 2005;9:211-218.
- (4) Chibnall JT, Videen SD, Duckro PN, Miller DK. Psychosocial-spiritual correlates of death distress in patients with life-threatening medical conditions. *Palliat Med*. 2002;16:331-338.
- (5) Kelly B, Burnett P, Pelusi D, Badger S, Varghese F, Robertson M. Terminally ill cancer patients' wish to hasten death. *Palliat Med*. 2002;16:339-345.
- (6) Fawzy FI, Fawzy NW, Arndt LA, Pasnau RO. Critical review of psychosocial interventions in cancer care. *Arch Gen Psychiatry*. 1995;52:100-113.
- (7) Fawzy FI, Fawzy NW, Hyun CS, et al. Malignant melanoma. Effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival 6 years later. *Arch Gen Psychiatry*. 1993;50:681-689.
- (8) Spiegel D. Psychosocial aspects of breast cancer treatment. *Semin Oncol*. 1997;24:S1.
- (9) Spiegel D. Cancer and depression. *Br J Psychiatry Suppl*. 1996;30:109-116.
- (10) Badger TA, Braden CJ, Mishel MH. Depression burden, self-help interventions, and side effect experience in women receiving treatment for breast cancer. *Oncol Nurs Forum*. 2001;28:567-574.
- (11) Ryan H, Schofield P, Cockburn J, et al. How to recognize and manage psychological distress in cancer patients. *Eur J Cancer Care*. 2005;14:7-15.
- (12) Watson M, Haviland JS, Greer S, Davidson J, Bliss JM. Influence of psychological response on survival in breast cancer: a population-based cohort study. *Lancet*. 1999;354:1331-1336.
- (13) Sist TC, Florio GA, Miner MF, Lema MJ, Zevon MA. The relationship between depression and pain language in cancer and chronic non-cancer pain patients. *J Pain Symptom Manage*. 1998;15:350-358.
- (14) Maly RC, Umezawa Y, Leake B, Silliman RA. Mental health outcomes in older women with breast cancer: impact of perceived family support and adjustment. *Psychooncology*. 2005;14:535-545.
- (15) Fallowfield L, Ratcliffe D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. *Br J Cancer*. 2001;84:1011-1015.
- (16) Newell S, Sanson-Fisher RW, Girgis A, Bonaventura A. How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems? Data from a survey of five oncologists. *Cancer*. 1998;83:1640-1651.
- (17) Sheard T, Maguire P. The effect of psychological interventions on anxiety and depression in cancer patients: results of two meta-analyses. *Br J Cancer*. 1999;80:1770-1780.
- (18) Maguire P, Faulkner A, Booth K, Elliott C, Hillier V. Helping cancer patients disclose their concerns. *Eur J Cancer*. 1996;32A:78-81.
- (19) 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.

(20) Epstein RM, Shields CG, Meldrum SC, et al. Physicians' responses to patients' medically unexplained symptoms. *Psychosom Med*. 2006;68:269-276.

(21) Carney PA, Eliassen MS, Wolford GL, et al. How physician communication influences recognition of depression in primary care. *J Fam Pract*. 1999;48:958-964.

(22) Carlick A, Biley FC. Thoughts on the therapeutic use of narrative in the promotion of coping in cancer care. *Eur J Cancer Care (Engl)*. 2004;13:308-317.

(23) Iwamitsu Y, Shimoda K, Abe H, et al. Differences in emotional distress between breast tumor patients with emotional inhibition and those with emotional expression. *Psychiatry Clin Neurosci*. 2003;57:289-294.

(24) Rosenberg HJ, Rosenberg SD, Ernstoff MS, et al. Expressive disclosure and health outcomes in a prostate cancer population. *Int J Psychiatry Med*. 2002;32:37-53.

(25) Zakowski SG, Ramati A, Morton C, Johnson P, Flanigan R. Written emotional disclosure buffers the effects of social constraints on distress among cancer patients. *Health Psychol*. 2004;23:555-563.

(26) Chapple A, Ziebland S. The role of humor for men with testicular cancer. *Qual Health Res*. 2004;14:1123-1139.

(27) Figueiredo MI, Fries E, Ingram KM. The role of disclosure patterns and unsupportive social interactions in the well-being of breast cancer patients. *Psychooncology*. 2004;13:96-105.

(28) Moore RJ, Chamberlain RM, Khuri FR. Communicating suffering in pri-

mary stage head and neck cancer. *Eur J Cancer Care (Engl)*. 2004;13:53-64.

(29) Cohen H, Britten N. Who decides about prostate cancer treatment? A qualitative study. *Fam Pract*. 2003;20:724-729.

(30) Ong LM, Visser MR, Lammes FB, de Haes JC. Doctor-patient communication and cancer patients' quality of life and satisfaction. *Patient Educ Couns*. 2000;41:145-156.

(31) Timmermans LM, van der Maazen RW, Verhaak CM, et al. Patient participation in discussing palliative radiotherapy. *Patient Educ Couns*. 2005;57:53-61.

(32) Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives: a review. *Eur J Cancer*. 2003;39:1517-1524.

(33) Osse BH, Vernooij-Dassen MJ, Schade E, et al. Problems to discuss with cancer patients in palliative care: a comprehensive approach. *Patient Educ Couns*. 2002;47:195-204.

(34) Butow PN, Brown RF, Cogar S, Tattersall MH, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. *Psychooncology*. 2002;11:47-58.

(35) Heaven CM, Maguire P. Disclosure of concerns by hospice patients and their identification by nurses. *Palliat Med*. 1997;11:283-290.

(36) Farrell C, Heaven C, Beaver K, Maguire P. Identifying the concerns of women undergoing chemotherapy. *Patient Educ Couns*. 2005;56:72-77.

(37) Hope-Stone LD, Mills BJ. Developing empathy to improve patient care: a pilot study of cancer nurses. *Internat J Palliat Nurs*. 2001;7:146-150.

(38) Razavi D, Delvaux N, Marchal S, et al. Does training increase the use of

more emotionally laden words by nurses when talking with cancer patients? A randomised study. *Br J Cancer*. 2002;87:1-7.

(39) Gordon GH. Care not cure: dialogues at the transition. *Patient Educ Couns*. 2003;50:95-98.

(40) Coia P, Morley S. Medical reassurance and patients' responses. *J Psychosom Res*. 1998;45:377-386.

(41) Luccock MP, Morley S, White C, Peake MD. Responses of consecutive patients to reassurance after gastroscopy: results of self administered questionnaire survey. *BMJ*. 1997;315:572-575.

(42) McDonald IG, Daly J, Jelinek VM, Panetta F, Gutman JM. Opening Pandora's box: the unpredictability of reassurance by a normal test result. *BMJ*. 1996;313:329-332.

(43) Stark D, Kiely M, Smith A, Morley S, Selby P, House A. Reassurance and the anxious cancer patient. *Br J Cancer*. 2004;91:893-899.

(44) Salmon P, Peters S, Stanley I. Patients' perceptions of medical explanations for somatisation disorders: qualitative analysis. *BMJ*. 1999;318:372-376.

(45) Last BF, van Veldhuizen AM. Information about diagnosis and prognosis related to anxiety and depression in children with cancer aged 8-16 years. *Eur J Cancer*. 1996;32A:290-294.

(46) Lin CC, Tsay HF. Relationships among perceived diagnostic disclosure, health locus of control, and levels of hope in Taiwanese cancer patients. *Psychooncology*. 2005;14:376-385.

(47) Schofield PE, Butow PN, Thompson JF, et al. Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol*. 2003;14:48-56.

(48) Takayama T, Yamazaki Y, Katsumata N. Relationship between outpatients' perceptions of physicians' communication styles and patients' anxiety levels in a Japanese oncology setting. *Soc Sci Med*. 2001;53:1335-1350.

(49) Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 seconds of compassion reduce patient anxiety? *J Clin Oncol*. 1999;17:371-379.

(50) Zachariae R, Pedersen CG, Jensen AB, et al. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. *Br J Cancer*. 2003;88:658-665.

Decision-Making in Cancer Care*



Much of the research on decision-making in cancer care has focused on three issues:

- Patient preferences for involvement in decision-making
- Relationship between patient involvement in decision-making and postconsultation outcomes
- Understanding of the correlates of patients' decision preferences

Three phases of the cancer care continuum are predominant in the literature on decision-making: screening, treatment, and end of life. Decisions to screen for specific cancers arise when there is a choice of screening method (such as for colorectal cancer screening) or debate about the overall value of screening (such as with prostate cancer screening). Decisions about treatment arise when several treatment options are available and no single option is best for all patients (as often occurs with breast cancer). At the end of life, decisions involve discontinuing anticancer treatment, advance directives, treatment setting (including hospice), and assisted suicide. Decision aids are included in the discussion on interventions in Appendix E.

D.1 Decision-Making in the Screening Phase

Cancer screening programs—specifically those designed to

detect breast, prostate, cervical, and colorectal cancer—aim to sort asymptomatic people who have cancer from those who do not. Increasingly, efforts have been made to promote informed decision-making on the part of the health care consumer and the clinician when discussing and evaluating screening options. Decision-making about screening often involves complex personalized discussions with eligible individuals about the risks and benefits of screening procedures.

Communication about Risk

Screening programs and clinicians vary in how they communicate, especially the degree to which they promote informed decision-making with eligible individuals. A 2002 Cochrane review addressed the effects of personalized versus general risk communication on individuals' decisions about whether to participate in health screening programs.¹ The specific goal of that review was to see whether personalized communication about risk for disease influenced any of several possible outcomes. Personalized communication was defined as information tailored to an individual's personal history or medical conditions that affect his or her risk of cancer. Personalized risk communication varies in detail and complexity as

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well as in the medium used to communicate (e.g., direct mail campaigns, face-to-face discussion, or electronic media). The outcomes were categorized into the following groups:

- Behavioral, such as actual receipt of a screening test or adherence to choice regarding screening
- Cognitive, such as knowledge of risk or accurate risk perception
- Affective, such as anxiety, emotional well-being, satisfaction with decision made, or decisional conflict domains

The review included randomized controlled trials of people who were involved with “real life decisions” about whether to undergo screening, studies in which there was a risk communication information component to the intervention, studies that addressed decision-making about screening programs, and studies that included any of the aforementioned outcome measures. Of the 13 heterogeneous identified studies that met the inclusion criteria for the review, 10 addressed personalized risk communication related to breast cancer screening and one each, to cervical, colorectal, and prostate cancer screening. Only some studies incorporated patient-clinician communication; others focused on mass media and tailored communication interventions. In the six studies in which the intervention included a component of counseling (usually a health educator or graduate stu-

dent), the participants’ accuracy of risk perception and use of appropriate cancer screening services usually increased. There was no evidence that this increase in uptake of services was due to informed decision-making. An interesting finding was that if the personalized information was more detailed or numerically specific relative to the patient’s own risk, there was *less* receipt of cancer screening than when the information was provided in a more general way.

Patient involvement and postconsultation outcomes

Studies on decision-making about screening thus far have primarily focused on breast cancer compared with other types of cancer. The studies have tended to include only a limited number of outcomes, usually, the actual receipt of screening services. Knowledge of the processes by which communication and decision-making informs other screening-related outcomes remains limited, yet these other outcomes may also be responsive to change. Effect modifiers (such as high risk status) may also contribute to decision-making regarding cancer screening and detection. Research published since 2002 has involved examination of aspects of communication and decision-making processes about screening for types of cancer other than breast cancer) and have also included diverse populations.

More recent studies have yielded additional information about com-

munication and decision-making about screening for colorectal cancer. In a qualitative study of members of an African American church in rural North Carolina,² the quality of the communication with their physicians influenced patients’ decisions to undergo colorectal cancer screening. In a larger cross-sectional survey (397 individuals) following the qualitative phase of the study, participants who reported that they had good communication with their clinician were more likely to have been screened (36%) according to the recommended guidelines than were participants reporting poor communication (17%). The strongest predictors of colorectal cancer screening or intent to complete screening among individuals with low income included higher baseline risk of disease, self-efficacy, and recall of physician recommendation.³ This finding was further explored by Manne et al.,⁴ who collected data from 534 siblings of individuals diagnosed with colorectal cancer and found that physician support, family support, and cancer-related distress were related to perceived benefits of screening.

In another study, the desired and actual levels of patient control over decisions regarding prostate-specific antigen (PSA) screening were examined.⁵ Both before and after visits, patients expressed a preference for a shared approach to the actual decision. The study focused on decision-making outcomes and role preferences when encountering differing communi-

cation styles and media. The intervention included different scripted communication (“discussion”) elements. The participants wanted to share decision-making more than they had, yet the actual decision was shifted toward greater patient control. Twenty-five percent of men reported having *greater* decisional control over the PSA test than they had wanted, and 30% of men who wanted a shared approach made the decision themselves. The findings of another study⁶ demonstrated that the rate of PSA screening decreased from 98% to 50% when information was given with greater intensity and through a higher number of media (in person, video, etc.).

Correlates of patients’ decision preferences

Another line of research has involved evaluation of the role that belief systems and sociocultural characteristics play in decision-making about cancer screening. Among black women, for example, those who had had mammography were more likely to report having had recent contact with a physician; not surprisingly, they tended to believe that screening should be done annually and that early detection improves outcomes.⁷ In a study about barriers to screening in rural Appalachia,⁸ physicians identified such barriers as time constraints and conflicting guidelines. Physicians’ perceptions that patients do not value prevention had a negative impact on communication about cancer screening.

Implications for future study

The focus of studies thus far has been on risk communication and role preferences for decision-making about cancer screening rather than the development of a trusting relationship, clinician responsiveness to patients’ concerns, and understanding of the patients’ views. Future work on decision-making in cancer screening needs to explore other outcomes, such as the cognitive and affective pathways of decision-making, rather than measuring only the receipt of screening service. Also, measures or tools to assess decision-making, rather than just personalized risk communication per se, are needed. The association between more detailed information and lower uptake of screening services is a curious finding that deserves further study, suggesting there may be a “dose-response” relationship to information about personalized risk and intention or receipt of cancer screening services. Perhaps more detailed communication about the relationship between one’s personal risk and population-wide benefits of cancer screening may attenuate one’s sense of personal need to undergo screening, given the marginal personal gain. Thus, increasing the communication may have the paradoxical effect of lowering an individual’s use of cancer screening services. Other poorly characterized factors may also be effect modifiers on decision-making about cancer screening.

D.2 Decision-Making in the Treatment Phase

High-stakes decisions about treatment choices that are either reversible (such as initiation of chemotherapy) or irrevocable (such as mastectomy vs. lumpectomy) dominate the cancer communication literature. The most difficult decisions are those that involve tradeoffs between quantity and quality of life and those that involve small but statistically significant difference in clinical outcomes.

Patient preferences for involvement in decision-making

The findings of surveys of patients with cancer regarding their preferences for involvement in treatment decisions suggest that patients’ wishes are often difficult to predict and that they change over time. Some studies have indicated that most patients prefer an active or collaborative role,⁹⁻¹³ and other studies have demonstrated that patients generally prefer the physician to make the final treatment decisions.¹⁴⁻¹⁶ More importantly, evidence suggests that patient preferences are affected by a number of factors. In cancer care, one of the key factors is the severity of illness. Patients who are sicker and/or more distressed generally prefer to relinquish control of decisions to clinicians.^{17,18} Patients who are older and less educated also are more likely to prefer paternalistic decision-making models, whereas younger and more educated patients desire more active and collaborative roles.^{14,18-21} In one

study, women were more likely than men to prefer shared decision-making with the physician.²² However, there was more heterogeneity within groups than between them. Although a patient's health literacy has not been clearly linked to patient preferences for involvement, it is related to their ability to actively participate in these interactions,^{23,24} an issue discussed later.

The wide variation in patients' preferences regarding involvement in decision-making has prompted some investigators to call for tailored approaches to assessing patient preferences.^{9,25} Support for this position is found in several studies that have indicated that a substantial number of patients with cancer do not achieve their desired level of participation in the decision-making process.^{15,18} Butow²⁶ found that most patients with breast cancer did not obtain their preferred level of involvement (29% and 37% were more and less involved than preferred, respectively). Patients who had a mismatch on preferred and actual involvement expressed greater anxiety following the consultation. Physicians are not particularly good judges of patient preferences^{9,27} nor do patients and physicians perceive the decision-making process in the same way (e.g., shared or physician control¹²).

Patient involvement and postconsultation outcomes

A number of studies have been conducted to examine the relation-

ships between the decision-making involvement of patients with cancer and a variety of postconsultation outcomes. The authors of early studies reported that simply offering patients with breast cancer a choice for initial treatment (e.g., breast removal or breast conservation) was correlated with a short-term reduction in depression and anxiety following treatment.^{28,29} However, in another study, the perceptions of patients with breast cancer regarding the choice of adjuvant chemotherapy were not related to subsequent quality of life.³⁰ The findings of another study showed that the degree to which patients with early breast cancer actively participated in their treatment consultations was related to the degree to which they assumed responsibility for the decision one year following treatment.³¹ The patient's self-report of involvement in the consultation at the time of consultation also was predictive of having a choice for treatment one year later. In turn, decision responsibility and perceived choice were predictive of health-related quality of life at one year.

Patient satisfaction with care and decisional regret has been the subject of considerable attention in research on communication between clinicians and patients with cancer. Some evidence has indicated that the greater the match between the preferences for involvement of patients with breast cancer and their perceived actual involvement, the less decisional regret and greater patient satisfac-

tion with care.³² However, the results of one study showed that patients' perceived actual role in the consultation, and not the preferred role, was the stronger predictor of evaluations of care. Patients reporting a shared role with the physician were more satisfied and evaluated their physicians' communication more favorably than did patients reporting that their physicians exclusively made treatment decisions.³³ Decision aids can help facilitate patient-clinician communication about treatment preferences, which, in turn, contributes to greater patient satisfaction and less decisional conflict.^{34,35}

The relationship between patient involvement in the decision-making process and outcomes may in part be mediated by clinicians' efforts to encourage greater patient participation. For example, in studies that have involved the use of observational and self-report measures, patients with cancer were more active participants when their clinicians used partnership-building to encourage patient involvement.^{36,37} In turn, clinician support of patient participation can foster a sense of having a choice of treatment and greater satisfaction with care.³⁸

Correlates of patients' decision preferences

The quality of patient-clinician communication can affect patients' decisions and decision preferences, and some research has examined other factors affecting patients'

decisions about treatment. Patient preferences for decisions may in part be influenced by their perception of their physicians' preferences.³⁹ Patients' decisions to forego traditional therapies for alternative and nonconventional treatments are influenced by a host of factors, such as having a close friend or relative who has died from cancer when receiving conventional treatments, beliefs, need for control, side effects of conventional treatments, poor communication with physicians, and expected benefits of treatment.⁴⁰ Media hype about remarkable cures can also predispose individuals with cancer to choose experimental and nontested treatment.⁴¹ Regardless of the source of influence, clinicians often have little understanding of patients' reasons to forego traditional therapy and/or choose alternative approaches.

There is a large body of literature on decision aids for assessing patients' decision preferences in general, and in the setting of cancer care specifically. The vast majority of studies on decision aids do not address their impact on patient-clinician communication. Research that has investigated their impact on communication will be reviewed later, in the discussion of patient activation interventions. In reviews of nearly 200 decision aids pertaining to health care decisions of all types, O'Connor et al. reported that most of the aids were provided before the consultation to make decisions, included an emphasis on information about treatment options and

relative advantages and disadvantages of options and were generally free of conflict of interest.³⁵ However, many of these aids were not fully evaluated. Decision aids generally increased knowledge about options, lowered decisional conflict, and reduced the proportion of people remaining undecided about the treatment. Importantly, simple decision aids seemed to be more effective than complex ones with respect to knowledge gained, more realistic expectations, and greater concordance between values and preferences. Contributions of decision aids to health outcomes and cost of implementing such interventions require further study. A follow-up to that review highlighted the fact that many of the decision aids described in the literature lack clear conceptual explanations of processes by which they are expected to achieve their goals, fail to recognize or acknowledge the values embraced by the decision aid itself, and are not thoroughly evaluated.^{35,42}

In cancer care, resources to support decision-making should take into account not only patient values but also patient competencies; patients with cancer often want as much information as possible but can be overwhelmed with the information available and the complexity of decisions. Continued development and evaluation of decision aids, especially ones that use interactive technology, may be resources for optimizing patient involvement in decision-making in a progressive, iterative fashion.⁴³

Implications for future study

Collectively, the findings of the studies on decision-making indicate that the quality of the patient-clinician interaction, and not patient involvement in treatment decision-making per se, is the most important factor affecting cancer outcomes. For example, in a study of patients with colorectal cancer, the perception that their clinicians explained treatment options in a clear and unhurried manner was especially important to most patients, regardless of their preferences for decision-making roles.²² This finding is very similar to that of a qualitative study⁴⁴ in which women with a variety of cancers differed in their preferences for involvement in decision-making but were similar in that most reported that judgments about whether the right decision was reached was related to a feeling of being listened to, inclusion in the decision-making process (regardless of who made the final decision), and trust in the physician. Specific communication strategies that may facilitate patient-clinician communication about treatment include explicit agenda setting, active listening, checking understanding, offering opportunities for involvement, endorsing participation, and using nonverbal behaviors that convey empathy and warmth.⁴⁵ It remains unclear how often the patient-clinician conflict about the treatment and screening decisions occurs.

D.3 Decision-Making in the End-of-Life Phase

Palliation should occur at all phases of the cancer care continuum, but end-of-life care refers to the point at which relief of pain and other symptoms takes precedence over prolonging survival. There are no clear landmarks for the transition to end-of-life care, complicating both the communication challenges and their study. Much of the literature on decision-making at the end of life is based on individual case reports, qualitative interviews and focus groups, attitudinal surveys, and expert opinion rather than on observation of interactions and surveys addressing specific communication tasks.⁴⁶ Older studies from the hospice literature are not easy to access with use of standard search strategies. The studies that do exist indicate gaps in communication that result in inadequate symptom management, lack of emotional support, excessive use of medical technology, and insufficient use of hospice care.⁴⁷

In general, patients, families, and clinicians consider patient involvement in decisions during the end-of-life phase to be important,⁴⁸ and most patients want to participate in such decisions.⁴⁹ However, the results of studies have suggested that there is substantial variability in patients' wishes to be involved, that discussions about end-of-life issues are often inadequate,⁵⁰ and that clinicians usually underestimate patients' desires to participate in decisions.⁹ Outcome measures have been developed to determine the quality of life for patients

at the end of life. Although these measures correlate with symptom scores and family ratings of care after the patient's death, challenges remain in validating the measures prospectively in a variety of populations and settings.⁵¹

End-of-life decision-making focuses on four areas: discontinuing anticancer therapies, the settings for end-of-life care, advance directives, and assisted suicide. Decisions in each of these areas involve the patient as well as the family;⁵²⁻⁵⁵ in fact, about half of all patients lose decision-making capacity before their deaths, so family-based decision-making is common.⁵⁶

Discontinuing anticancer therapies

The decision to forego or cease anticancer therapies may occur at the point when gains in survival and functioning and reduction of symptoms may be offset by a decrease in the quality of life due to the treatment itself. However, studies suggest that consideration of quality of life has had little influence on clinicians' recommendations and subsequent decisions to continue or cease chemotherapy.⁵⁷ Clinicians who use third-line and fourth-line chemotherapy in the last months of life in the absence of clinical evidence of its effectiveness⁵⁸ tend to be less skilled in communicating.⁵⁹ Presumably, decisions on such treatment are based on clinicians' emotions (feelings of guilt, failure, and blame) rather than open discussions about alternatives

and choices.^{60,61} Case reports and anecdotal evidence suggest, however, that many patients and families view the stopping of disease-directed therapy as "giving up." They may confuse the failure of treatment with the failure of their clinician and prefer to continue even long-shot experimental therapy to transitioning to a hospice approach.^{62,63} Correspondingly, many patients' decisions are based on personal and spiritual belief systems, advice from others, and fear.⁶⁴

Accurate and complete information about options at the end of life are necessary for informed decision-making, but according to questionnaire surveys, most patients did not fully understand their rights to withdraw treatment once initiated or their rights to aggressive symptom management with medication doses that may unintentionally hasten death.⁶⁵ Less than half of patients were presented with treatment choices and information about quality of life.⁶⁶ However, patients who reported participating in decisions about end-of-life care had higher levels of anxiety for at least two weeks following the decision. In one intervention to facilitate patients' participation in care and decisions, question prompt lists were well received and reduced the level of anxiety, but the impact on the process of decision-making was unclear.⁶⁷

Settings for end-of-life care

The decision about the setting in which end-of-life care will occur

is also important. Options for the setting include the patient's home, with or without hospice services; a nursing home; or a dedicated hospice unit. Despite a large body of literature about patient attitudes regarding the setting of end-of-life care, no studies have specifically addressed patient-clinician discussions about this topic.

Advance directives

Discussions about advance directives and substituted judgment about life-sustaining treatments should the patient lose the capacity to decide are contextualized by numerous sociological, psychological, legal, and ethical factors that are beyond the scope of this monograph. A self-determination model suggests that patients would want to use a principle of substituted judgment if they lose capacity, but this application of self-determination theory is increasingly being called into question.⁶⁸ There is empirical support that some patients (especially those who are older and sicker) are more comfortable delegating such decisions to family members and, under certain circumstances, letting surrogates override the patient's own living will, depending on the context, recognizing that decisions are unstable over time.^{69,70} However, patients and their surrogates do not always make the same decisions when presented with hypothetical scenarios, nor are their advance care decisions completely stable over time. Yet, most patients still favor the decision-making authority of

their selected surrogate, should they lose capacity in the future.⁷¹⁻⁷³ Although patients and clinicians believe that frank discussions about end-of-life choices are important and necessary, clinicians should be aware that patients' ability to maintain a positive attitude is associated with increased survival and quality of life⁷⁴ and that clinician recommendations can have psychological benefit for patients.⁷⁵ Thus, presenting "just the facts" and expecting patients to take a primary decision-making role may not always be good for the patient's health and well-being. Clinicians also have an important role in fostering positive attitudes and hope. They must often share responsibility for the decision with the patient and his or her family. One qualitative study emphasized the importance of determining whether the patient was an "activist" or a "delegator" before approaching discussions of advance directives.⁷⁶

The SUPPORT study was an important effort to promote discussions about end-of-life issues with seriously ill patients, some of whom had cancer.⁷⁷ However, the intervention—nurses informing teams about the patient's values and prognosis—produced no changes in the use of advance directives, and care was no more concordant with patients' values in the intervention group than in the control group.⁷⁷ Even when discussions occurred, physician understanding of patients' preferences were no better than when such discussions were reported not to have

occurred.⁷⁸ Tulsky et al.⁷⁹ and Fischer et al.⁸⁰ recorded consultations addressing advance directives and then surveyed both physicians and patients. The discussions included questions about preferences and surrogate decision-making but rarely addressed values or uncertainty. The researchers found that most patients had misconceptions about the process and outcomes of cardiopulmonary resuscitation. Although physicians accurately predicted who the patient would choose as a health care proxy 89% of the time, they were unable to predict patients' preferences in 18 of 20 scenarios involving advance directives.^{79,80} Our knowledge about the content and process of discussions about advance directives or do-not-resuscitate orders with patients with incurable cancer is limited. Furthermore, traditional models of decision-making consider only two parties—the patient and the clinician. However, families are normally involved in end-of-life decisions, even in Anglo-Saxon cultures, and more so in Asian, African, Mediterranean, and native American cultures.^{81,82} Models for communicating about end-of-life issues have only begun to take the family into account,⁸³ and family interventions have not been tested empirically.

Assisted suicide

Assisted suicide and euthanasia are also issues that arise during the end-of-life phase. Even in locations where assisted death is illegal, 12% of physicians report having received explicit requests for

this.⁸⁴ In one study, half of oncologists surveyed reported having received such requests and 13.5% complied with them.⁸⁵ Although there are several published guidelines on the use of assisted suicide,⁸⁶⁻⁸⁸ their implementation has been studied with only qualitative interview techniques with clinicians⁸⁹ and patient/family units.⁹⁰ Clinicians' reports suggested that their initial responses to such requests are to ask the patient to clarify his or her reasons for the request, address the physical symptoms and psychological issues underlying the request, and identify and treat depression. However, clinicians' greatest difficulty in responding to such requests and reaching a decision was related to existential suffering—patients' loss of meaning, loss of role function, and feeling that they are burdensome to their families. Patients and their families reported on clinicians' qualities necessary to facilitate these discussions, including openness to discussing assisted suicide, expertise dealing with the dying process, and maintaining a trusting relationship despite potential disagreements.⁹⁰ These interactions, however, have not been recorded or observed directly, nor is there information about how clinical communication affects suffering and quality of life in these settings.

Implications for future study

Little known about the content and process of discussions between clinicians, patients at the end of life, and their families regarding treat-

ment decisions, advance directives, do-not-resuscitate orders, hospice care, family involvement in decision-making, and assisted dying. Study of communication in this domain must take into account, more than in other domains of cancer communication, the patient's implicit model of self-determination, desire for autonomy versus delegation to family or friends, desire for physician recommendations and willingness to confront difficult circumstances, all of which exist with an undercurrent of prognostic uncertainty. Addressing patients' emotions and existential suffering appears to be a necessary first step in reaching decisions regarding end-of-life care.

References

- (1) Edwards A, Unigwe S, Elwyn G, Hood K. Effects of communicating individual risks in screening programmes: Cochrane systematic review. *BMJ*. 2003;327:703-709.
- (2) Katz ML, James AS, Pignone MP, et al. Colorectal cancer screening among African American church members: a qualitative and quantitative study of patient-provider communication. *BMC Public Health*. 2004;4:62.
- (3) Friedman LC, Webb JA, Everett TE. Psychosocial and medical predictors of colorectal cancer screening among low-income medical outpatients. *J Cancer Educ*. 2004;19:180-186.
- (4) Manne S, Markowitz A, Winawer S, et al. Understanding intention to undergo colonoscopy among intermediate-risk siblings of colorectal cancer patients: a test of a mediational model. *Prev Med*. 2003;36:71-84.

- (5) Woolf SH, Krist AH, Johnson RE, Stenborg PS. Unwanted control: how patients in the primary care setting decide about screening for prostate cancer. *Patient Educ Couns*. 2005;56:116-124.
- (6) Frosch DL, Kaplan RM, Felitti V. The evaluation of two methods to facilitate shared decision making for men considering the prostate-specific antigen test. *J Gen Intern Med*. 2001;16:391-398.
- (7) Greene AL, Torio CM, Klassen AC. Measuring sustained mammography use by urban African-American women. *J Community Health*. 2005;30:235-251.
- (8) Shell R, Tudiver F. Barriers to cancer screening by rural Appalachian primary care providers. *J Rural Health*. 2004;20:368-373.
- (9) Bruera E, Sweeney C, Calder K, Palmer L, Benisch-Tolley S. Patient preferences versus physician perceptions of treatment decisions in cancer care. *J Clin Oncol*. 2001;19:2883-2885.
- (10) Buchanan J, Borland R, Cosolo W, et al. Patients' beliefs about cancer management. *Support Care Cancer*. 1996;4:110-117.
- (11) Davison BJ, Parker PA, Goldenberg SL. Patients' preferences for communicating a prostate cancer diagnosis and participating in medical decision-making. *BJU Int*. 2004;93:47-51.
- (12) Janz NK, Wren PA, Copeland LA, et al. Patient-physician concordance: preferences, perceptions, and factors influencing the breast cancer surgical decision. *J Clin Oncol*. 2004;22:3091-3098.
- (13) Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and decision-making preferences of hospitalized adult cancer patients. *Soc Sci Med*. 1988;27:1139-1145.

- (14) Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? *J Clin Epidemiol.* 1992;45:941-950.
- (15) Sutherland HJ, Llewellyn-Thomas HA, Lockwood GA, Trichter DL, Till JE. Cancer patients: their desire for information and participation in treatment decisions. *J Roy Soc Med.* 1989;82:260-263.
- (16) Davison BJ, Degner LF, Morgan TR. Information and decision-making preferences of men with prostate cancer. *Oncol Nurs Forum.* 1995;22:1401-1408.
- (17) Butow PN, Maclean M, Dunn SM, Tattersall MH, Boyer MJ. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann Oncol.* 1997;8:857-863.
- (18) Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. *JAMA.* 1997;277:1485-1492.
- (19) Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med.* 1980;92:832-836.
- (20) Janz NK, Mujahid M, Lantz PM, et al. Population-based study of the relationship of treatment and sociodemographics on quality of life for early stage breast cancer. *Qual Life Res.* 2005;14:1467-1479.
- (21) Hack TF, Degner LF, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Soc Sci Med.* 1994;39:279-289.
- (22) Salkeld G, Solomon M, Short L, Butow PN. A matter of trust—patient's views on decision-making in colorectal cancer. *Health Expect.* 2004;7:104-114.
- (23) Davis TC, Williams MV, Marin E, Parker RM, Glass J. Health literacy and cancer communication. *CA Cancer J Clin.* 2002;52:134-149.
- (24) Kim SP, Knight SJ, Tomori C, et al. Health literacy and shared decision making for prostate cancer patients with low socioeconomic status. *Cancer Invest.* 2001;19:684-691.
- (25) Fallowfield L. Offering choice of surgical treatment to women with breast cancer. *Patient Educ Couns.* 1997;30:209-214.
- (26) Butow P. The importance of communication skills to effective cancer care and support. *N S W Public Health Bull.* 2001;12:272-274.
- (27) Bruera E, Willey JS, Palmer JL, Rosales M. Treatment decisions for breast carcinoma: patient preferences and physician perceptions. *Cancer.* 2002;94:2076-2080.
- (28) Morris J, Royle GT. Offering patients a choice of surgery for early breast cancer: a reduction in anxiety and depression in patients and their husbands. *Soc Sci Med.* 1988;26:583-585.
- (29) Fallowfield LJ, Baum M. Psychological welfare of patients with breast cancer. *J Roy Soc Med.* 1989;82:4-5.
- (30) Jansen SJ, Otten W, van de Velde C, Nortier JW, Stiggelbout AM. The impact of the perception of treatment choice on satisfaction with treatment, experienced chemotherapy burden and current quality of life. *Br J Cancer.* 2004;91:56-61.
- (31) Street RL Jr, Voigt B. Patient participation in deciding breast cancer treatment and subsequent quality of life. *Med Decis Mak.* 1997;17:298-306.
- (32) 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.
- (33) Gattellari M, Butow PN, Tattersall MH. Sharing decisions in cancer care. *Soc Sci Med.* 2001;52:1865-1878.
- (34) Whelan T, O'Brien MA, Villasis-Keever M, et al. Impact of cancer-related decision aids. *Evid Rep Technol Assess (Summ).* 2002;1-4.
- (35) 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.
- (36) Street RL Jr, Voigt B, Geyer C Jr, Manning T, Swanson GP. Increasing patient involvement in choosing treatment for early breast cancer. *Cancer.* 1995;76:2275-2285.
- (37) Maly RC, Leake B, Silliman RA. Breast cancer treatment in older women: impact of the patient-physician interaction. *J Am Geriatr Soc.* 2004;52:1138-1145.
- (38) Liang W, Burnett CB, Rowland JH, et al. Communication between physicians and older women with localized breast cancer: implications for treatment and patient satisfaction. *J Clin Oncol.* 2002;20:1008-1016.
- (39) Molenaar S, Oort F, Sprangers M, et al. Predictors of patients' choices for breast-conserving therapy or mastectomy: a prospective study. *Br J Cancer.* 2004;90:2123-2130.
- (40) Verhoef MJ, White MA. Factors in making the decision to forgo conventional cancer treatment. *Cancer Pract.* 2002;10:201-207.

- (41) Passalacqua R, Caminiti C, Salvagni S, et al. Effects of media information on cancer patients' opinions, feelings, decision-making process and physician-patient communication. *Cancer*. 2004;100:1077-1084.
- (42) Charles C, Gafni A, Whelan T, O'Brien MA. Treatment decision aids: conceptual issues and future directions. *Health Expect*. 2005;8:114-125.
- (43) Edwards A, Evans R, Elwyn G. Manufactured but not imported: new directions for research in shared decision making support and skills. *Patient Educ Couns*. 2003;50:33-38.
- (44) Henman MJ, Butow PN, Brown RF, Boyle F, Tattersall MH. Lay constructions of decision-making in cancer. *Psychooncology*. 2002;11:295-306.
- (45) 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.
- (46) de Haes H, Teunissen S. Communication in palliative care: a review of recent literature. *Curr Opin Oncol*. 2005;17:345-350.
- (47) Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004;291:88-93.
- (48) Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284:2476-2482.
- (49) Rothenbacher D, Lutz MP, Porzolt F. Treatment decisions in palliative cancer care: patients' preferences for involvement and doctors' knowledge about it. *Eur J Cancer*. 1997;33:1184-1189.
- (50) Virmani J, Schneiderman LJ, Kaplan RM. Relationship of advance directives to physician-patient communication. *Arch Intern Med*. 1994;154:909-913.
- (51) Patrick DL, Curtis JR, Engelberg RA, Nielsen E, McCown E. Measuring and improving the quality of dying and death. *Ann Intern Med*. 2003;139:410-415.
- (52) Weissman DE. Decision making at a time of crisis near the end of life. *JAMA*. 2004;292:1738-1743.
- (53) Clayton JM, Butow PN, Tattersall MH. The needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end-of-life issues. *Cancer*. 2005;103:1957-1964.
- (54) Back AL. How should physicians communicate the transition to palliative care? *Nat Clin Pract Oncol*. 2005;2:136-137.
- (55) 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.
- (56) Committee on Care at the End of Life. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academies Press; 1997.
- (57) Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Role of health-related quality of life in palliative chemotherapy treatment decisions. *J Clin Oncol*. 2002;20:1056-1062.
- (58) Emanuel EJ, Young-Xu Y, Levinsky NG, et al. Chemotherapy use among Medicare beneficiaries at the end of life. *Ann Intern Med*. 2003;138:639-643.
- (59) Foley KM, Gelband H. *Improving Palliative Care for Cancer: Summary and Recommendations*. Washington, DC: National Academies Press; 2001.
- (60) Gabbay BB, Matsumura S, Etzioni S, et al. Negotiating end-of-life decision making: a comparison of Japanese and U.S. residents' approaches. *Acad Med*. 2005;80:617-621.
- (61) Baile WF, Globler GA, Lenzi R, Beale EA, Kudelka AP. Discussing disease progression and end-of-life decisions. *Oncology (Williston Park)*. 1999;13:1021-1031.
- (62) Fox R. *Experiment Perilous: Physicians and Patients Facing the Unknown*. Glencoe, IL: Free Press; 1959.
- (63) Quill TE, Suchman AL. Uncertainty and control: learning to live with medicine's limitations. *Humane Med*. 1993;9:109-120.
- (64) Jenkins C, Lapelle N, Zapka JG, Kurent JE. End-of-life care and African Americans: voices from the community. *J Palliat Med*. 2005;8:585-592.
- (65) Silveira MJ, DiPiero A, Gerrity MS, Feudtner C. Patients' knowledge of options at the end of life: ignorance in the face of death. *JAMA*. 2000;284:2483-2488.
- (66) Gattellari M, Voigt KJ, Butow PN, Tattersall MH. When the treatment goal is not cure: are cancer patients equipped to make informed decisions? *J Clin Oncol*. 2002;20:503-513.
- (67) Clayton J, Butow P, Tattersall M, et al. Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients. *Br J Cancer*. 2003;89:2069-2077.
- (68) Ditto PH, Hawkins NA. Advance directives and cancer decision making near

the end of life. *Health Psychol.* 2005;24: S63-S70.

(69) Hawkins NA, Ditto PH, Danks JH, Smucker WD. Micromanaging death: process preferences, values, and goals in end-of-life medical decision making. *Gerontologist.* 2005;45:107-117.

(70) Winzelberg GS, Hanson LC, Tulsy JA. Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. *J Am Geriatr Soc.* 2005;53:1046-1050.

(71) Sehgal A, Galbraith A, Chesney M, et al. How strictly do dialysis patients want their advance directives followed? *JAMA.* 1992;267:59-63.

(72) Zweibel NR, Cassel CK. Treatment choices at the end of life: a comparison of decisions by older patients and their physician-selected proxies. *Gerontologist.* 1989;29:615-621.

(73) Emanuel LL, Emanuel EJ, Stoeckle JD, Hummel LR, Barry MJ. Advance directives. Stability of patients' treatment choices. *Arch Intern Med.* 1994;154:209-217.

(74) Allison PJ, Guichard C, Fung K, Gilain L. Dispositional optimism predicts survival status 1 year after diagnosis in head and neck cancer patients. *J Clin Oncol.* 2003;21:543-548.

(75) Ubel PA. "What should I do, doc?": Some psychologic benefits of physician recommendations. *Arch Intern Med.* 2002;162:977-980.

(76) Kelner M. Activists and delegators: elderly patients' preferences about control at the end of life. *Soc Sci Med.* 1995;41:537-545.

(77) Hofmann JC, Wenger NS, Davis RB, et al. Patient preferences for communication with physicians about end-of-life decisions. *Ann Intern Med.* 1997;127:1-12.

(78) Haidet P, Hamel MB, Davis RB, et al. Outcomes, preferences for resuscitation, and physician-patient communication among patients with metastatic colorectal cancer. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Am J Med.* 1998;105:222-229.

(79) Tulsy JA, Fischer GS, Rose MR, Arnold RM. Opening the black box: how do physicians communicate about advance directives? *Ann Intern Med.* 1998;129:441-449.

(80) Fischer GS, Tulsy JA, Rose MR, Siminoff LA, Arnold RM. Patient knowledge and physician predictions of treatment preferences after discussion of advance directives. *J Gen Intern Med.* 1998;13:447-454.

(81) Carrese JA, Rhodes LA. Western bioethics on the Navajo reservation. Benefit or harm? *JAMA.* 1995;274:826-829.

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

(83) Lang F, Quill T. Making decisions with families at the end of life. *Am Fam Physician.* 2004;70:719-723.

(84) Back AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington State. Patient requests and physician responses. *JAMA.* 1996;275:919-925.

(85) Emanuel EJ, Fairclough D, Clarridge BC, et al. Attitudes and practices of U.S. oncologists regarding euthanasia and physician-assisted suicide. *Ann Intern Med.* 2000;133:527-532.

(86) Quill TE. Opening the black box: physicians' inner responses to patients' requests for physician-assisted death. *J Palliat Med.* 2004;7:469-471.

(87) Emanuel LL. Facing requests for physician-assisted suicide: toward a practical and principled clinical skill set. *JAMA.* 1998;280:643-647.

(88) Tulsy JA, Ciampa R, Rosen EJ. Responding to legal requests for physician-assisted suicide. University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. *Ann Intern Med.* 2000;132:494-499.

(89) Kohlwes RJ, Koepsell TD, Rhodes LA, Pearlman RA. Physicians' responses to patients' requests for physician-assisted suicide. *Arch Intern Med.* 2001;161:657-663.

(90) Back AL, Starks H, Hsu C, et al. Clinician-patient interactions about requests for physician-assisted suicide: a patient and family view. *Arch Intern Med.* 2002;162:1257-1265.

Interventions to Improve Communication between Patients with Cancer and Clinicians

Encounters between clinicians and patients with cancer are complex. Such experiences are often emotion-laden, and the participants must discuss a complex array of diagnostic and treatment information. As a result, many clinicians have expressed the need for communication skills training to help them, their patients, and their patients' families have more positive, productive encounters.^{1,2} Research to date has focused on three issues: communication skills training for clinicians (mostly for physicians and nurses), cultural competency training, and communication skills training for patients. Very little research has been conducted to determine how interventions focused on changing the structure of clinical practices and health care systems may affect communication and related outcomes.

E.1 Communication Skills Training for Clinicians

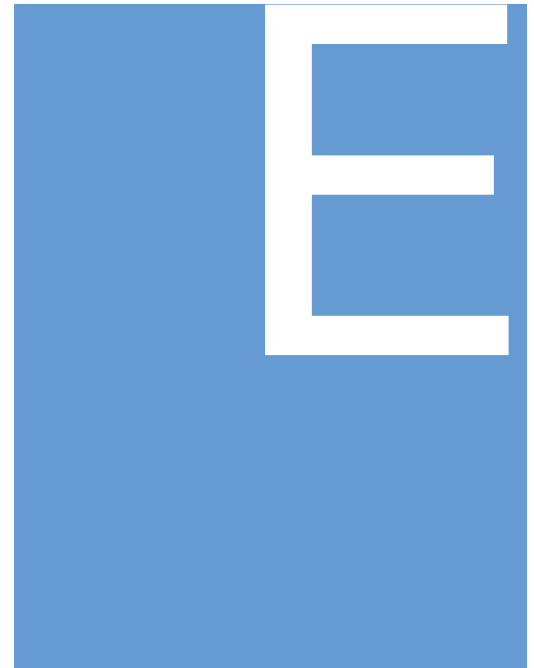
In cancer care, clinicians have a number of communication tasks that must be accomplished skillfully. According to Beckman and Frankel,³ these include the following:

- Delivering bad news
- Helping patients make truly informed choices

- Effectively working with families
- Facilitating the transition to palliative care
- Ensuring that end-of-life care honors the patient's requests
- Working with grief

Clinicians generally feel more comfortable discussing diagnosis and treatment than emotional and psychological issues.⁴ Even the management of information is challenging; patients with cancer typically report that they want to know all the available information about their type of cancer and its treatment⁵ yet are often overwhelmed by the sheer amount of information provided by clinicians, the mass media, and the Internet.⁶

Various communication training programs for clinicians have been described and evaluated in several studies. Typically, clinicians report that they find these programs to be satisfying and meaningful and to result in more confidence in handling difficult communication issues with patients who have cancer.⁷⁻¹¹ For example, in one study, before beginning a communication skills training program, oncologists expressed difficulty with a number of communication issues, such as giving complex information, obtaining informed consent, and handling cultural differences. Three months after the three-day



course, physicians reported having greater confidence in handling these matters, a more positive attitude toward patients' psychosocial needs, and a more patient-centered orientation.^{12,13}

Other studies have focused on the effectiveness of interventions to teach clinicians emotion-management skills, such as expressing empathy, responding to patient cues, and handling psychological distress.¹⁴ A recent review of randomized controlled trials and controlled before and after studies designed to assess the effectiveness of communication skill programs demonstrated that physicians and nurses improved on several patient-centered skills, including communicating empathy, using open-ended questions, and providing appropriate responsiveness to patient cues. These improvements were sustained over several weeks.¹⁵ With the proper training, improvements in communication skills can be sustained over longer periods. In one study, 12 months following a physician intervention, there was no noticeable attrition in physicians' improvement in the use of open-ended questions and responsiveness to patient cues (although there was a decline in empathy).¹⁶ The physicians also interrupted less and made more of an effort to summarize information for patients, skills that had not been observed immediately following training. In a Japanese study, oncologists' confidence in communicating with patients increased significantly after train-

ing, but the oncologists' emotional exhaustion worsened three months after the workshop.¹⁷ This study raises the possibility that although communication training may increase clinicians' skills in patient-centered communication in cancer care, it may have the unintended consequence of adding to the clinician's stress.

Other interventions have specifically focused on the effects of training to uncover and discuss emotional distress in patients with cancer. In one study, nurses trained in ways to discuss and handle patients' emotions were indeed able to elicit more affective communication from patients than were untrained nurses.¹⁸ In another study, nurses trained to address the emotional content of medical encounters used more words related to emotions immediately and three months after training compared with a control group.¹⁹ Communication interventions for clinicians have also been linked to patients' perceptions of quality of care. Patients of trained physicians reported that they understood their disease better,²⁰ felt less depressed, and believed they were more in control than did patients whose physicians did not have training.²¹ In the most recent study, physicians who participated in an intensive training program (a series of six three-hour workshops) used more open-ended questions and were more effective at eliciting and clarifying the psychological concerns of simulated patients than were physicians who participated in a less intensive training

program.²² Moreover, patients (but not necessarily their relatives) were more satisfied with the physicians who received the more intensive training.

Although most studies have demonstrated improved communication skills following training, a few have had negative findings. A training program designed to increase physicians' ability to detect patients' distress led to no significant differences between those who participated in the workshops and the control group.²³ Instead, physicians' ability to assess patients' distress was negatively associated with patients' education level and self-reported distress both before and after the intervention. A study of nurses indicated that an intervention designed to help detect psychological difficulties in patients with cancer was successful in enhancing the detection of difficulties, but few of the patients were referred to psychological services. Unfortunately, there was no follow-up on patient health outcomes.²⁴ In another study, patient satisfaction associated with a physician communication training program was attenuated because of practical problems, such as waiting too long to see the physician.²⁵ These studies point to the possibility that system and organizational barriers can hinder the effectiveness of communication training programs.

It is also worth noting that the studies reviewed here generally focused on skills training for cancer consultations in general, but

other programs have been developed for more specific tasks and patient populations, including breaking bad news,²⁶⁻²⁸ genetic counseling,²⁹ management of pain,³⁰ and communicating with patients with limited literacy.³¹

The most effective training programs for clinicians are those that^{32,33}

- Are carried out over a long period of time
- Use multiple pedagogical methods
- Allow for rehearsal
- Provide timely feedback
- Allow clinicians to work in groups with skilled facilitators

Moreover, because clinicians develop routines for interacting with patients, communication training interventions should be introduced early in the medical school curriculum. Such interventions have been successful. In one program for students in which patients with cancer were enlisted as part of an educational program, students in the intervention group valued listening, trust, and showing concern for patients to a greater degree than did students who did not participate in the program.³⁴ Although three to five-day training courses can contribute to behavior and attitude change in students, these workshops may not be as effective as incorporating communication skills development throughout the medical and nursing curriculum.

E.2 Cultural Competency Training for Clinicians

We include cultural competence within this section on communication skills interventions because the construct has evolved beyond an awareness of language barriers and the ways cultures differ to the implementation of patient-centered communication (e.g., empathy and responsiveness to patients' values and preferences).^{35,36} According to Paasche-Orlow,³⁷ the essential principles of cultural competence are the following:

- Acknowledgment of the importance of culture in people's daily lives
- Acceptance and respect for these differences
- Minimization of the negative effects of cultural differences

Clinicians and patients must adhere to these principles in order to communicate effectively. Cultural competency is important at all points across the cancer care continuum—during cancer screening, the informed consent process, decision-making about treatment after diagnosis, and palliative care.³⁸ Despite the need for programs in cultural competency,³⁹⁻⁴¹ very few of these programs have been developed or evaluated to date.

The challenges facing cultural competence training are manifold. Most medical students are not highly culturally competent with respect to understanding health disparities, stereotyping, and cultural differences in communication styles.⁴² When patients and clini-

cians discuss cultural barriers in health care, each often has different conceptions of what cultural competence entails.⁴³ Nevertheless, a recent review of the published research on cultural competency training indicated that these programs generally increase clinicians' knowledge of cultural issues and their communication skills when interacting with diverse patients and that patients report greater satisfaction with such clinicians.⁴⁴ However, there has been little indication to date that this education contributes to greater patient adherence and improved health outcomes. We suspect that, like communication skills training, the most effective cultural competency education will be programs that provide intensive education before, during, and after clinical training⁴⁵ and that involve multiple pedagogical methods (role-playing, feedback, simulated patients, group discussion). Moreover, having culturally competent clinicians is but one requirement for a culturally responsive health care system. Patients and clinicians also must be supported with staff and practitioners who reflect the community served, with linguistically and culturally appropriate health education materials, and with access to interpreters when needed.⁴⁶

E.3 Communication Skills Training for Patients

Patients, too, play an important role in the success of clinical encounters in cancer settings. The key premise underlying patient "activation" or communication

skills interventions is to increase patient participation in the consultation and, if they desire, to enhance their involvement in decision-making. The current research has shown that the most successful “patient activation” interventions are those that⁴⁷⁻⁴⁹

- Promote the legitimacy of the patient’s participation in care
- Provide information about the patient’s health condition and treatment options
- Provide specific communication strategies and behaviors for patients to use in their interactions with clinicians
- Deliver the intervention in a timely fashion so that the patient has an opportunity to act on behavioral intentions resulting from the program

Patients in gynecology clinics who were advised to write down specific questions and take the list into the consultation reported that they had asked more of the questions they wanted to, felt more in control, and were more satisfied with the information they had received.⁵⁰ With another intervention, patients were explicitly encouraged to be active information seekers and were advised to write down specific questions and concerns before the visit with their physician.⁵¹ Patients who received the intervention asked significantly more questions and had better recall of the information provided by physicians than did patients not receiving the intervention. It has been shown that having patients

watch video recordings of role models successfully asking questions and introducing topics for discussion also increases patient participation.⁵² It is important to note that the effectiveness of these interventions may depend in part on providing patients with specific skills and goals for the encounter.⁵³⁻⁵⁵ Simply encouraging patients to be more involved may not sufficiently help them overcome barriers to participation. In addition, interventions are more effective if the physician has a positive attitude toward patient participation.⁵⁶

There is a large body of literature on the use of decision aids to inform patients about their type of disease and help them identify their treatment preferences,⁵⁷ and several studies have involved the evaluation of decision aids designed to enhance patient communication and participation in cancer consultations. The findings of many studies of aids to facilitate the involvement of patients with cancer in the decision-making process have demonstrated that patients receiving these interventions had greater knowledge about the surgical treatment of breast cancer, assumed a more active role in the process, had less decisional conflict, and were more satisfied with the decision-making process.^{58,59} In contrast, some studies have indicated less success with interventions designed to help patients in the decision-making process. For example, Davison and Degner⁶⁰ reported that, paradoxically, women with breast cancer who used computer-assisted education designed to promote their

involvement in decision-making actually participated less than the control group. Women in the control group completed measures of decision preference before their clinic appointments, whereas women in the intervention group were encouraged to use the information and decision preference profiles generated by the computer program at their clinic appointments. In general, the majority of women in both groups achieved their preferred roles in decision-making, but a higher proportion of women in the intervention group reported playing a more passive role than expected. One potentially moderating factor not examined in this study was the way in which physicians communicated with patients. In another study, women with newly diagnosed early-stage breast cancer⁶¹ either received a multimedia program or an educational brochure; women in both groups achieved significant gains in knowledge about treatment and the two groups did not differ with respect to their rates of participation in decision-making. Rather, as with question prompt sheets, the degree to which patients asked questions, expressed concerns, and offered opinions was related to their age, education, and the extent to which physicians facilitated their involvement. This finding highlights the fact that the clinician’s attitudes toward patient activation and behavior in the consultation likely moderate the effects of patient activation interventions and that the effectiveness of such interventions, in part, depends on physician endorsement.^{61,62}

As noted by Parker et al.,⁶² research on patient-based communication interventions show that a variety of methods (e.g., audio recordings, prompt sheets, coaching) generally work well at increasing patients' information-seeking and decision-making behavior. Yet, in cancer care, how patients manage their emotions and personal meaning of illness are also important. For example, in palliative care, patients' participation may be less focused on medical information and more focused on discussing their experiences and life circumstances.⁶³ Even when interventions are designed to facilitate patients' information-gathering and decision-making behavior, patients may be more interested in sharing their experiences with others rather than learning specific communication skills. In short, these results suggest that interventions designed to foster patient participation in cancer consultations should also focus on facilitating patients' emotional processing of the disease, particularly when it is incurable.

In summary, the research on activation and communication skills training for patients highlights the importance of providing specific communication strategies (e.g., through role models, prompt sheets, and writing down questions and concerns) when interacting with clinicians. Health information and encouragement also facilitate patient participation, but, to be most effective, patient activation interventions

should provide resources to help patients select and enact specific communication tasks. Patients should be encouraged to express emotion and meaning. Providing the education immediately before the consultation is particularly effective because patients can use these communication strategies while they are salient and relevant. It is important to note that, when programs to enhance patient communication are well designed, they can be effective in a variety of media, including pamphlets or booklets,^{50,55} prompt sheets,⁵⁹ video recordings,⁵² multimedia programs,⁶¹ coaching sessions,⁶⁴⁻⁶⁶ or diaries.⁶⁷ However, it is not known how long the effects of the intervention persist or how to simultaneously augment physician endorsement and facilitation of patients' active involvement so that patients' values and experiences are thoroughly discussed and incorporated into actual decisions.

E.4 Interventions at the Team, Practice, and Health Care Systems Levels to Improve Communication between Patients with Cancer and Clinicians

There are very few studies of the effect of changes at the team, practice, and health care systems levels on communication between patients with cancer and clinicians.

Interventions at the team level

Patients normally encounter multiple clinicians during the cancer

trajectory. Observational studies have indicated that clear and respectful communication is an essential quality of well-functioning teams^{68,69} and that these qualities are not always present.⁷⁰ Many researchers have called for improved communication within health care teams,⁷¹ but there are few interventions overall and even fewer in cancer contexts.

Interventions in intensive care settings have had a positive impact on communication and leadership within health care teams,⁶⁸ however, the impact on patients is unknown. Interventions to provide structured written communication between primary care physicians and oncologists⁷⁰ and between general practitioners and oncology nurses⁷² appeared to facilitate information transfer, but a subsequent study showed that a similar intervention had little impact on patient health care and information-seeking behavior.⁷³ The findings of one cohort study suggested that palliative care teams result in better patient insight into their illnesses than standard care,⁷⁴ but the results of a study of a team-building intervention indicated that interventions to improve team functioning may not be effective if there is understaffing.⁷⁵ Patient-held medical records have some promise in improving communication among team members and in facilitating patient understanding,⁷⁶ but effects on communication between clinicians and patients have not been reported. A shared-care intervention to promote teamwork between general practitioners and oncologists appear to influ-

ence patients' attitudes positively,⁷⁷ but, as with many of the studies cited, patient-clinician communication was not evaluated directly.

Interventions at the practice level

In a series of studies, Stange and colleagues⁷⁸⁻⁸² demonstrated that use of individualized interventions at the practice level could increase rates of cancer prevention and screening. These interventions involved research personnel trained in ethnographic and survey methods who would spend from several days to several weeks observing the organization, patient flow, and teamwork in primary care practices. These personnel would then meet regularly with the entire practice to propose changes in the structure of the practices tailored to the particular problems encountered. However, the impact of such interventions on communication between clinicians and patients, and the degree to which the effects of these interventions are mediated by changes in communication, is unknown.

Interventions at the health care systems level

One randomized trial identified problems in the physical layout of a cancer outpatient clinic and developed an intervention to make changes in that layout and to educate staff on communication techniques.⁸³ Patients in the intervention group were more likely to report higher satisfaction with communication, better privacy, fewer interruptions, clearer language, suffi-

cient time, and greater understanding. However, it is not clear whether the change in physical layout or the communication training was responsible for the results.

Systems interventions to facilitate transfer of information between patients and physicians include care diaries in which patients and all members of the health care team could share information,⁶⁷ patient-held medical records,⁷⁶ and direct access by patients to electronic medical records. In one study, patients expressed satisfaction with the care diary approach,⁶⁷ but no other randomized trials have been conducted to assess the effects of these approaches on communication, quality of life, and other outcomes. These interventions present compelling areas for future research.

E.5 Implications for Future Study

The evidence to date suggests that communication training interventions are generally effective for enhancing clinicians' patient-centered behaviors and patients' information-seeking and decision-making skills. In cancer care settings, more attention should be directed at developing programs designed to enhance clinicians' cultural competency and to help patients discuss and manage their emotions and feelings. Despite the promising results of these interventions, such programs have not been implemented system-wide within cancer care settings. Moreover, there is a paucity of research on how changes in the structure of

teams, clinical practices, and health care institutions, as well as use of other system resources—such as Web-based resources, multimedia programs, and electronic medical records—can be used to improve cancer care consultations. Interventions generally have not involved family members and friends, nor have the effects of the intervention on caregivers' well-being been assessed. Interventions have very rarely combined clinician and patient training, despite evidence that lack of physician endorsement can undermine patient interventions that are otherwise successful. Very few interventions incorporate means for reinforcing the effects of the intervention over time. These robust technologies hold much promise for improving patient-clinician communication.⁸⁴

References

- (1) Maguire P, Pitceathly C. Improving the psychological care of cancer patients and their relatives. The role of specialist nurses. *J Psychosom Res.* 2003;55:469-474.
- (2) Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. *Eur J Cancer.* 1999;35:1592-1597.
- (3) Beckman HB, Frankel RM. Training practitioners to communicate effectively in cancer care: it is the relationship that counts. *Patient Educ Couns.* 2003;50:85-89.
- (4) Cantwell BM, Ramirez AJ. Doctor-patient communication: a study of junior house officers. *Med Educ.* 1997;31:17-21.
- (5) Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and decision-making preferences of hospitalized adult cancer patients. *Soc Sci Med.* 1988;27:1139-1145.
- (6) Hoffman J. Awash in information, patients face a lonely, uncertain road. *The New York Times.* August 14, 2005.
- (7) Walley DR, Augustine E, Saslow D, et al. American Cancer Society Lymphedema Workshop. Workgroup IV: Lymphedema treatment resources—professional education and availability of patient services. *Cancer.* 1998;83:2886-2887.
- (8) Hoffman M, Steinberg M. Development and implementation of a curriculum in communication skills and psycho-oncology for medical oncology fellows. *J Cancer Educ.* 2002;17:196-200.
- (9) Grassi L, Travado L, Gil F, et al. A communication intervention for training southern European oncologists to recognize psychosocial morbidity in cancer. I—development of the model and preliminary results on physicians' satisfaction. *J Cancer Educ.* 2005;20:79-84.
- (10) Faulkner A. Using simulators to aid the teaching of communication skills in cancer and palliative care. *Patient Educ Couns.* 1994;23:125-129.
- (11) Donovan T, Hutchison T, Kelly A. Using simulated patients in a multiprofessional communications skills programme: reflections from the programme facilitators. *Eur J Cancer Care.* 2003;12:123-128.
- (12) Fallowfield L, Lipkin M, Hall A. Teaching senior oncologists communication skills: results from phase I of a comprehensive longitudinal program in the United Kingdom. *J Clin Oncol.* 1998;16:1961-1968.
- (13) Jenkins V, Fallowfield L. Can communication skills training alter physicians' beliefs and behavior in clinics? *J Clin Oncol.* 2002;20:765-769.
- (14) Booth K, Maguire P, Hillier VF. Measurement of communication skills in cancer care: myth or reality? *J Adv Nurs.* 1999;30:1073-1079.
- (15) Fellowes D, Wilkinson S, Moore P. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Systematic Review.* 2004.
- (16) 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;89:1445-1449.
- (17) Fujimori M, Oba A, Koike M, et al. Communication skills training for Japanese oncologists on how to break bad news. *J Cancer Educ.* 2003;18:194-201.
- (18) Kruijver IP, Kerkstra A, Kerssens JJ, et al. Communication between nurses and simulated patients with cancer: evaluation of a communication training programme. *Eur J Oncol Nurs.* 2001;5:140-150, 151-153.
- (19) Razavi D, Delvaux N, Marchal S, et al. Does training increase the use of more emotionally laden words by nurses when talking with cancer patients? A randomised study. *Br J Cancer.* 2002;87:1-7.
- (20) Razavi D, Merckaert I, Marchal S, et al. How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of posttraining consolidation workshops. *J Clin Oncol.* 2003;21:3141-3149.
- (21) Rutter DR, Iconomou G, Quine L. Doctor-patient communication and outcome in cancer patients: an intervention. *Psychol Health.* 1996;12:57-71.
- (22) Delvaux N, Merckaert I, Marchal S, et al. Physicians' communication with a cancer patient and a relative: a randomized study assessing the efficacy of consolidation workshops. *Cancer.* 2005;103:2397-2411.
- (23) Merckaert I, Libert Y, Delvaux N, et al. Factors that influence physicians' detection of distress in patients with cancer: can a communication skills training program improve physicians' detection? *Cancer.* 2005;104:411-421.
- (24) Parle M, Gallagher J, Gray C, Akers G, Liebert B. From evidence to practice: factors affecting the specialist breast nurse's detection of psychological morbidity in women with breast cancer. *Psychooncology.* 2001;10:503-510.
- (25) Shilling V, Jenkins V, Fallowfield L. Factors affecting patient and clinician satisfaction with the clinical consultation: can communication skills training for cli-

nicians improve satisfaction?
Psychooncology. 2003;12:599-611.

(26) Abel J, Dennison S, Senior-Smith G, et al. Breaking bad news—development of a hospital-based training workshop. *Lancet Oncol*. 2001;2:380-384.

(27) Knox JD, Thomson GM. Breaking bad news: Medical undergraduate communication skills teaching and learning. *Med Educ*. 1989;23:258-261.

(28) Baile WF, Kudelka AP, Beale EA, et al. Communication skills training in oncology. Description and preliminary outcomes of workshops on breaking bad news and managing patient reactions to illness. *Cancer*. 1999;86:887-897.

(29) Daly MB, Barsevick A, Miller SM, et al. Communicating genetic test results to the family: A six-step, skills-building strategy. *Fam Community Health*. 2001;24:13-26.

(30) Loscalzo MJ, Bucher JA. The COPE model: Its clinical usefulness in solving pain-related problems. *J Psychosoc Oncol*. 1999;16:93-117.

(31) Plomer K, Schneider L, Barley G, Cifuentes M, Dignan M. Improving medical students' communication with limited-literacy patients: project development and implementation. *J Cancer Educ*. 2001;16:68-71.

(32) Gysels M, Richardson A, Higginson IJ. Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care Cancer*. 2005;13:356-366.

(33) Rath D, Poldre P, Fisher BJ, et al. Commitment of a cancer organization to a program for training in communication skills. *J Cancer Educ*. 1998;13:203-206.

(34) Klein S, Tracy D, Kitchener HC, Walker LG. The effects of the participation of patients with cancer in teaching communication skills to medical undergraduates: a randomised study with follow-up after 2 years. *Eur J Cancer*. 2000;36:273-281. [republished from *Eur J Cancer*. 1999;35:1448-1456].

(35) Betancourt JR. Cultural competence—marginal or mainstream movement? *N Engl J Med*. 2004;351:953-955.

(36) Fox RC. Cultural competence and the culture of medicine. *N Engl J Med*. 2005;353:1316-1319.

(37) Paasche-Orlow M. The ethics of cultural competence. *Acad Med*. 2004;79:347-350.

(38) Simon CM, Kodish ED. Step into my zapatos, doc: understanding and reducing communication disparities in the multi-cultural informed consent setting. *Perspect Biol Med*. 2005;48:S123-S138.

(39) Ramirez AG. Consumer-provider communication research with special populations. *Patient Educ Couns*. 2003;50:51-54.

(40) Kagawa-Singer M. Addressing issues for early detection and screening in ethnic populations. *Oncol Nurs Forum*. 1997;24:1705-1711.

(41) Cooley ME, Jennings-Dozier K. Cultural assessment of black American men treated for prostate cancer: clinical case studies. *Oncol Nurs Forum*. 1998;25:1729-1736.

(42) Bussey-Jones J, Genao I, St George DM, Corbie-Smith G. Knowledge of cultural competence among third-year medical students. *J Natl Med Assoc*. 2005;97:1272-1276.

(43) Shapiro J, Hollingshead J, Morrison EH. Primary care resident, faculty, and patient views of barriers to cultural competence, and the skills needed to overcome them. *Med Educ*. 2002;36:749-759.

(44) Beach MC, Hill-Briggs F, Cooper LA. Racial and ethnic differences in receipt and use of health information in encounters between patients and physicians. *Med Care*. 2006;44:97-99.

(45) Horner RD, Salazar W, Geiger HJ, et al. Changing healthcare professionals' behaviors to eliminate disparities in healthcare: What do we know? How might we proceed? *Am J Manag Care*. 2004;10 Spec No:SP12-SP19.

(46) Anderson LM, Scrimshaw SC, Fullilove MT, Fielding JE, Normand J. Culturally competent healthcare systems. A systematic review. *Am J Prev Med*. 2003;24:68-79.

(47) Street RL Jr, Gordon HS, Ward MM, Krupat E, Kravitz RL. Patient participation in medical consultations: why some patients are more involved than others. *Med Care*. 2005;43:960-969.

(48) Cegala DJ. Patient communication skills training: a review with implications for cancer patients. *Patient Educ Couns*. 2003;50:91-94.

(49) Post DM, Cegala DJ, Miser WF. The other half of the whole: teaching patients to communicate with physicians. *Fam Med*. 2002;34:344-352.

(50) Thompson SC, Nanni C, Schwankovsky L. Patient-oriented interventions to improve communication in a medical office visit. *Health Psychol*. 1990;9:390-404.

(51) McGee DS, Cegala DJ. Patient communication skills training for

improved communication competence in the primary care medical consultation. *J Appl Commun Res.* 1998;26:412-430.

(52) Anderson LA, Devellis BM, DeVellis RF. Effects of modeling on patient communication, satisfaction, and knowledge. *Med Care.* 1987;25:1044-1056.

(53) Butow PN, Dunn SM, Tattersall MH, Jones QJ. Patient participation in the cancer consultation: evaluation of a question prompt sheet. *Ann Oncol.* 1994;5:199-204.

(54) Cegala DJ, McClure L, Marinelli TM, Post DM. The effects of communication skills training on patients' participation during medical interviews. *Patient Educ Couns.* 2000;41:209-222.

(55) Robinson EJ, Whitfield MJ. Improving the efficiency of patients' comprehension monitoring: a way of increasing patients' participation in general practice consultations. *Soc Sci Med.* 1985;21:915-919.

(56) Butow P, Devine R, Boyer M, et al. Cancer consultation preparation package: changing patients but not physicians is not enough. *J Clin Oncol.* 2004;22:4401-4409.

(57) O'Connor AM, Stacey D, Rovner D, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Systematic Review.* 2001.

(58) Whelan T, Levine M, Willan A, et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. *JAMA.* 2004;292:435-441.

(59) Davison BJ, Degner LF. Empowerment of men newly diagnosed with prostate cancer. *Cancer Nurs.* 1997;20:187-196.

(60) Davison BJ, Degner LF. Feasibility of using a computer-assisted intervention to enhance the way women with breast cancer communicate with their physicians. *Cancer Nurs.* 2002;25:417-424.

(61) Street RL Jr, Voigt B, Geyer C Jr, Manning T, Swanson GP. Increasing patient involvement in choosing treatment for early breast cancer. *Cancer.* 1995;76:2275-2285.

(62) Parker PA, Davison BJ, Tishelman C, Brundage MD. What do we know about facilitating patient communication in the cancer care setting? *Psychooncology.* 2005;14:848-858.

(63) Timmermans LM, van der Maazen RW, Verhaak CM, et al. Patient participation in discussing palliative radiotherapy. *Patient Educ Couns.* 2005;57:53-61.

(64) Sepucha KR, Belkora JK, Mutchnick S, Esserman LJ. Consultation planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians. *J Clin Oncol.* 2002;20:2695-2700.

(65) Greenfield S, Kaplan S, Ware JE Jr. Expanding patient involvement in care. Effects on patient outcomes. *Ann Intern Med.* 1985;102:520-528.

(66) Rost KM, Flavin KS, Cole K, McGill JB. Change in metabolic control and functional status after hospitalization. Impact of patient activation intervention in diabetic patients. *Diabetes Care.* 1991;14:881-889.

(67) Sharp L, Laurell G, Tiblom Y, Andersson A, Birksjo RM. Care diaries: a way of increasing head and neck cancer patient's involvement in their own care and the communication between clinicians. *Cancer Nurs.* 2004;27:119-126.

(68) Boyle FM, Robinson E, Heinrich P, Dunn SM. Cancer: communicating in the team game. *ANZ J Surg.* 2004;74:477-481.

(69) Carline JD, Curtis JR, Wenrich MD, et al. Physicians' interactions with health care teams and systems in the care of dying patients: perspectives of dying patients, family members, and health care professionals. *J Pain Symptom Manage.* 2003;25:19-28.

(70) Braun TC, Hagen NA, Smith C, Summers N. Oncologists and family physicians. Using a standardized letter to improve communication. *Can Fam Physician.* 2003;49:882-886.

(71) Wood ML, McWilliam CL. Cancer in remission. Challenge in collaboration for family physicians and oncologists. *Can Fam Physician.* 1996;42:899-904.

(72) Jaafar F, Davison AG, Beaty T, et al. Increasing social and psychological information conveyed to general practitioners after bad news consultations by use of separate letters from the lung cancer nurse specialist. *Lung Cancer.* 2004;46:57-59.

(73) Luker K, Beaver K, Austin L, Leinster SJ. An evaluation of information cards as a means of improving communication between hospital and primary care for women with breast cancer. *J Adv Nurs.* 2000;31:1174-1182.

(74) Jack B, Hillier V, Williams A, Oldham J. Hospital based palliative care teams improve the insight of cancer patients into their disease. *Palliat Med.* 2004;18:46-52.

(75) Donaghy K, Devlin B. An evaluation of teamwork within a specialist palliative care unit. *Int J Palliat Nurs.* 2002;8:518-525.

(76) Hooker L, Williams J. Parent-held shared care records: bridging the communication gaps. *Br J Nurs*. 1996;5:738-741.

(77) Nielsen JD, Palshof T, Mainz J, Jensen AB, Olesen F. Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital. *Qual Safety Health Care*. 2003;12:263-272.

(78) Stange KC. One size doesn't fit all. Multimethod research yields new insights into interventions to increase prevention in family practice. *J Fam Pract*. 1996;43:358-360.

(79) 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.

(80) Stroebel CK, McDaniel RR Jr, Crabtree BF, et al. How complexity science can inform a reflective process for improvement in primary care practices. *Jt Com J Qual Patient Saf*. 2005;31:438-446.

(81) Ruhe MC, Weyer SM, Zronek S, et al. Facilitating practice change: lessons from the STEP-UP clinical trial. *Prev Med*. 2005;40:729-734.

(82) Cohen D, McDaniel RR Jr, Crabtree BF, et al. A practice change model for quality improvement in primary care practice. *J Health Manage*. 2004;49:155-168, 169-170.

(83) Nayak S, Pradhan JP, Reddy S, et al. Cancer patients' perception of the quality of communication before and after the implementation of a communication strategy in a regional cancer center in India. *J Clin Oncol*. 2005;23:4771-4775.

(84) Street RL Jr. Mediated consumer-provider communication in cancer care: the empowering potential of new technologies. *Patient Educ Couns*. 2003;50:99-104.

Survey Instruments Used to Measure Patient and Clinician Communication Behavior in Cancer Settings



Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured†
Ajaj A, et al. <i>BMJ</i> . 2001; 323:1160	—	Patient preference for level of information desired if diagnosed with cancer ¹
Argyris C. <i>Knowledge for Action: A Guide to Overcoming Barriers to Organization Change</i> . San Francisco, CA: Jossey-Bass; 1993 Argyris C (ed). <i>On Organizational Learning</i> . Cambridge, UK: Blackwell; 1992	—	Patient report of why the appointment was scheduled, what he/she intends to say or do in the appointment, and what thoughts or feelings he or she intends to share with the physician ²
Ashworth CD, et al. <i>Soc Sci Med</i> . 1984;19:1235-1238	Physician Psychosocial Beliefs Scale (PPBS)	Physician beliefs about psychosocial aspects of patient care ^{3,4}
Baile WF, et al. <i>J Cancer Educ</i> . 1997;12:166-173	—	Physician self-appraisal of communication skills ⁵
Baile WF, et al. <i>J Clin Oncol</i> . 2002;20:2189-2196	—	Physician attitudes and practices in disclosing information to patients with advanced disease ⁶

*Author given only if different from first author of citation for instrument (in left column).

†References indicate studies in which the survey instrument was used in the cancer setting.

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured†
Barnett M, McMichael H. <i>J Cancer Care.</i> 1992;1:145-149	Words Emotionally Related to Dying (WERD) (adapted from Henbest and Stewart)	Clinician rating of difficult or bad news scenarios as being centered on the disease, physician, or patient ³
Berlin L. <i>Brainstorming Sessions Summary Report.</i> Palo Alto, CA, Community Breast Health Project; 1994 (www-med.stanford.edu/CBHP/Brainstorming.html)	Community Breast Health Project Scale of Communication Barriers	Patient perceptions of communication barriers with physician ²
Blanchard CG, et al. <i>Soc Sci Med.</i> 1988;27:1139-1145	—	Patient preferences for types of information ⁷
Butow P, et al. <i>J Clin Oncol.</i> 2004;22:4401-4409	—	Patient and physician satisfaction with decision-making process ⁸
Butow PN, et al. <i>Support Care Cancer.</i> 2002;10:161-168 Gattellari M, et al. <i>J Clin Oncol.</i> 2002;20:503-513 Leighl N, et al. <i>J Clin Oncol.</i> 2001;19:1768-1778	—	Patient preferences for the content and format of prognostic discussion ⁹
Caffo O, Amichetti M. <i>Br J Urol Internat.</i> 1999;83:462-468 Weijmar Schultz WCM, et al. <i>J Psychosom Obstet Gynecol.</i> 1986;5:119-127	—	Patient self assessment of information and support for cancer care ¹⁰

Appendix F: Survey Instruments Used to Measure Patient and Clinician Communication Behavior in Cancer Settings

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured*
Cancer Rehabilitation Evaluation System (CARES): Manual. Los Angeles, CA: CARES Consultants	Cancer Rehabilitation Evaluation System (CARES): Medical Interaction subscale (adapted from Schag and Heinrich)	Patient problems with interactions and communication with their physicians and nurses ¹¹
Cassileth BR, et al. <i>Ann Intern Med.</i> 1980;92:832-836	Information Styles Questionnaire	Patient preferences for level of information and involvement in consultation ^{8,12-14}
Curtis JR, et al. <i>Pain Symptom Manage.</i> 2002;24:17-31	—	Family satisfaction with family-clinician communication ¹⁵
Curtis JR, Patrick DL. <i>J Gen Intern Med.</i> 1997;12:736-741	—	Patient and physician perceptions of barriers and facilitators to patient-physician communication about end-of-life care ¹⁶
Degner LF, Sloane JA. <i>J Clin Epidemiol.</i> 1992;45:941-948	—	Patient preference for level of involvement in decision-making ^{8,13}
Delvaux N, et al. <i>Br J Cancer.</i> 2004;90:106-144	Satisfaction with the Interview Scale	Patient and nurse satisfaction with consultation ¹⁷
Delvaux N. Dissertation, Universite Libre de Bruxelles; 1999 Razavi D, et al. <i>J Clin Oncol.</i> 2003;16:3141-3149	Perception of the Interview Questionnaire (Delvaux)	Physician satisfaction with the interview Patient and family perceptions of physician behaviors in the interview ^{18,19}
Detmar SB, et al. <i>J Clin Oncol.</i> 2000;18:3295-3301	—	Patient and physician preferences for discussing health-related quality-of-life issues ²⁰

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured*
Detmar SB, et al. <i>JAMA. 2002;</i> 288:3027-3034	Post Intervention Questionnaire	Patient and physician evaluation of intervention ²¹
Dunn SM, et al. <i>J Clin Oncol.</i> 1993;11:2279-2285	—	Patient recall of aspects of consultation ¹⁴
Fogarty LA, et al. <i>J Clin Oncol.</i> 1999;17:371-379	—	Patient perception of the effect of physician compassion on participants' anxiety, information recall, treatment decisions, and assessment of physician characteristics ²²
Hagerty RG, et al. <i>J Clin Oncol.</i> 2004;22:1721-1730	—	Patient preference regarding: ²³ <ul style="list-style-type: none"> • Presentation of survival statistics • Specific prognostic information • When to discuss prognosis and who should initiate the discussion • Prognostic information, timing, and manner of presentation
Hagerty RG, et al. <i>J Clin Oncol.</i> 2005;23:1278-1288	—	Patient preferences for content and format of prognostic discussion ²³

Appendix F: Survey Instruments Used to Measure Patient and Clinician Communication Behavior in Cancer Settings

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured†
Hays RD, et al. Scoring the medical outcomes study patient satisfaction questionnaire: PSQI-II.MOS memorandum. Santa Monica, CA: Rand Corporation, 1987 (unpublished)	Patient Satisfaction Questionnaire	Patient satisfaction with interview (needs addressed, active involvement in the interaction, interaction in general, information received, and emotional support received) ²⁴
Higginson I, McCarthy M. <i>Palliat Med.</i> 1994;8:282-290 Higginson IJ, McCarthy M. <i>Palliat Med.</i> 1993;7:219-228 Support Team Assessment Schedule	Support Team Assessment Schedule (STAS)	Palliative care team assessment of information-giving and empathic approach of physician communication between patients and family about end of life ^{25,26}
Jenkins V, Fallowfield L. <i>J Clin Oncol.</i> 2002;20:765-769	Physician Psychosocial Belief Scale	Physician perception of practice change after a communication intervention ⁴
Kidd J, et al. <i>Patient Educ Couns.</i> 2004;52:107-112	—	Patient satisfaction with consultation and perceptions of self-efficacy in asking questions ²⁷
Krantz DS, et al. <i>J Pers Soc Psychol.</i> 1980;39:977-990	Krantz Health Opinion Survey	Patient preferences for information-seeking and for involvement in care ^{8,23}
Krupat E, et al. <i>Patient Educ Couns.</i> 2000;39:49-59	Patient-Practitioner Orientation Scale (PPOS)	Clinician and patient orientations toward control in their relationship ²⁸

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured†
Langewitz W. <i>Psychother Psychosom Med Psychol.</i> 1995;45:351-357 [transl]	—	Patient satisfaction with physician and consultation ²⁹
Lerman CE, et al. <i>J Gen Intern Med.</i> 1990;5:29-33	Perceived Involvement in Care Scale	Patient self-report of patient—and surgeon-initiated communication ³⁰
Lobb EA, et al. <i>Health Expect.</i> 2001;4: 48-57 Sardell AN, Trierweiler SJ. <i>Cancer.</i> 1993;72:3355-3365	—	Patient preferences, clinician views, and current practice regarding the communication of disease prognosis ²³
Matsumura S, et al. <i>J Gen Intern Med.</i> 2002;17:531-539	—	Physicians' attitudes about making prognostic disclosures ³¹
Nayak S, et al. <i>J Clin Oncol.</i> 2005;23:4771-4775	—	Patient satisfaction with physician communication after a communication improvement strategy ³²
O'Connor AM. <i>Med Decis Making.</i> 1995;15:25-30	Decisional Conflict Scale	Patient and physician perceptions of potential benefit and harm from treatment (experimental and standard), relative value of quality and length of life, and perceived content of patient-physician consultations ³³

Appendix F: Survey Instruments Used to Measure Patient and Clinician Communication Behavior in Cancer Settings

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured†
<p>Ong LML, et al. <i>Psycho-oncology.</i> 1998;8:155-166 van Zuuren FJ, Hanewald GJFP. <i>Gedragstherapie.</i> 1993;26:33-48 [transl] van Zuuren FJ, et al. <i>Pers Indiv Diff.</i> 1996;21:21-31</p>	<p>Threatening Medical Situations Inventory (van Zuuren and Hanewald)</p>	<p>Patient self-assessment of monitoring (cognitive confrontation) and blunting (cognitive avoidance) coping styles²⁴</p>
<p>Parker PA, et al. <i>J Clin Oncol.</i> 2001;19:2049-2056</p>	<p>Measure of Patients' Preferences (MPP)</p>	<p>Patient preference for social support³⁴</p>
<p>Parle M, et al. <i>Soc Sci Med.</i> 1997;44:231-40</p>	<p>Confidence in Interviewing Skills Questionnaire (Maguire)</p>	<p>Physician confidence in interview skills⁵</p>
<p>Roberts C, et al. <i>J Cancer Educ.</i> 2005;20:113-118</p>	<p>Health Care Professional (HCP) Survey</p>	<p>Clinician attitudes regarding communication with patients</p> <p>Clinician perceptions of effectiveness of their personal communication skills; self-ratings of communication skills in difficult situations; and perceptions of challenges to professional satisfaction³⁵</p>
<p>Sardell AN, Trierweiler SJ. <i>Cancer.</i> 1993;72:3355-3365 Butow PN, et al. <i>Support Care Cancer.</i> 2002;10:161-168</p>	<p>(Sardell and Trierweiler)</p>	<p>Patient perceptions of what kinds of communication convey hope²³</p>

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured†
Schmid Mast M, et al. <i>Patient Educ Couns.</i> 2005;58:244-251	—	Patient perception of disclosure of bad news, regarding: ²⁹ <ul style="list-style-type: none"> • Appropriateness of information provided by clinician • Availability of physician • Physician dominance • Physician emotionality • Physician expression of hope
Sepucha KR, et al. <i>J Clin Oncol.</i> 2002;20:2695-2700	Physician Satisfaction Scale Patient Satisfaction with Interview Scale	Physician satisfaction with interview and patient satisfaction with preparation interview prior to consultation ²
Shilling V, et al. <i>Psycho-oncology.</i> 2003;12:599-611	—	Physician satisfaction with interview ³⁶
Silberfarb PM, Levine PM. <i>Gen Hosp Psychiatr.</i> 1980;3:192-197	Semantic Differential Attitude Questionnaire	Nurses' attitudes about psychosocial aspects of cancer ¹⁷
Smith JK, et al. <i>Eval Health Prof.</i> 1984;7:77-94 Bowman MA, et al. <i>Patient Educ Couns.</i> 1992;19:75-80	Patient-Doctor Interaction Scale (Smith)	Patient satisfaction with interview ²
Sneeuw KC, et al. <i>J Clin Oncol.</i> 1997;15:1206-1217	—	Patient and physician preferences for discussing health-related quality-of-life issues ²⁰

Appendix F: Survey Instruments Used to Measure Patient and Clinician Communication Behavior in Cancer Settings

Citation for Survey Instrument	Title/ of Survey Instrument (Author)*	Communication Behavior Measured†
Takayama K, et al. <i>Soc Sci Med</i> 2001;53:1335-1350	—	Patient perception of participation in patient-physician interactions ³⁷
Ware JE, Snyder MK. <i>Med Care.</i> 1975;13:669-682 Ware JE, Davies AR. <i>Eval Program Plan.</i> 1983;6:247-263	Patient Satisfaction with Communication Questionnaire (PSCQ) (adaptation)	Patient and physician satisfaction with communication during patient-physician consultation ³⁶
Wolf MH, et al. <i>J Behav Med.</i> 1978;1:391-401 Baker R. <i>Br J Gen Pract.</i> 1990;40:487-490	—	Patient satisfaction with medical interview ³⁸
Wolf MS, et al. <i>Patient Educ Couns.</i> 2005;57:333-341	Communication and Attitudinal Self-Efficacy (CASE) Scale	Patient report of self-efficacy ³⁹

References

- (1) Ajaj A, Singh MP, Abdulla AJJ. Should elderly patients be told they have cancer? Questionnaire survey of older people. *BMJ*. 2001;323:1160.
- (2) Sepucha KR, Belkora JK, Mutchnick S, Esserman LJ. Consultation planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians. *J Clin Oncol*. 2002;20:2695-2700.
- (3) Fallowfield L, Lipkin M, Hall A. Teaching senior oncologists communication skills: results from phase I of a comprehensive longitudinal program in the United Kingdom. *J Clin Oncol*. 1998;16:1961-1968.
- (4) Jenkins V, Fallowfield L. Can communication skills training alter physicians' beliefs and behavior in clinics? *J Clin Oncol*. 2002;20:765-769.
- (5) Baile WF, Lenzi R, Kudelka AP, et al. Improving physician-patient communication in cancer care: outcome of a workshop for oncologists. *J Cancer Educ*. 1997;12:166-173.
- (6) Baile WF, Lenzi R, Parker PA, Buckman R, Cohen L. Oncologists' attitudes toward and practices in giving bad news: an exploratory study. *J Clin Oncol*. 2002;20:2189-2196.
- (7) Ong LM, Visser MR, Lammes FB, et al. Effect of providing cancer patients with the audiotaped initial consultation on satisfaction, recall, and quality of life: a randomized, double-blind study. *J Clin Oncol*. 2000;18:3052-3060.
- (8) Butow P, Devine R, Boyer M, et al. Cancer consultation preparation package: changing patients but not physicians is not enough. *J Clin Oncol*. 2004;22:4401-4409.
- (9) Hagerty RG, Butow PN, Ellis PA, et al. Cancer patient preferences for communication of prognosis in the metastatic setting. *J Clin Oncol*. 2004;22:1721-1730.
- (10) Jonker-Pool G, Hoekstra HJ, van Imhoff GW, et al. Male sexuality after cancer treatment—needs for information and support: testicular cancer compared to malignant lymphoma. *Patient Educ Couns*. 2004;52:143-150.
- (11) Collie K, Wong P, Tilston J, et al. Self-efficacy, coping, and difficulties interacting with health care professionals among women living with breast cancer in rural communities. *Psychooncology*. 1993;14:901-912.
- (12) Brown RF, Butow PN, Dunn SM, Tattersall MH. Promoting patient participation and shortening cancer consultations: a randomised trial. *Br J Cancer*. 2001;85:1273-1279.
- (13) Butow PN, Brown RF, Cogar S, Tattersall MH, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. *Psychooncology*. 2002;11:47-58.
- (14) Butow PN, Dunn SM, Tattersall MH, Jones QJ. Computer-based interaction analysis of the cancer consultation. *Br J Cancer*. 1995;71:1115-1121.
- (15) McDonagh JR, Elliott TB, Engelberg RA, et al. Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. *Crit Care Med*. 2004;32:1484-1488.
- (16) Curtis JR, Patrick DL, Caldwell ES, Collier AC. Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. *Arch Intern Med*. 2000;160:1690-1696.
- (17) Delvaux N, Razavi D, Marchal S, et al. Effects of a 105 hours psychological training program on attitudes, communication skills and occupational stress in oncology: a randomised study. *Br J Cancer*. 2004;90:106-114.
- (18) Delvaux N, Merckaert I, Marchal S, et al. Physicians' communication with a cancer patient and a relative: a randomized study assessing the efficacy of consolidation workshops. *Cancer*. 2005;103:2397-2411.
- (19) Razavi D, Merckaert I, Marchal S, et al. How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of posttraining consolidation workshops. *J Clin Oncol*. 2003;21:3141-3149.
- (20) Detmar SB, Aaronson NK, Wever LD, Muller M, Schornagel JH. How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality-of-life issues. *J Clin Oncol*. 2000;18:3295-3301.
- (21) 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;288:3027-3034. [erratum appears in *JAMA*. 2003;289:987]
- (22) Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 seconds of compassion reduce patient anxiety? *J Clin Oncol*. 1999;17:371-379.
- (23) Hagerty RG, Butow PN, Ellis PM, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol*. 2005;23:1278-1288.

Appendix F: Survey Instruments Used to Measure Patient and Clinician Communication Behavior in Cancer Settings

- (24) Arora NK, McHorney CA. Patient preferences for medical decision making: who really wants to participate? *Med Care*. 2000;38:335-341.
- (25) Higginson IJ, Costantini M. Communication in end-of-life cancer care: a comparison of team assessments in three European countries. *J Clin Oncol*. 2002;20:3674-3682.
- (26) Mess E, Kempiska E, Leppert W, et al. Assessment of quality of life, pain and effectiveness of treatment in palliative care patients. *Roczniki Akademii Medycznej W Bialymstoku*. 2005;50;Suppl 1:207-209.
- (27) Kidd J, Marteau TM, Robinson S, Ukoumunne OC, Tydeman C. Promoting patient participation in consultations: a randomised controlled trial to evaluate the effectiveness of three patient-focused interventions. *Patient Educ Couns*. 2004;52:107-112.
- (28) Street RL Jr, Gordon HS, Ward MM, Krupat E, Kravitz RL. Patient participation in medical consultations: why some patients are more involved than others. *Med Care*. 2005;43:960-969.
- (29) Schmid Mast M, Kindlimann A, Langewitz W. Recipients' perspective on breaking bad news: how you put it really makes a difference. *Patient Educ Couns*. 2005;58:244-251.
- (30) Liang W, Burnett CB, Rowland JH, et al. Communication between physicians and older women with localized breast cancer: implications for treatment and patient satisfaction. *J Clin Oncol*. 2002;20:1008-1016.
- (31) Gabbay BB, Matsumura S, Etzioni S, et al. Negotiating end-of-life decision making: a comparison of Japanese and U.S. residents' approaches. *Acad Med*. 2005;80:617-621.
- (32) Nayak S, Pradhan JP, Reddy S, et al. Cancer patients' perception of the quality of communication before and after the implementation of a communication strategy in a regional cancer center in India. *J Clin Oncol*. 2005;23:4771-4775.
- (33) Meropol NJ, Weinfurt KP, Burnett CB, et al. Perceptions of patients and physicians regarding phase I cancer clinical trials: implications for physician-patient communication. *J Clin Oncol*. 2003;21:2589-2596.
- (34) Parker PA, Baile WF, de Moor C, et al. Breaking bad news about cancer: patients' preferences for communication. *J Clin Oncol*. 2001;19:2049-2056.
- (35) Roberts C, Benjamin H, Chen L, et al. Assessing communication between oncology professionals and their patients. *J Cancer Educ*. 2005;20:113-118.
- (36) Shilling V, Jenkins V, Fallowfield L. Factors affecting patient and clinician satisfaction with the clinical consultation: can communication skills training for clinicians improve satisfaction? *Psychooncology*. 2003;12:599-611.
- (37) Takayama T, Yamazaki Y. How breast cancer outpatients perceive mutual participation in patient-physician interactions. *Patient Educ Couns*. 2004;52:279-289.
- (38) Ishikawa H, Takayama T, Yamazaki Y, Seki Y, Katsumata N. Physician-patient communication and patient satisfaction in Japanese cancer consultations. *Soc Sci Med*. 2002;55:301-311.
- (39) Wolf MS, Chang CH, Davis T, Makoul G. Development and validation of the Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer). *Patient Educ Couns*. 2005;57:333-341.

Observation-based Instruments for Coding and Rating Patient-Clinician Communication



Citation for Observation-based Instrument	Title of Observation Instrument (Author)*	Communication Behavior Measured†
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Adelman RD, et al. <i>Gerontologist</i> . 1987;27:729-734	—	Whether the utterance was addressed to patient, relative, or both ¹
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Beach WA, et al. <i>Soc Sci Med</i> . 2005;60:893-910	(no title)	Participants' methods for organizing and accomplishing social actions ⁴
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Booth C, Maguire P. <i>Report to Cancer Research Campaign, London</i> ; 1991 Razavi D. <i>Eur J Cancer</i> . 1993;29A:1858-1863 [transl]	Cancer Research Campaign Workshop Evaluation Manual (CRCWEM) (Booth and Maguire)	Form, function, and emotional level of each utterance ^{1,5-10}
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Brown RF, et al. <i>Br J Cancer</i> . 2001;85:1273-1279	Coding manual developed for this study	Patient request for information or guidance ¹¹
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Butow PN, et al. <i>Br J Cancer</i> . 1995; 71:1115-1121	Cancer-specific Interaction Analysis System (CN-LOGIT)	Comprehensive measure of patient-physician consultation ¹²
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Carcuff RR, Pierce RM. <i>Interviewing Strategies for Helpers —Fundamental Skills and Cognitive Behavioral Interventions</i> . Brooks/Cole Publishing: Pacific Grove, CA; 1975: 36-41	—	Physicians' verbal responses to emotional cues ¹³
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*Author given only if different from first author of citation for instrument (in left column).

†References indicate studies in which the observation-based instrument was used in the cancer setting.

Citation for Observation-based Instrument	Title of Observation Instrument (Author)*	Communication Behavior Measured†
Dent E, et al. <i>Patient Educ Couns.</i> 2005;56:35-44	Cancode Interaction Analysis System	Comprehensive view of the interaction; coding within four categories: source, content, function, and emotion ¹⁴
Del Piccolo L, et al. <i>Epidemiol Psichiat Soc.</i> 1999;8:56-67 [transl]	Verona Medical Interview Classification System (VR-MICS)	Information and instructions on illness management and information and instructions on psychosocial aspects ¹⁵
Detmar SB, et al. <i>JAMA.</i> 2001;285:1351-1357	—	Whether tumor response was discussed in the context of palliative care consultations ¹⁶
Detmar SB, et al. <i>JAMA.</i> 2002;288:3027-3034	—	Checklist to determine which health-related quality-of-life topics were discussed ¹⁷
Ford S, et al. <i>Soc Sci Med.</i> 2000;50:553-566	Medical Interaction Process System (MIPS)	Classifies all utterances by patient and physician into content categories ^{18,19}
Beach WA, Dixon CN. <i>Soc Sci Med.</i> 2001;52:25-45 Beach WA. <i>Conversations about Illness: Family Preoccupations with Bulimia.</i> Mahwah, NJ: Lawrence Erlbaum Associates; 1996	—	Patient-initiated actions (PIAs), and doctor-responsive actions (DRAs) ²⁰

Appendix G: Observation-based Instruments for Coding and Rating Patient-Clinician Communication

Citation for Observation-based Instrument	Title of Observation Instrument (Author)*	Communication Behavior Measured†
Kidd J, et al. <i>Patient Educ Couns.</i> 2004;52:107-112	—	Number of questions asked by the patient ²¹
Mays N, Pope C. <i>BMJ.</i> 1995;311:182-184	—	Factors in communication that contribute to false optimism ²²
Noldus LP, et al. <i>Behav Res Methods Instrum Comput.</i> 2000;32:197-206	The Observer System	Comprehensive collection and analysis of communication ^{2,3}
Ong LM, et al. <i>J Clin Oncol.</i> 2000;18:3052-3060	—	Patient recall of information ²³
Roter DL. <i>Health Educ Monogr.</i> 1977;5:281-315 Roter DL. In <i>RIAS Manual.</i> Baltimore: Johns Hopkins University; 1995	Roter Interactional Analysis System (RIAS)	Comprehensive utterance-based categories within three conceptual clusters: process, affective, and content ^{3,16,24-27}
Siminoff LA, et al. <i>Psycho-Oncology.</i> (in press)	—	Discord between patient and family members in treatment decision-making ²⁸
Stead ML, et al. <i>Br J Cancer.</i> 2003;88:666-671	—	Whether patient received information about sexual issues ²⁹

Citation for Observation-based Instrument	Title of Observation Instrument (Author)*	Communication Behavior Measured†
<p>Street RL. <i>Health Communication</i> 2001;13:61-73 Street RL, et al. <i>Diabetes Care.</i> 1993;16:714-721 Street RL. <i>Soc Sci Med.</i> 1992;34:1155-1163 Street RL. <i>Soc Sci Med.</i> 1991;32:541-548</p>	—	Patient participation, physician partnership building, and supportive talk ^{30,31}
<p>Tulsky JA et al. <i>Ann Intern Med.</i> 1998;129:441-449</p>	—	How physicians communicate about advance directives ³²
<p>Zandbelt LC, et al. <i>Soc Sci Med.</i> 2005;61:661-671</p>	Patient-Centered Behaviour Coding Instrument (PBCI)	Physician facilitating and inhibiting behaviors ³³

Reference List

- (1) Delvaux N, Merckaert I, Marchal S, et al. Physicians' communication with a cancer patient and a relative: a randomized study assessing the efficacy of consolidation workshops. *Cancer*. 2005;103:2397-2411.
- (2) Eide H, Graugaard P, Holgersen K, Finset A. Physician communication in different phases of a consultation at an oncology outpatient clinic related to patient satisfaction. *Patient Educ Couns*. 2003;51:259-266.
- (3) Eide H, Quera V, Graugaard P, Finset A. Physician-patient dialogue surrounding patients' expression of concern: applying sequence analysis to RIAS. *Soc Sci Med*. 2004;59:145-155.
- (4) Beach WA, Easter DW, Good JS, Pigeron E. Disclosing and responding to cancer "fears" during oncology interviews. *Soc Sci Med*. 2005;60:893-910.
- (5) Libert Y, Janne P, Razavi D et al. Impact of medical specialists' locus of control on communication skills in oncological interviews. *Br J Cancer*. 2003;88:502-509.
- (6) Razavi D, Merckaert I, Marchal S, et al. How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of posttraining consolidation workshops. *J Clin Oncol*. 2003;21:3141-3149.
- (7) Libert Y, Merckaert I, Reynaert C, et al. Does psychological characteristic influence physicians' communication styles? Impact of physicians' locus of control on interviews with a cancer patient and a relative. *Support Care Cancer*. 2006;14:230-242.
- (8) Merckaert I, Libert Y, Delvaux N, et al. Factors that influence physicians' detection of distress in patients with cancer: can a communication skills training program improve physicians' detection? *Cancer*. 2005;104:411-421.
- (9) Delvaux N, Razavi D, Marchal S, et al. Effects of a 105 hours psychological training program on attitudes, communication skills and occupational stress in oncology: a randomised study. *Br J Cancer*. 2004;90:106-114.
- (10) Razavi D, Delvaux N, Marchal S, et al. Testing health care professionals' communication skills: the usefulness of highly emotional standardized role-playing sessions with simulators. *Psychooncology*. 2000;9:293-302.
- (11) Brown JB, Stewart MA, Ryan BL. *Assessing Communication Between Patients and Physicians: The Measure of Patient-Centered Communication (MPCC)*. Working Paper Series, Paper # 95-2, 2nd ed. London, Ontario, Canada: Thames Valley Family Practice Research Unit and Centre for Studies in Family Medicine; 2001.
- (12) 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.
- (13) Butow PN, Brown RF, Cogar S, Tattersall MH, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. *Psychooncology*. 2002;11:47-58.
- (14) Dent E, Brown R, Dowsett S, Tattersall M, Butow P. The Cancode interaction analysis system in the oncological setting: reliability and validity of video and audio tape coding. *Patient Educ Couns*. 2005;56:35-44.
- (15) Goss C, Mazzi MA, Del PL, Rimondini M, Zimmermann C. Information-giving sequences in general practice consultations. *J Eval Clin Pract*. 2005;11:339-349.
- (16) Detmar SB, Muller MJ, Wever LD, Schornagel JH, Aaronson NK. The patient-physician relationship. Patient-physician communication during outpatient palliative treatment visits: an observational study. *JAMA*. 2001;285:1351-1357.
- (17) 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;288:3027-3034.
- (18) 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.
- (19) Jenkins V, Fallowfield L. Can communication skills training alter physicians' beliefs and behavior in clinics? *J Clin Oncol*. 2002;20:765-769.
- (20) Easter DW, Beach W. Competent patient care is dependent upon attending to empathic opportunities presented during interview sessions. *Curr Surg*. 2004;61:313-318.
- (21) Kidd J, Marteau TM, Robinson S, Ukoumunne OC, Tydeman C. Promoting patient participation in consultations: a randomised controlled trial to evaluate the effectiveness of three patient-focused interventions. *Patient Educ Couns*. 2004;52:107-112.
- (22) The AM, Hak T, Koeter G, van der WG. Collusion in doctor-patient communication about imminent death: an ethnographic study. *West J Med*. 2001;174:247-253.

- (23) Ong LM, Visser MR, Lammes FB, de Haes JC. Doctor-patient communication and cancer patients' quality of life and satisfaction. *Patient Educ Couns.* 2000;41:145-156.
- (24) Schmid MM, Kindlimann A, Langewitz W. Recipients' perspective on breaking bad news: how you put it really makes a difference. *Patient Educ Couns.* 2005;58:244-251.
- (25) Timmermans LM, van der Maazen RW, Verhaak CM, et al. Patient participation in discussing palliative radiotherapy. *Patient Educ Couns.* 2005;57:53-61.
- (26) Takayama T, Yamazaki Y. How breast cancer outpatients perceive mutual participation in patient-physician interactions. *Patient Educ Couns.* 2004;52:279-289.
- (27) Ishikawa H, Takayama T, Yamazaki Y, Seki Y, Katsumata N. Physician-patient communication and patient satisfaction in Japanese cancer consultations. *Soc Sci Med.* 2002;55:301-311.
- (28) Siminoff LA, Rose JH, Zhang A., Zyzanski SJ. Measuring discord in treatment decision making: progress towards development of a cancer communication and decision-making assessment tool. *Psychooncology.* 2006;15:528-540.
- (29) Stead ML, Brown JM, Fallowfield L, Selby P. Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *Br J Cancer.* 2003;88:666-671.
- (30) Street RL Jr, Krupat E, Bell RA, Kravitz RL, Haidet P. Beliefs about control in the physician-patient relationship: effect on communication in medical encounters. *J Gen Intern Med.* 2003;18:609-616.
- (31) Street RL Jr, Gordon HS, Ward MM, Krupat E, Kravitz RL. Patient participation in medical consultations: why some patients are more involved than others. *Med Care.* 2005;43:960-969.
- (32) Tulskey JA, Fischer GS, Rose MR, Arnold RM. Opening the black box: how do physicians communicate about advance directives? *Ann Intern Med.* 1998;129:441-449.
- (33) Zandbelt LC, Smets EM, Oort FJ, de Haes HC. Coding patient-centred behaviour in the medical encounter. *Soc Sci Med.* 2005;61:661-671.