

# **EPECTM-O**

Education in Palliative and End-of-Life Care for Oncology:

## **Cultural Considerations When Caring for African Americans**

**Module 7-AA:**

## **Communicating Effectively**

## **Abstract:**

Effective communication is essential for the delivery of quality cancer palliative care. And yet, healthcare providers often lack the skills to communicate effectively with their patients and families. This difficulty is compounded when healthcare providers and their patients and families perceive that they don't share a common identity. Lack of racial concordance is one area where deficits in provider-patient communication have been documented. This module explores what constitutes "good" communication, what the literature tells us about how our patients and families want us to communicate with them, what the current issues are in communicating with patients and families, and what has been found to be effective in bridging communication gaps between healthcare providers and patients and families. Finally, a practical strategy for improving provider-patient and family communication, the SPIKES Model, is presented.

## **Key Words:**

Person-centered care, cultural competence, health literacy, breaking bad news, hope

## **Definitions:**

***Bias:*** The tendency to make negative judgments about a person because of racial affiliation or the culture, sex, or class from which that person comes. It may be conscious (explicit) or unconscious (implicit).<sup>1, 2</sup>

***Concordance:*** Shared identity between patients and physicians/ health professionals across visible (race/ethnicity, age, sex, education, language) and less visible (beliefs, values, preferences) dimensions.<sup>3</sup>

***Culture:*** Refers to a group or community with which we share common experiences that shape the way we understand the world, and includes groups that we are born into, such as gender, race, national origin, class, or religion; and the social groups that influence our self-identity, including sexual orientation, age, disability, and socioeconomic status.<sup>4</sup>

***Cultural competence:*** A set of attitudes, skills, behaviors, and policies that enable organizations and staff to work effectively in cross-cultural situations. It reflects the ability to acquire and use knowledge of the health-related beliefs, attitudes, practices, and communication patterns of clients and their families to improve services, strengthen programs, increase community participation, and close the gaps in health status among diverse population groups.<sup>4, 5</sup>

***Culturally competent providers:*** Consistently and systematically:

- Understand and respect their patients' values, beliefs, and expectations
- Understand the cause and control of specific diseases and the effectiveness of treatments in different population groups
- Adapt the way they deliver care to each patient's needs and expectations<sup>6</sup>

***Cultural humility:*** Incorporates a lifelong commitment to self-evaluation and critique, to redressing the power imbalances in the health provider-patient dynamic, and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals

and defined populations. Embodied in the health provider who practices cultural humility is the patient-focused interviewing process. Patient-focused interviewing uses a less controlling, less authoritative style which signals to the patient that the practitioner values the patient's agenda and perspectives.<sup>7</sup>

**Health Literacy:** The degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions. It is influenced by multiple factors, including patient-provider communication skills, patient knowledge of health topics, culture, requirements of the health care system, situation and context, disabilities.<sup>4</sup>

**Hope:** A confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant.<sup>8,9</sup>

**Patient-centered care:** Respecting and responding to patients' wants, needs and preferences, so that they can make choices about their care that best fit their individual circumstances.<sup>10</sup> Such care is characterized by continuous healing relationships, shared understanding, emotional support, trust, patient enablement and activation, and informed choices.<sup>11</sup>

**Stereotyping:** A cognitive shortcut whereby group characteristics are ascribed to individuals.<sup>3</sup>

**Trust:** The degree to which people see one another as competent, responsible, caring, tactful, and ethical.<sup>3</sup>

## **Objectives:**

After studying this module, participants will be able to:

- Describe essential components of effective healthcare provider-patient/family communication, including those identified by patients and families
- Describe outcomes associated with effective communication
- Describe deficiencies in communication between healthcare providers and patients and families, particularly those experienced by African Americans
- Describe the variables that impact the perception of trust when communicating with African American patients and families
- List evidence-based interventions that improve communication between healthcare providers and patients and families, with special attention to the African American experience
- Use a six-step protocol (SPIKES) to deliver bad news

## **Case Study Vignette**

In this video segment, you will observe a family meeting between the medical team and a large African American family who are engaged in conversation whether or not to start tube feeding the terminally ill matriarch of the family, who is ill with metastatic colon cancer to the liver. She is losing weight, has intermittent nausea and vomiting, experiences intermittent bowel obstruction and lacks an appetite.

The video can be accessed by clicking on the following url:

<http://www.youtube.com/watch?v=NudNTVRSKiw>

## Introduction

Communicating information, whether it is good or bad news, is an essential skill for healthcare providers. In the Institute of Medicine's report, "Crossing the Quality Chasm," patient-centered care is identified as a key measure of quality.<sup>10</sup> Integral to patient-centered care is patient-centered communication. Professional bodies—such as the American Board of Medical Specialties, the American Osteopathic Association, the American College of Graduate Medical Education, the American Association of Colleges of Nursing, the American Nurses Association, the National Organization of Nurse Practitioner Faculties, and the National Association of Clinical Nurse Specialists—view communication and interpersonal skills as core competencies consisting of a set of measurable and modifiable behaviors that can be taught and can evolve, including techniques for listening, explaining, questioning, counseling, and motivating.<sup>12, 13, 14, 15, 16, 17, 18, 19</sup>

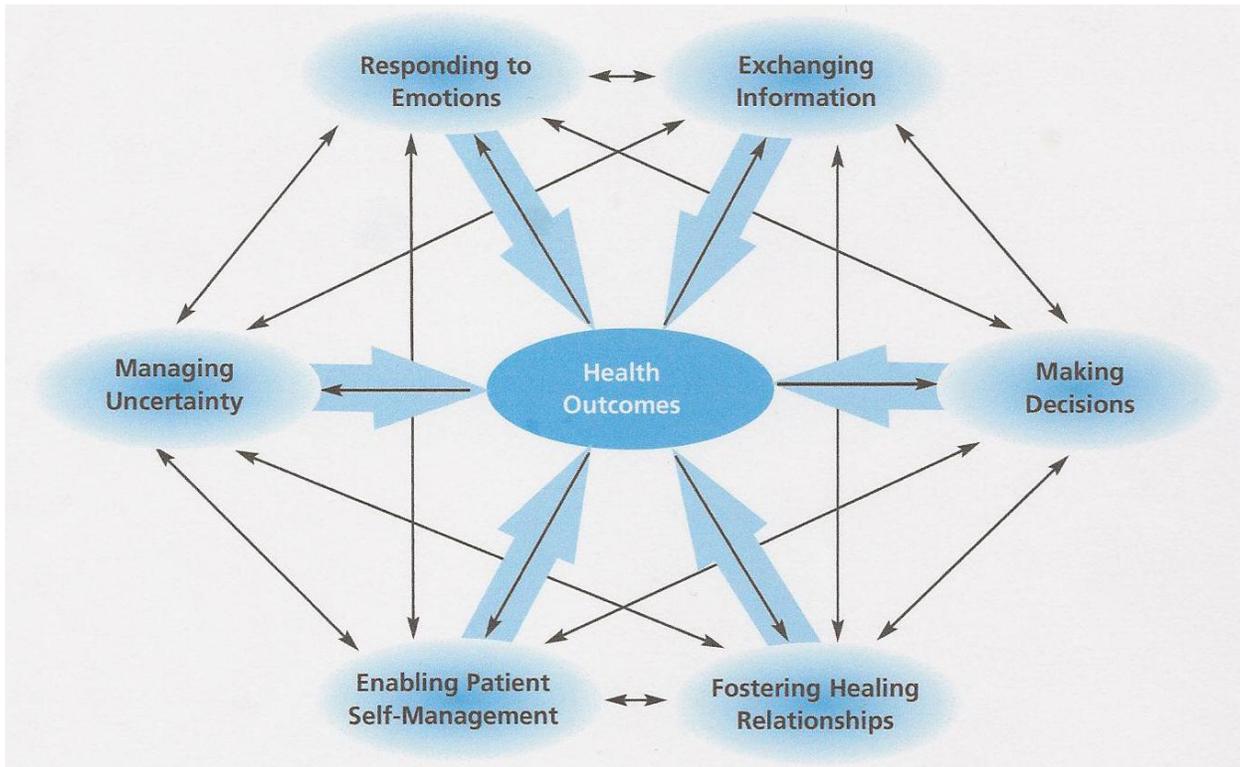
Yet, many healthcare providers feel deficient in the area of communication.<sup>20</sup> Until recently, training programs in communication skills for physicians have been lacking. Numerous studies have documented deficiencies in communication skills among healthcare providers, with most studies focusing on physicians.<sup>5, 21, 22, 23, 24</sup> Even though nursing undergraduate and graduate education programs have included communication skills training, studies have documented deficiencies among practicing nurses in the area of communication.<sup>25</sup>

Communication in cancer care can be especially challenging, since it so often involves giving bad news to patients and families and communicating about very complex diseases and treatment options that may have favorable or devastating outcomes.<sup>26</sup>

The National Cancer Institute lists six fundamental functions of physician-patient communication: (see Figure 1)

1. Fostering healing relationships
2. Exchanging information
3. Responding to patients' emotions
4. Managing uncertainty
5. Making informed decisions
6. Enabling patient self-management<sup>26, 27</sup>

**Figure 1: Six core functions of patient-clinician communication**



Epstein et al<sup>26</sup> p18

In addition to the above functions, the nursing literature also emphasizes the importance of helping the patient in the task of self-actualization; that is, using the relationship between the nurse and the patient to facilitate the growth and development of the person as they experience traumatic events.<sup>28</sup> Nurses also see their role as facilitating communication between the patient/family unit and the healthcare team, and also among the members of the team.<sup>29</sup> And, of course, nurses stress their role in teaching the patient and family, and in interpreting what other health providers such as the physician have discussed.<sup>30</sup>

The challenge is not only fulfilling these functions, but doing them well.

### **What constitutes “good” communication?**

Katz et al. characterized “good” communication as that where the patient believes they received enough information from their provider, is involved in medical decisions, and thinks that their provider understood their health needs almost all the time or always.<sup>31</sup>

### ***What do patients and families tell us they want?***

#### **In general:**

Patients and families want to be involved in the process of care, be informed of all the treatment options, feel listened to, and feel that their physicians and other healthcare providers know them

as people, not simply diseases.<sup>26</sup> Patient morbidity can be higher in patients who are not given treatment choices.<sup>32</sup> In focus groups, African Americans consistently stress the importance of the healthcare providers knowing them and their families as individuals, and of tailoring communication to their specific needs.<sup>33</sup> African Americans report more satisfaction with their care when physicians and other healthcare professionals on the team employ a participatory style that frames them as partners in their own care.<sup>3, 34, 35, 36</sup> Although physicians are looked to for their expertise, and are expected to establish effective communication and to initiate important conversations related to their health, African Americans value their decision-making autonomy.<sup>33, 36</sup>

Focus groups consisting of low-income people from diverse ethnic/cultural backgrounds can help identify universal themes of culturally sensitive health care; these include people skills, individualized treatment, effective communication, and technical competence. African Americans identified the following people skills that made them feel supported: empathy, thoughtfulness, acceptance, respectfulness, being a good listener, and patience. Elements of effective communication identified by African Americans included offering thorough explanations of procedures and regimens in language they could understand, and emphasized the importance of direct and forthright communication. African Americans and Latinos also identified the importance of the characteristics of the physical environment, such as culturally sensitive art, music, and reading materials in waiting rooms, and the behaviors of office staff.<sup>37</sup>

#### **In patients with life-limiting illness:**

The majority of patients in America who have life-limiting illness (and their families) want their healthcare providers to be honest when discussing prognosis and end-of-life issues, but they also want to be able to negotiate the timing of the discussions.<sup>8, 38</sup> This is true in other cultures as well.<sup>39, 40</sup> In an investigation of the preferred timing for end-of-life discussions, Hagerly found that 84 percent wanted to discuss treatment goals and options at the time of diagnosis, but only 59 percent wanted to discuss survival and only a third wanted to discuss dying or palliative care at that time.<sup>23, 41</sup>

Focus groups consisting of interdisciplinary healthcare providers, volunteers, and patients identified six components of a “good death,” including pain and symptom management, clear decision-making ability, preparation for death, life completion, ability to contribute to others, and receiving affirmation as a whole person. Participants wanted their relationship with their healthcare providers to encompass all these dimensions.<sup>42</sup> Patients with life-limiting illness and their family members preferred a trusted, expert health professional who showed empathy and honesty, encouraged questions, and clarified each individual’s information needs and level of understanding. They preferred some discussion at diagnosis about the illness, likely future symptoms and management, life expectancy, and treatment options, with a balance between realism and hope, but wanted to negotiate the content and extent of the information. They also desired reassurance that they would not suffer.<sup>8, 23, 32</sup> Conversely, a “bad death” was feared more than the fact of dying; patients don’t want to be denied the opportunity to plan ahead, arrange personal affairs, decrease family burden, or say good-bye.<sup>42</sup>

The most important characteristics of palliative nurses that patients and families identified were interpersonal skills and qualities such as kindness, warmth, compassion and genuineness. Dying

patients and their nurses also emphasized the dying patients' need to maintain independence and control.<sup>29</sup>

Patients who were terminally ill, bereaved family members, and healthcare providers identified and rated 26 factors that were important to them; 16 of these have relevance to patient-clinician communication. (See Table 1) Patients appreciated when the doctor personally told them their results, examined scans and test results in their presence, clarified understanding, and emphasized what can be done as opposed to what cannot.<sup>43</sup>

**Table 1: Attributes rated as important by more than 70 percent of participants**  
(bolded/highlighted relate to communication between patient and clinicians)

Attributes	Patients (n=340)	Bereaved (n=332)	Physicians (n=99)	Other HCPs (n=429)
Be kept clean	99	99	99	99
<b>Name a decision-maker</b>	98	98	98	99
<b>Have a nurse with whom one feels comfortable</b>	97	98	91	98
<b>Know what to expect about one's physical condition</b>	96	93	88	94
<b>Have someone who will listen</b>	95	98	99	99
<b>Maintain one's dignity</b>	95	98	99	99
<b>Trust one's physician</b>	94	97	99	97
Have financial affairs in order	94	94	91	90
<b>Be free of pain</b>	93	95	99	97
<b>Maintain sense of humor</b>	93	87	79	85
Say goodbye to important people	90	92	95	99
<b>Be free of shortness of breath</b>	90	87	93	87
<b>Be free of anxiety</b>	90	91	90	90
<b>Have a physician with whom one can discuss fears</b>	90	91	94	93
<b>Have a physician who knows one as a whole person</b>	88	92	92	95
Resolve unfinished business with family or friends	86	85	87	97
Have physical touch	86	94	90	97
<b>Know that one's physician is comfortable talking about death and dying</b>	86	85	93	97
Share time with close friends	85	91	91	96
Believe family is prepared for one's death	85	88	83	90

Attributes	Patients (n=340)	Bereaved (n=332)	Physicians (n=99)	Other HCPs (n=429)
<b>Feel prepared to die</b>	84	81	79	87
Presence of family	81	95	95	96
<b>Treatment preferences in writing</b>	81	85	73	90
Not die alone	75	93	84	88
Remember personal accomplishments	74	80	78	91
<b>Receive care from personal physician</b>	73	77	82	82

Steinhauser et al.<sup>43</sup>

Parker identified the most important healthcare provider behaviors during prognostic/end-of-life discussions as:

- Willingness to initiate and engage in conversations about death, specifically an ability to use the words “death” and “dying”
- Employing eye contact (if culturally appropriate)
- Active listening
- Exploring emotional reactions
- Providing the patient with a sense of control
- Giving information in a digestible manner
- Using appropriate language and avoiding euphemisms and jargon
- Assessing the patient’s ability to comprehend statistics and interpreting them for the patient’s own situation<sup>23</sup>

Needs for medical information tend to change over time, especially among patients with advanced stages of life-limiting illnesses and their caregivers. These needs are high at all stages of the disease process, but a pattern emerges as the disease progresses and the patient becomes increasingly sick and debilitated: his/her desire for information regarding the disease process tends to wane, while the family’s information needs increase. Preference for active vs. passive participation in decision making also changes over time, with as many as a third of patients preferring not to be involved in decision-making.<sup>23</sup> The healthcare provider, however, should not make any assumptions as to the patient’s preference for information, but should ask the patient. When the patient defers information or decisions to other family members, breaking bad news and truth-telling become a delicate dance among patient/family and healthcare providers.

### ***The importance of hope***

It is vital to sustain hope when communicating with terminally ill patients and families. This can be achieved by combining honesty with sensitivity and empathy. Patients have wide-ranging hopes, including hope for a cure, hope for living longer than expected, making it to certain events, exploring achievable goals, participating in everyday living, finding meaning in their own life, good pain and symptom management, being well cared for and supported, and having

a peaceful death.<sup>8</sup> Patients' sense of hope is obtained from relationships, beliefs and faith, maintaining dignity, finding inner peace, and enjoying a sense of humor.<sup>8,44</sup> Especially among many African Americans, faith is a primary resource to cope and deal with bad news and a poor prognosis. Learning how to respond to comments that appear unrealistic by reframing is an essential tool that gives respect and validation to the belief and tradition of the African American family. (See also Module AA Spirituality.) Hope can also be maintained by the healthcare provider 'being there' and treating the patient as whole person.<sup>8</sup> In addition, hope for African Americans was also seen as connected to having a sense of control over treatment choices.<sup>33</sup>

Cutliffe discusses ways that nurses inspire hope: reflection in action; affirmation of worth; creation of partnerships (decision-making is a democratic process, care is negotiated, patients have control over some of remaining life); and affirming the totality of the person (attention to patient's holistic well-being).<sup>8,45</sup>

The focus of hope can evolve over time.<sup>8, 23, 42, 44</sup>

### ***What is patient-centered care?***

The Institute of Medicine (IOM) advocates patient-centered care as an essential component of quality health care.<sup>10</sup> Core attributes of patient-centered care include: 1) considering patients' needs, perspectives, and individual experiences, 2) providing opportunities to patients to participate in their care, and 3) enhancing the patient-clinician relationship.<sup>26</sup>

In discussing the communication interaction between nurses and patients, Green speaks about the importance of "unconditional positive regard" for the patient, as well as empathic understanding.<sup>28</sup> Patients are validated as "experts" in their own health.<sup>30</sup>

### ***What is patient-centered communication?***

Patient-centered communication is an integral component of patient-centered care that involves:

- Eliciting understanding and validating the patient's perspective (for example, concerns, feelings, expectations)
- Understanding the patient within his or her own psychological and social context
- Reaching a shared understanding of the patient's problem and its treatment
- Helping a patient share power by offering him or her meaningful involvement in choices relating to his or her health<sup>26</sup>

Responding to emotions is one of the core aspects of patient-clinician communication.<sup>20</sup>

Effective communication includes many behaviors; for example, using open-ended questions to probe patients' perspectives, asking patients about their information needs, providing information in short clear statements followed by opportunities for patients to ask questions, avoiding jargon, helping patients understand what they can expect from treatments, repeating important information, asking patients to restate information to ensure they understand it, encouraging questions, listening more and talking less, and responding with empathy to patients' concerns.<sup>3,26</sup> (see Table 2)

**Table 2: Examples of Patient-Centered Clinician Behaviors**

Nonverbal Behaviors	Verbal Behaviors
Maintaining eye contact (if culturally appropriate) Forward lean to indicate attentiveness Nodding to indicate understanding Absence of distracting movements (e.g., fidgeting)	Avoiding interruptions Establishing purpose of visit Encouraging patient participation Soliciting the patient’s beliefs, values, and preferences Eliciting and validating the patient’s emotions Asking about family and social context Providing sufficient information Providing clear, jargon-free explanations Checking for patient understanding Offering reassurance Offering encouragement and support

Adapted from Epstein et al<sup>26</sup> p.4

Wittenberg-Lyles proposes a patient-centered style of communication for nurses that is grounded in a narrative approach incorporating seven basic principles. (See Table 3) This non-linear, non-scripted, non-dyadic style of communicating seems particularly well-suited to the way nurses continuously interact with patients and families, and allows patients and families to control the content and flow of the nurse-patient interaction.<sup>46</sup>

**Table 3: Overview of the COMFORT Initiative**

The COMFORT Initiative	Early Palliative Care With Patient & Caregiver/Family
C Communicate	Narrative clinical practice  Verbal clarity  Non-verbal immediacy (eye contact, attentiveness, self-awareness)
O Orientation and opportunity	Support health literacy  Acknowledge vulnerability  Formulate pathway of care
M Mindfulness	Staying in the moment  Lack of prejudgment  Adaptation to rapid changes
F Family	Family as a second-order patient  Family as a conduit to the patient  Family meetings to help clarify goals of care for patient
O Oversight	Installation of coordinated care

The COMFORT Initiative	Early Palliative Care With Patient & Caregiver/Family
	Relieve caregiver/patient burden in complicated serious cases
R Reiterative and radically adoptive	Time invested and quality of encounter are most important Nonlinear communication Patient's acceptance drives communication
T Team	Interdisciplinary/multidisciplinary team members trained in various aspects of palliative care Non-abandonment assurance Continuity of care

From: Wittenberg-Lyles<sup>46</sup>

### ***What is Culturally Competent communication?***

Culturally competent communication refers to communicating with awareness and knowledge of healthcare disparities, understanding that socio-cultural factors have important effects on health beliefs and behaviors, and having the skills to manage these factors appropriately.<sup>34, 47</sup>

In general, a process-oriented or attitude/skill-centered approach to cultural competency is preferable to a categorical or fact-centered approach where specific information about certain cultures is taught to healthcare providers. The categorical approach has the potential to lead to stereotyping of patients and families, and no provider can know all of the intricacies of the thousands of differing cultures to which patients may belong.

A process-oriented approach focuses on:<sup>4, 34</sup>

- The process of communication
- Cross-cutting cultural and social issues and health beliefs
- The individual patient as teacher
- Identifying and negotiating different styles of communication, decision-making preferences, roles of family, and issues of mistrust, prejudice, and racism

(See Appendix for several models of cultural communication)

### **Why does communication matter?**

Simply put, effective provider-patient communication impacts patient outcomes, including measurables such as increased patient satisfaction with care, increased trust between patients and providers, greater patient adherence to recommended therapy, and receipt of recommended preventive services. Even more tangible are positive health outcomes such as improved blood pressure and glycemic control, lower rates of psychological distress and pain, decreased depression, improved emotional well-being, and improved quality of life.

Patients have greater levels of trust in physicians who: show empathy and respect; take time to listen; engage in more partnership-building and collaboration; are honest, informative, thorough,

and accurate in their evaluations; and provide appropriate and effective treatments.<sup>3</sup> Patient-centered communication has been shown to improve patient self-management behaviors.<sup>3, 4, 11, 12, 21, 31, 34, 35, 48, 49</sup> Provider-patient interactions characterized by positive affect has been associated with patient satisfaction and adherence.<sup>43, 44, 45</sup> Psychosocial exchange and an almost equal distribution of patient and physician talk have been associated with the highest levels of patient satisfaction and the lowest level of malpractice claims.<sup>35, 50, 51</sup> (See Table 4 for a summary of outcomes of effective communication.)

In addition to the beneficial effects experienced by patients and families, the ability to communicate effectively with cancer patients and their families is associated with reduced clinician “burn-out”.<sup>52</sup>

**Table 4: Outcomes of Effective Communication**

<b>Communication Outcomes</b>	<b>Intermediate Outcomes</b>	<b>Health Outcomes</b>	<b>Societal Outcomes</b>
Strong patient/family-clinician relationship (trust, rapport, respect, involvement of family and caregivers)	Strong therapeutic alliances	Survival and disease-free survival – Prevention and early detection of cancer – Accurate diagnosis and completion of evidence-based treatment	Cost-effective utilization of health services
Effective information exchange (recall of information, feeling known and understood)	Patient knowledge and understanding	– Maintenance of remission – Safe and comfortable dying	Reduction in disparities in health and health care
Validation of emotions (e.g., empathy)	Emotional self-management	Health-related quality of life - Functioning: cognitive, physical, mental, social, role	Ethical practice (e.g., informed consent)
Acknowledgment, understanding, and tolerance of uncertainty	High-quality medical decisions (informed by clinical evidence, concordant with patient values, and mutually endorsed)	– Well-being: physical, emotional, spiritual – Health perceptions	
Patient participation in decision-making	Family/social support and advocacy		
Coordination of care	Patient self-efficacy, empowerment, and enablement		
	Improved adherence, health habits, and self-care		
	Access to care and effective use of the health		

<b>Communication Outcomes</b>	<b>Intermediate Outcomes</b>	<b>Health Outcomes</b>	<b>Societal Outcomes</b>
	system		

adapted from Epstein et al<sup>26</sup> p.9

Conversely, poor patient-provider communication—which can be compounded by cultural and linguistic barriers—can lead to: increased non-adherence to treatment recommendations, delays in seeking treatment, failure to follow-up on abnormalities with health providers, poorer health outcomes, and increased malpractice claims.<sup>11, 21</sup> The most frequent patient complaints cited in malpractice claims is that physicians do not listen to their concerns, care about their problems, or provide enough information about their treatment.<sup>11</sup> Patients who rate a physician as less participatory are more likely to leave that physician’s practice within a year, which adversely affects continuity of care.<sup>35</sup>

Effective communication between patients and healthcare providers also increases the likelihood that patients’ treatment preferences will be followed. Patients with cancer who have had the opportunity to discuss their wishes for end-of-life care with their physician were significantly more likely to receive care consistent with their preferences. Patients who were aware they were terminally ill were both more likely to have discussed end-of-life preferences with their physicians and also more likely to choose symptom-directed care with no life-extending measures; that choice was associated with less physical distress at end-of-life. Patients who received life-extending therapies, whether this was their preference or not, did not live longer than those who did not, but they tended to experience poorer quality of life and increased physical and psychological distress.<sup>53</sup>

Unfortunately, African American patients were found to be at increased risk of not having their end-of-life preferences honored, even though they were just as likely to have engaged in such discussions with their physicians as White patients were. For instance, even when African American patients had Do Not Resuscitate (DNR) orders in place, they were as likely to receive life-prolonging care as those who did not have DNR orders. Having a DNR order in place did not increase the likelihood that African American patients received care consistent with their preferences, which was not so for White patients, who were more likely to receive care consistent with their preferences when a DNR order was in place.<sup>54</sup>

As part of the Coping with Cancer study conducted between 2002 and 2008, Wright et al. found that about one in three patients and families have had end-of-life discussions with their provider, and went on to receive less aggressive medical care near death and earlier hospice referrals; that treatment approach was associated with improved quality of life in both patients and caregivers and also carried less risk of major depressive disorders for bereaved caregivers. There was no evidence of increased psychological distress in patients or families who engaged in end-of-life discussions.<sup>55</sup>

In contrast, caregivers of patients who received any aggressive care (such as ventilation, resuscitation, ICU admission, chemotherapy, or use of a feeding tube near death) were at higher risk for developing a major depressive disorder, experiencing regret, and feeling unprepared for

the patient's death and they also reported worse quality of life outcomes. African Americans comprised 20 percent of the study sample.<sup>55</sup>

Discussion of the option of hospice should take place routinely in this, as well as every other, patient population; this recommendation follows from data showing improved outcomes experienced by terminally ill patients who receive earlier referrals to hospice. Unfortunately, this is often not the case. In a mortality follow-back survey, Rhodes et al. found that more than half of African Americans who had died of chronic illness had not been informed of the hospice option. Those who died of cancer were more likely to have been informed about hospice. Among those who were informed about hospice, less than 10 percent declined enrollment.<sup>56</sup> In a study of provider-patient communication in a population of patients with end stage heart disease or cancer that was 57 percent African American and 43 percent Caucasian, Zapka et al. found generally low rates of discussion of hospice (35 percent) or spiritual support (20 percent) across the board, regardless of racial concordance between physician and patient, and low rates of awareness of prognosis (49 percent) among patients who had been identified as terminally ill by their physician. Those with cancer were more likely to be enrolled in hospice (37 percent vs. 14 percent for non-cancer patients) and more likely to receive pain and symptom management at home (60 percent vs. 21 percent). Patients who were aware of their prognosis were 10 times as likely to report use of hospice.<sup>57</sup>

### **Factors affecting communication:**

Communication is a complex interactive process affected by many factors, including patient and provider factors.

African Americans focus group participants reported the following factors impede medical information-seeking and treatment compliance:

- Fear: Stemming from the perception of cancer as a death sentence;
- Family history of cancer: Credence placed on the "lived experience" as opposed to the opinion of a professional, combined with suspicion about treatments and pessimism about outcomes;
- Privacy issues: Inhibiting pursuit of medical information, treatment, or emotional support; a tendency to deal with problems on one's own so as not to burden family and friends; embarrassment and shame at having cancer; avoidance and taboo associated with cancer;
- Cancer misinformation: Serves as a barrier to active information seeking and treatment participation; such as the belief that surgery causes cancer to spread, or that it is dangerous to allow a tumor to be exposed to air, or that cancer is contagious;
- Coping style: Social stigma against seeking help;
- Lack of resources: contributes to delays in seeking medical help and perceptions of lower quality of care in community-based hospitals;
- Privacy: preference for receipt of information from family and friends more than from health professionals, or reliance on "word-of-mouth" dissemination of information;
- Mistrust of doctors and the medical community: Historically based mistrust can be mitigated or reinforced by personal experiences with the healthcare system;

- Religion: may act as a barrier if the person relies on faith to the exclusion of medical information-seeking and interventions.<sup>36</sup>

According to Cooper, the dimensions of the relationship between patient and provider that may affect health care disparities include:

1. **Communication**
2. **Partnership:** Participatory communication style characterized by clear instructions and information about the treatment and purpose; relating to patients in an approachable, friendly, or supportive manner; soliciting and listening to the patient's views; using a non-authoritarian manner of problem solving and conflict resolution; offering patient choices, control and responsibility.
3. **Power** which can consist of one of 4 models
  - *mutuality*, where both physician and patient power are high; goals and agenda are mutually negotiated, patient's values are jointly examined, and the physician has an advisory role. This model has the most beneficial patient outcomes, even when the patient does not explicitly prefer an active role;
  - *consumerism*, where the patient has high power and sets the agenda; the physician has a consultant role;
  - *paternalism*, where the physician has high power and sets the goals and agenda, the patient's values are assumed, and the physician has a guardian role;
  - *default condition*, where power is low for both the patient and physician; the agenda, goals, the patient's values, and the physician's role are all unclear.
4. **Trust:** Minorities have less trust in physicians.
5. **Knowing:** To be familiar with a person and his/her life story; knowledge of the unique attributes of individual patients.
6. **Concordance:** Shared identity between patients and physicians across visible (race/ethnicity, age, sex, education, language) and less visible (beliefs, values, preferences) dimensions.<sup>3</sup>

Siminoff et al. examined the characteristics of 6 communication variables, from both the patient and the physician point of view, in patients with breast cancer: biomedical information, psychosocial information, questions, attempts at relationship building, discussion of emotional issues, and degree to which patient is proactive. They found that patient demographic factors—including race, income level, education, and age—influenced the amount of time physicians spent with patients in almost all communication categories. The influence of race was prominent across all categories. Patients who were white, younger than 60, with more than a high school education, and with higher income were more pro-active and more verbal. Physicians provided very little counseling—only 2 percent of all utterances—regarding psychosocial issues regardless of race.<sup>24</sup>

Physicians' perceptions of patients have been found to be influenced by patients' socio-demographic characteristics. Physicians tended to have more negative perceptions of African Americans and members of low and middle socioeconomic status (SES) groups compared with Whites and upper-SES patients. These negative perceptions included: assessment of patient intelligence, feelings of affiliation toward the patient, beliefs about the patient's likelihood of

risk behaviors and adherence with medical advice, as well as perceptions of the patient's personality, abilities, behavioral tendencies and role demands.<sup>3, 35, 58</sup> These perceptions can have a profound impact on patient outcomes. Tessler-Lindau et al. found that the physician *perception* that a woman had low literacy skills was more predictive of likelihood that a woman would not follow up after an abnormal pap smear than the actual health literacy level of the patient.<sup>59</sup>

Ethnic differences between physicians and patients can be a barrier to partnership and effective communication.<sup>35</sup> In many studies, physicians provide less information, engage in more narrowly biomedical conversation, spend less time building rapport (for example, less social talk), and are more verbally dominant and less patient-centered with African American patients.<sup>48, 60</sup> African Americans in general rate visits with physicians as less participatory.<sup>3, 29</sup>

Racial concordance between patient and physician has been found in many studies to be associated with greater patient satisfaction and higher self-rated quality of care. Race-concordant visits were 10 percent longer ( 2.2-2.5 minutes) for both African American and White patients, and were characterized by slower speech speed and more positive patient affect.<sup>34</sup> Johnson et al., using audio-taped and questionnaire data, found that physicians were 23 percent more verbally dominant and engaged in 33 percent less patient-centered communication with African American patients than with White patients, and that both African American patients and their physicians exhibited lower levels of positive affect than White patients and their physicians. Johnson did not find statistically significant differences in visit duration or speech speed comparing African American and White patients.<sup>61</sup> Other researchers have found that patients in race-concordant relationships rated their physicians as more participatory and were more satisfied with the visit regardless of whether patient-centered communication was found on objective audio analysis.<sup>3, 35, 60</sup> Cooper found no relationship between patient-centered interviewing ratio or physician verbal dominance and race-concordance, although patients in race-concordant visits *rated* their physicians as more participatory than did patients in race-discordant visits, which suggests that race-concordance has an independent effect on patients' judgment of the visit, whatever the verbal nature of the medical dialogue.<sup>60</sup>

Street et al. wanted to examine the factors that might underlie the observation that concordance by race has been associated with patient ratings of better care. They designed a cross-sectional study with 214 patients and 29 primary care physicians from 10 private and public outpatient clinics. They found that there were 2 dimensions of similarity: personal (in beliefs, values: a multidimensional construct) and ethnic. In multivariate models they found that perceived personal similarity, but not racial or sexual concordance, was predicted by the patient's age, education, and physicians' patient-centered communication. Perceived personal similarity and physicians' patient-centered communications predicted patients' trust, satisfaction, and intent to adhere. The significance of this study is that, unlike ethnic similarities, perceived personal similarities and physicians' patient-centered communication style are mutable, and thus amenable to interventions to improve communication. "A physician who is skilled in informing, showing respect, and supporting patient involvement can transcend issues of race and sex to establish a connection with the patient that in turn contributes to greater patient satisfaction, trust, and commitment to treatment."<sup>27</sup>

Problems have been found in provider-patient/family communication among those who were terminally ill as well. Welch et al. conducted a retrospective survey with the families of African American and White decedents. African American family members were more likely to report absent or problematic physician communication, concerns with being informed, and concerns with family support.<sup>62</sup>

Not all studies report deficient communication between African Americans and racially discordant healthcare providers. A study by Piette et al. of patient-provider communication and diabetes self-care in an ethnically diverse population found that (in contrast with other studies) among those individuals with an identified primary care provider, sociodemographically vulnerable patients reported communication that was as good as or better than that reported by their less-vulnerable counterparts. The author cites other studies of managed-care enrollees that reported similar findings.<sup>63</sup>

### **Effective interventions to improve communication:**

Basic methods to help improve communication:

- Slow down
- Use plain, non-medical language
- Show or draw pictures
- Limit the amount of information provided, and repeat it
- Produce/use easy-to-read written materials
- Confirm the patient's understanding of your message
- Create a shame-free environment
- Address the needs of patients with disabilities (e.g., hearing or vision-impaired)<sup>4</sup>

General methods shown to improve patient adherence to treatment include:

- Simplify the treatment regimen
- Use motivational interviewing principles such as the 5 A's Behavior Change Model for Self-Management Support Intervention<sup>64, 65</sup> (see Appendix)
- Use a participatory approach
- Use team-change interventions (assigning some responsibilities to health professionals other than physician)<sup>3</sup>

Involving a coordinated interdisciplinary team in the care of the patient and family is more effective in improving communication than relying on a single healthcare provider such as the physician.<sup>3</sup>

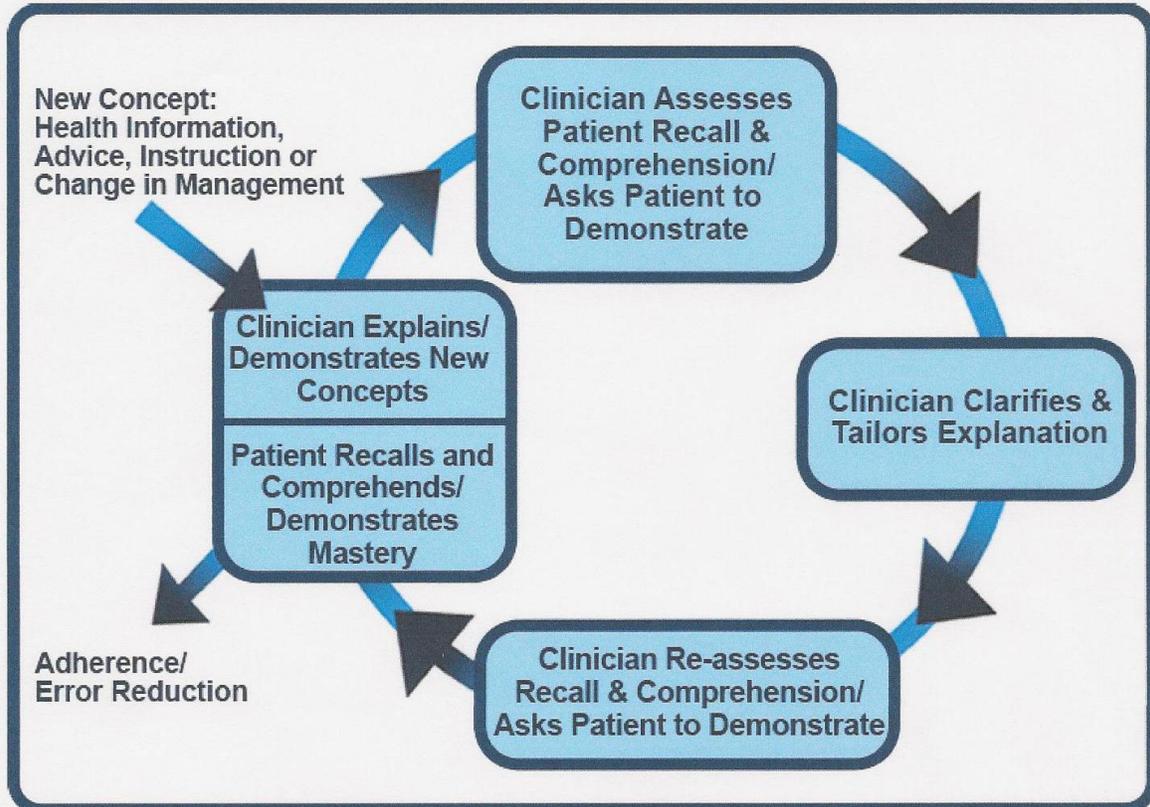
Training programs in communication skills for healthcare providers that emphasize patient-centeredness and focus on the affective dimensions of communication have face validity for improving patient-physician communication in race-discordant relationships.<sup>60</sup> The odds of patient adherence are 1.62 times higher when the physician has had communication training than when the physician has received no training.<sup>21</sup>

Health literacy affects patient understanding and adherence. A large portion of the population does not have adequate health literacy to understand treatment regimens and make informed decisions regarding their health care, and the problem is exacerbated among vulnerable populations such as the elderly, minority and immigrant populations, those with low income, and those who are physically or mentally impaired.<sup>66, 67</sup> Screening for health literacy, especially among vulnerable populations, has been recommended as a way to discern the information needs of the patient and to tailor communication to the patient's level of understanding. Several job aids are available from the Health Resources and Services Administration to aid in screening for health literacy. These include: The Newest Vital Sign Assessment, the Rapid Estimate of Adult Literacy in Medicine (REALM), and the Plain Language G.R.I.D. (See Health Professional Resources section) A simple method of assessing patient understanding is the Teach-Back/Show-Me Method.<sup>4</sup> (see Figure 2)

**Figure 2: Teach-Back/ Show-Me Method**

# Teach-Back / Show-Me Method

## Confirming Your Message is Understood



The content for this material was excerpted from Schillinger, D.—*Case and Commentary: Lethal Cap. Morbidity & Mortality Rounds on the Web*, Agency for Healthcare Research and Quality. Available at: <http://webmm.ahrq.gov/case.aspx?caseID=53#figure1>

The views expressed in these documents, Web sites, or other products do not necessarily reflect the official policies of the U.S. Department of Health and Human Services or the Health Resources and Services Administration, nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.

From HRSA Unified Health Communication: Addressing Health Literacy, Cultural Competency, and Limited English Proficiency. Module 2: Health Literacy Teach-Back Method: Job Aid

Davis et al. found that by involving the target population (which was approximately 70 percent African American) in the design of an intervention to increase mammography utilization at a public hospital, that design was more effective than physician recommendation alone or physician recommendation plus an easy-to-read brochure. The intervention, built on top of physician recommendation and the brochure, included a 12-minute, interactive educational and motivational program that incorporated a soap-opera-style video developed in collaboration with women from the target population. Twenty-nine percent of those in the intervention group

followed recommendations for mammography screening, compared with 18-21 percent in the other group.<sup>68</sup>

Kim et al. studied the use of a CD-ROM shared decision-making program at the Veterans Administration Health Center, and found that patients with newly diagnosed prostate cancer found the information satisfactory and useful in self-selecting a treatment option. However, prostate cancer knowledge scores were variable, and treatments that patients actually underwent differed from their initial selection about two times in three. This raised doubts as to whether the participants were sufficiently well informed after the video intervention to make appropriate treatment choices. Prostate cancer knowledge was more closely correlated with health literacy than with use of the intervention.<sup>69</sup>

In general, studies of use of decision aids such as consult tapes, letters, or videotapes, indicate they were useful in improving knowledge and satisfaction, though not necessarily in decreasing anxiety. Patients who used a question prompt list provided to them prior to palliative consultation asked significantly more questions and discussed significantly more issues with physicians than those who did not use the list, and users found the list helpful, but there were no differences between groups in how they perceived their information needs were met. Viewing a pre-consult videotape by recently diagnosed breast cancer patients lessened distress in single patients and increased satisfaction with the consultation among minority patients. Use of decision-aids seems to increase patient knowledge (though not uniformly) and reduce decisional uncertainty without increasing anxiety, and these aids were acceptable to patients.<sup>32</sup>

### ***The usefulness of the family conference:***

Family conferences can facilitate communication, enhance family inclusion, promote interdisciplinary coordination, improve the exchanging and sharing of information, and help to negotiate decisions. One of most important concepts identified by patients and families—the importance of everyone being on “same page”—can be accomplished through the use of the family conference.<sup>20</sup>

In studies of family meetings in the intensive care unit setting, families were more satisfied with communication and perceived less conflict with clinicians when clinicians spent more time listening and less time talking, and assured the family that the patient would not be abandoned prior to death and would be kept comfortable.<sup>70, 71</sup> In addition, families feel more supported and express increased satisfaction with care when physicians address spiritual needs of the patient and family, volunteer clinician statements of support for the family’s decisions about care, and provide explicit recommendations regarding withdrawal of life support.<sup>72</sup>

Sharma et al. discuss the importance of the following in cross-cultural family meetings:

- Explicitly assessing patient and family preferences related to the communication of “bad news”, including the right of informed refusal;
- Exploring the family’s preferred role in decision-making (individual autonomy vs. family-centered decision making);

- Exploring patient and family values and preferences, including religious and spiritual beliefs that may impact end-of-life preferences, filial roles, respect for authority, and attitudes toward advance directives;
- Understanding and supporting the family’s treatment decisions (including accommodating desires for more aggressive care, and use of respectful negotiation when this is contraindicated);
- Use of compassion, kindness, and respect to help build trust.<sup>71</sup>

### Six Steps for Communicating Effectively: The SPIKES Model

The recommended six-step protocol has been adapted from *How to Break Bad News: A Guide for Health Care Professionals* by Robert Buckman.<sup>73, 74</sup> He and colleagues have subsequently developed a mnemonic, SPIKES, that helps providers remember the protocol.<sup>75</sup> Others have reported similar approaches.<sup>76, 77</sup>

Although the SPIKES model is designed as a guide to effectively communicate bad news to patients, the protocol may be viewed more generally as *a model for communicating any important information* to patients and families, or within the cancer care team. The process allows for cultural exploration and sensitivity.

**Table 5: SPIKES Protocol**

<b>SPIKES</b>	<b>Six-step protocol to communicate effectively</b>
<b>S</b> etting. Getting started.	Set the stage.
<b>P</b> erception.	What does the patient know?
<b>I</b> nvitation.	How much does the patient want to know?
<b>K</b> nowledge.	Share the information.
<b>E</b> motion.	Respond to feelings.
<b>S</b> ubsequent.	Plan next steps and follow-up.

During the first three steps, prepare to share the information. Start by gathering the facts. Then sit down comfortably and assess the patient’s understanding. Inquire what the patient knows and what he or she would like to know.

Some of these first three steps can be completed before the session at which the news is actually delivered.

During the last three steps, manage the information carefully. Deliver the news clearly, succinctly, and without using jargon. Once the facts have been stated, stop talking. Allow time for the patient’s reactions and respond to them. Once the patient is settled, plan for follow-up.

Don't consider this protocol to be a script to be followed rigorously. Use it as a tool to guide important aspects of an interaction in which difficult information is shared.

### ***Step 1: Set the stage***

Before starting to communicate any news, plan what will be discussed. Confirm the medical facts of the case. Ensure that all needed information is available. If this is an unfamiliar task, rehearse what you will say. Don't delegate the task. If several team members will be present, it may be helpful for the team to meet to plan the communication in advance.

Create an environment that is conducive to effective communication. Ensure privacy and adequate seating. Ensure that a box of facial tissues and a glass of water are handy.

Allot adequate time for the discussion. Do not slip this into a short interval between other critical tasks. Prevent interruptions. Arrange to hold telephone calls and pages or give them to someone else.

Determine who else the patient would like to have present for the discussion. This might include family, significant others, surrogate decision makers, and/or key members of the interdisciplinary team (such as a nurse, social worker, chaplain, etc.).

### ***Step 2: What does the patient know?***

Start the discussion by establishing what the patient and family know about the patient's health. With this information ascertain whether the patient and family will be able to comprehend the information.

Questions might include:

- "What do you understand about your illness?"
- "How would you describe your medical situation?"
- "Have you been worried about your illness or symptoms?"
- "What did other doctors tell you about your condition or procedures that you had?"
- "When you first had symptom X, what did you think it might be?"
- "What did Doctor X tell you when he sent you here?"
- "Did you think something serious was going on when...?"

Occasionally a patient will fall silent and seem completely unprepared or unable to respond. To ease the situation and stimulate discussion, try to clarify what the patient understands about his or her medical history and recent investigations. Identify absent family members or others on whom the patient relies. If this is ineffective and the patient remains silent, or if it appears the patient requires more support, it may be better to reschedule the meeting for another time.

### ***Step 3: How much does the patient want to know?***

Next, establish what and how much each patient wants to know.

People handle information differently, depending on their race, ethnicity and culture, religion, socioeconomic class, and individual characteristics. Each person has the right to voluntarily decline to receive any information and may designate someone else to communicate on his or her

behalf. Ask the patient and family how they would like to receive information. If the patient prefers not to receive critical information, establish to whom to give information.

Possible questions include:

- “If this condition turns out to be something serious, do you want to know?”
- “Are you the kind of person who likes to know all the facts?”
- “Would you like me to tell you the full details of your condition? If not, is there somebody else you would like me to talk to?”
- “Some people really do not want to be told what is wrong with them, but would rather their families be told instead. Which do you prefer?”
- “Do you want me to go over the test results now, and explain exactly what I think is wrong?”
- “Whom would you like me to talk to about these issues?”

The way the patient answers the questions will give clues as to her or his educational level, verbal fluency, and family dynamics. Listen carefully and observe everyone’s responses to your questions. Use this experience to influence how you deliver your news.

### **Advance preparation**

All of the discussion to this point is about preparation to give the diagnosis and prognosis. Some of that preparation might best occur well before the information is actually given. The initial assessment, and subsequent discussions that prepare the patient for critical tests, all provide opportunities to determine what the patient already knows and how he or she would like to have information handled.

Provide periodic information and caution that the news might not always be good. With this incremental approach and periodic “warning shots,” the patient and family may be better prepared for bad news.

### **When the family says “don’t tell”**

Many times, family members will ask the physician not to tell the patient the diagnosis or other important information. While it is the physician’s legal obligation to obtain informed consent from the patient, an effective therapeutic relationship requires a congenial alliance with the family.

Rather than confronting the request with, “I have to tell the patient,” inquire why they are concerned. Possible questions include:

- “Why don’t you want me to tell the patient?”
- “What is it that you are afraid I will say?”
- “Tell me about your past experience with cancer.”
- “Is there a personal, cultural, or religious context that you want me to know about?”

Suggest that you go to the patient together to ask how much he or she wants to know about his or her health and what questions there might be. Share anecdotes and talk about the pain of secrecy and the opportunities that come with open communication.

These situations may require significant negotiation. In particularly difficult cases, support from the institutional ethics committee may be helpful. Ultimately it may be decided, after discussion with the patient, that details of diagnosis and prognosis and treatment decisions will be discussed only with the family. However, unless the patient has previously indicated that s/he wants no information, hiding the diagnosis or important information about prognosis or treatment from the patient is neither ethical nor legally acceptable.

Physicians do not need to feel constrained to practice in a way that compromises care or feels unethical. If the physician and the family cannot come to agreement, the physician may choose to withdraw from the case and transfer care to another physician.

There are ethnic and cultural differences in the preferred handling of information. While knowledge of such differences is useful as a background, global conclusions about them rarely help with decision making for an individual. It is best to ask the patient early in the clinical relationship about general preferences for the handling of medical information, before significant information needs to be shared. This will help the clinician avoid making a misstep.

#### ***Step 4: Share the information***

Deliver the information in a sensitive but straightforward manner.

Start by letting the patient know that you have bad news, then share the facts. Say it, and then stop. Avoid delivering all of the information in a single, steady monologue. Use simple language that is easy to understand. Avoid technical jargon or euphemisms. Pause frequently. Check for understanding. Use silence and body language as tools to facilitate the discussion.<sup>41</sup>

Do not minimize the severity of the situation. Well-intentioned efforts to “soften the blow” may lead to vagueness and confusion.

You might choose to break the bad news by using language like:

- “I feel badly to have to tell you this, but the growth turned out to be cancer.”
- “I’m afraid the news is not good. The biopsy showed that you have colon cancer.”
- “Unfortunately, there’s no question about the test results: it is cancer.”
- “The report is back, and it’s not as we had hoped. It showed that there is cancer in your colon.”
- “I’m afraid I have bad news. The bone marrow biopsy shows that you have leukemia.”

#### **“I’m sorry.”**

The phrase “I’m sorry” may be interpreted by the patient or the family to imply that the physician is responsible for the situation. It may also be misinterpreted as pity or aloofness. If you use the phrase, adjust it to show empathy. For example, instead of saying, “I’m sorry to have to tell you this,” the phrase, “I wish things were different” may be equally effective at communicating empathy without conveying responsibility for the condition.<sup>78</sup>

### ***Step 5: Respond to feelings***

Patients and families respond to bad news in a variety of ways. Some respond emotionally with tears, anger, sadness, love, anxiety, relief, or other strong emotions. Others experience denial, blame, guilt, disbelief, fear, or a sense of loss or shame, or may even intellectualize why the situation is happening. A few may demonstrate reflexive psychophysiological responses such as “fight or flight” and may even try to bolt from the room or totally withdraw into themselves.

Outbursts of strong emotion make many physicians (and other clinicians) uncomfortable.<sup>79</sup> Give the patient and family time to react. Be prepared to support them through a broad range of reactions.

Listen quietly and attentively. Acknowledge their emotions. Ask them to describe their feeling:

- “I imagine this is difficult news...”
- “You appear to be angry. Can you tell me what you are feeling?”
- “Does this news frighten you?”
- “Tell me more about how you are feeling about what I just said.”
- “What worries you most?”
- “What does this news mean to you?”
- “I wish the news were different.”
- “I’ll try to help you.”
- “Is there anyone you would like me to call?”
- “I’ll help you tell your son.”
- “Your mom and dad are sad now. They’ll feel better when you get better.”

Remind them that their responses are normal. Have a box of facial tissues available. Nonverbal communication may also be very helpful. Consider touching the patient in an appropriate, reassuring manner, if this is culturally appropriate for the patient. Offer a drink of water, a cup of tea, or something else that might be soothing.

Allow time for the patient and family to express all of their immediate feelings. Don’t rush them. Once the emotion is spent, most people will be able to move on. This usually lasts only a few minutes. The most frequent physician error is to talk.<sup>80</sup> This can be counter-productive. A shared understanding of the news and its meaning enhances the clinician-patient relationship and facilitates future decision making and planning.

### ***Step 6: Plan next steps and follow-up***

Establish a plan for the next steps. This may include gathering additional information or performing further tests or treating current symptoms. It may include helping parents tell their child about the illness and what treatment will be like. Arrange for appropriate referrals. Explain plans for additional treatment. Discuss potential sources of emotional and practical support (such as family, significant others, friends, social worker, spiritual counselor, peer support group, professional therapist, hospice, home health agency, etc.).

Reassure the patient and family that they are not being abandoned and that the healthcare team will be actively engaged in an ongoing plan to help. Indicate how the patient and family can reach you to answer additional questions. Establish a time for a follow-up appointment.

Ensure that the patient will be safe when he or she leaves. Is the patient able to drive home alone? Is the patient distraught, feeling desperate, or suicidal? Is there someone at home to provide support?

At future visits, elements of this protocol may need to be revisited. Many patients and families require repetition of the news to gain a complete understanding of their situation.

### **When Language is a Barrier**

This same six-step protocol for communicating information effectively can be used when the patient and health provider do not speak the same language. The assistance of an experienced translator who understands medical terminology and is comfortable translating bad news is required. There are several services in North America that offer translation by telephone if there is no translator available onsite. Brief translators before the interview and reassure them that their role is only to translate. Verify that they will be comfortable translating the news you are about to give.

Avoid using family members as primary translators. It confuses their roles in the family unit and may raise issues of confidentiality. Additionally, family members may not know how to translate the medical concepts the health provider is trying to convey, and/or they may modify the news to protect the patient. Instead, when family members are present who do speak both languages, ask them to supplement the primary translation and support the patient and other members of the family.

When working with a translator, sit in a triangular arrangement so that you can face and speak directly to the patient, yet still turn to look at the translator. Speak in short segments, and then give the translator time to convey the information. Verify what the patient and family understand and check for an emotional response.

### **Summary:**

It is not possible to make assumptions about individuals' information needs and preferences based on their demographic characteristics or cultural background. Healthcare providers should clarify what information the patient and caregivers need individually, and tailor the information accordingly, recognizing that each person's needs are likely to vary at different times throughout the course of the illness. It is essential, however, that survival information be given in a way that allows the patient to prepare for death, finalize affairs, and say good-bye to loved ones.<sup>23</sup>

### **Key Take-Home Points**

1. The way healthcare providers communicate with patients and families affects important outcomes of care.
2. The vast majority of Americans, including African Americans, prefer honest, straightforward communication with healthcare providers that focuses on them as

persons, balances hope and realism, and involves them in the processes of care and in making treatment decisions.

3. African Americans represent a diverse cultural and religious diaspora. Obtain information directly from the patient and family rather than making assumptions about culture or beliefs.
4. Use the 6-step approach (SPIKES) to communicate with patients and families about diagnoses of life-threatening illnesses, prognosis, and treatment options.

*From SPIKES Step 1: Getting started:*

- Create an environment conducive to effective communication.
- Ensure that the right people are present.

*From SPIKES Step 2: Finding out what the patient knows:*

- Start by establishing what the patient and family know about the patient's health.

*From SPIKES Step 3: Finding out how much the patient wishes to know:*

- People handle information differently.
- Each person has the right to voluntarily decline to receive information and may designate someone else to communicate on his or her behalf. Find out how the patient would like to receive information.
- Rather than confronting family members' request not to tell with "I have to tell the patient," explore why they do not want you to tell the patient. Suggest going to the bedside together to find out what the patient wants to know.

*From SPIKES Step 4: Sharing the information:*

- Deliver the information in a sensitive but straightforward manner.

*From SPIKES Step 5: Responding to patient and family feelings:*

- Outbursts of strong emotion are an expected component of information sharing.
- Learn how to cope with this.

*From SPIKES Step 6: Planning, follow-up:*

- Establish a plan for next steps.
5. Verify that translators will be comfortable and sufficiently skilled in translating the news you are about to give.
  6. Avoid using family members as primary translators. It confuses their role, frequently compromises the therapeutic quality of the interview, and may compromise some patients' desire for confidentiality.

## **Pearls**

1. Using patient-centered communication helps to transcend issues of race and sex to establish a connection with patients and families that can lead to a better care experience.

2. Don't use jargon. Patients often don't know that 'lesion,' 'tumor,' 'growth,' 'nodule,' and 'cancer' may all be the same thing. Use the C (cancer) word. Be clear.
3. If you are feeling overwhelmed by the patient's and family's emotional response, name that emotion, that is, "I can see that you are feeling overwhelmed." Whatever you are feeling is usually a reflection of the patient's emotions.
4. Make a partnership with your patient and the family caregiver(s); draw them into the interdisciplinary team, and foster their active participation in the care plan.

## **Pitfalls**

1. Giving exact predictions of survival. Instead of saying, "your survival is 6 months," try, "On average, persons with your type and stage of cancer live for months, but everyone is different. How you do over the next month or so will help us better determine what to expect."
2. Talking too much. Instead, listen more, and give the patient and family time to react.
3. Using jargon and euphemisms such as "the growth," or "The response rate is 50 percent," instead of clear language; for example, the word "cancer," or "In half of patients the treatment will shrink the cancer for a time, but the cancer will not be cured".
4. Trying to 'soften the blow' by being falsely hopeful.

## **Health Professional Resources:**

Misra-Hebert AD. Physician cultural competence: Cross-cultural communication improves care. *Cleveland Clinic Journal of Medicine*. 2003;70(4):289-303.

<http://www.ccjm.org/content/70/4/289.full.pdf> Accessed 7/11/12

NCI Monograph: Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. <http://outcomes.cancer.gov/areas/pcc/communication/monograph.html> Accessed 6/29/12

HRSA Health Literacy. <http://www.hrsa.gov/publichealth/healthliteracy/index.html> Accessed 7/11/12

USDHHS: A Physician's Practical Guide to Culturally Competent Care.

<https://cccm.thinkculturalhealth.hhs.gov/> Accessed 6/29/12

USDHHS Office of Minority Health. National Standards for Culturally and Linguistically Appropriate Services in Health Care: Final Report. 2001

<http://minorityhealth.hhs.gov/assets/pdf/checked/finalreport.pdf> Accessed 6/29/12

## **Patient and Family Resources**

NCI Publications Locator <https://pubs.cancer.gov/ncipl/home.aspx?js=1> Accessed 7/11/12

NCI's Cancer Information Service. 1-800-4-CANCER

<http://www.cancer.gov/aboutnci/cis/page1> Accessed 7/11/12

Palliative Care: The Relief You Need When You're Experiencing the Symptoms of Serious Illness. <http://www.ninr.nih.gov/NR/rdonlyres/01CC45F1-048B-468A-BD9F->

[3AB727A381D2/0/NINR PalliativeBrochure Brochure 12 Layout Version 508.pdf](#)  
Accessed 7/11/12

## Appendix 1

# Models for Promoting Culturally Competent Patient-Provider Communication

### BATHE Model

B—Background  
A—Affect  
T—Trouble  
H—Handling  
E—Empathy

### CRASH Model

C—Consider culture  
R—Respect  
A—Assess and affirm  
S—Sensitivity and self-awareness  
H—Humility

### ESFT Model

E—Explanatory model of health and illness  
S—Social and environmental factors  
F—Fears and concerns  
T—Therapeutic contracting

### ETHNIC Model

E—Explanation  
T—Treatment  
H—Healers  
N—Negotiation  
I—Intervention  
C—Collaboration

### Kleinman's Nine Questions

- ♦ What do you call your problem?
- ♦ What name does it have?
- ♦ What do you think caused your problem?
- ♦ Why do you think it started when it did?
- ♦ What does your sickness do to you? How does it work?
- ♦ How severe is it? Will it have a short or long course?
- ♦ What do you fear most about your disorder?
- ♦ What are the chief problems that your sickness has caused for you?
- ♦ What kind of treatment do you think you should receive?
- ♦ What are the most important results you hope to receive from the treatment?

### LEARN Model

L—Listen  
E—Explain  
A—Acknowledge  
R—Recommend  
N—Negotiate

The content for this material was excerpted from the U.S. Department of Health and Human Services, Office of Minority Health. *A Physician's Practical Guide to Culturally Competent Care*. Available at: <https://cccm.thinkculturalhealth.org/default.asp>

## Use of 5 A's Behavior Change Model for Self-Management Support Intervention [Glagow et al., Whitlock et al.]

1. **Assess:** Beliefs, behavior & knowledge
2. **Advise:** Provide specific information about health risks and benefits of change
3. **Agree:** Collaboratively set goals based on patient's interest and confidence in their ability to change the behavior
4. **Assist:** Identify personal barriers, strategies, problem-solving techniques, and social/environmental support
5. **Arrange:** Specify plan for follow up

### References:

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<sup>1</sup> Green AR, Carney DR, Pallin DJ, et al. Implicit bias among physicians and its prediction of thrombolysis decisions for Black and White patients. *Society of General Internal Medicine*. 2007;22:1231-1238.

<sup>2</sup> Penner LA, Dovidio JF, West TV, et al. Aversive racism and medical interactions with Black patients: A field study. *Journal of Experimental Social Psychology* (2009), doi:10.1016/j.jesp.2009.11.004.

<sup>3</sup> Cooper LA. A 41-year-old African American man with poorly controlled hypertension: Review of patient and physician factors related to hypertension treatment adherence. *JAMA*. 2009;301(12):1260-1272.

<sup>4</sup> Health Resources and Services Administration. Effective Communication Tools for Health Professionals. [Free online course] <http://www.hrsa.gov/publichealth/healthliteracy/index.html> Accessed 7/11/12

<sup>5</sup> Quinn GP, Jimenez J, Meade CD, et al. Enhancing oncology health care provider's sensitivity to cultural communication to reduce cancer disparities: A pilot study. *J Canc Educ*. 2011;26:322-325.

<sup>6</sup> Management Sciences for Health & HRSA Office of Minority Health and Bureau of Primary Care. Introduction to Cultural Competence in: The Provider's Guide to Quality and Culture: Reducing Health Disparities in Asian American and Pacific Islander. <http://erc.msh.org/aapi/cc4.html> Accessed 7/11/12

<sup>7</sup> Tervalon M, Murray-Garcia J. Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. *J Health Care Poor Underserved*. 1998;9:117-125.

<sup>8</sup> Clayton JM, Hancock K, Parker S, et al. Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psycho-Oncology*. 2008;17:641-659.

- 
- <sup>9</sup> Dufault K, Martocchio BC. Symposium on compassionate care and the dying experience. Hope: its spheres and dimensions. *Nurs Clin North Am*. 1985;20(2):379-391.
- <sup>10</sup> Committee on Quality Health Care in America, Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*. Washington, DC: National Academies Press; 2001. p.48-50.
- <sup>11</sup> Levinson W, Lesser CS, Epstein RM. Developing physician communication skills for patient-centered care. *Health Affairs*. 2010;29(7):1310-1318.
- <sup>12</sup> Travaline JM, Ruchinskas R, D'Alonzo GE. Patient-physician communication: Why and how. *JAOA*. 2005;105(1):13-18.
- <sup>13</sup> Duffy FD, Gordon GH, Whelan G, et al. Assessing competence in communication and interpersonal skills: the Kalamazoo II report. *Acad Med*. 2004;79(6):495-507.
- <sup>14</sup> Gimpel JR, Boulet DO, Errichetti AM. Evaluating the clinical skills of osteopathic medical students. *J Am Osteopath Assoc*. 2003;103(6):267-279.
- <sup>15</sup> Makoul G. Communication skills education in medical school and beyond. *JAMA*. 2003;289(1):93.
- <sup>16</sup> American Association of Colleges of Nursing. *The essentials of baccalaureate education for professional nursing practice*. Washington, DC. 2008. pp7-8. Accessed online 7/11/12 <http://www.aacn.nche.edu/Education/pdf/BaccEssentials08.pdf>
- <sup>17</sup> ANA Position Statement (2010): *Registered Nurses' Roles and Responsibilities in Providing Expert Care and Counseling at the End of Life*.
- <sup>18</sup> Thomas AC, Chair. The National Organization of Nurse Practitioner Faculties Task Force. *Nurse Practitioner Core Competencies*. April 2011. <http://www.nonpf.com/displaycommon.cfm?an=1&subarticlenbr=14> Accessed 6/29/12
- <sup>19</sup> The National CNS Competency Task Force. *Clinical Nurse Specialist Core Competencies: Executive Summary. 2006-2008*. ©2010. National CNS Competency Task Force. <http://www.aacn.org/wd/certifications/Docs/corecnscompetencies-execsumm.pdf> Accessed 6/29/12
- <sup>20</sup> Cohen Fineberg I, Kawashima M, Asch SM. Communication with families facing life-threatening illness: A research-based model for family conferences. *J Palliat Med*. 2011;14(4):421-427.
- <sup>21</sup> Haskard Zolnierok KB, DiMatteo MR. Physician communication and patient adherence to treatment: A meta-analysis. *Med Care*. 2009;47(8):826-834.

- 
- <sup>22</sup> National Quality Forum (NQF). A Comprehensive Framework and Preferred Practices for Measuring and Reporting Cultural Competency: A Consensus Report. Washington, DC:NQF;2009.
- <sup>23</sup> Parker SM, Clayton JM, Hancock K, et al. A systematic review of prognostic/end-of-life communication with adults in advanced stages of a life-limiting illness: Patient/caregiver preferences for the content, style, and timing of information. *JPSM*. 2007;34(1):81-93.
- <sup>24</sup> Siminoff LA, Graham GC, Gordon NH. Cancer communication patterns and the influence of patient characteristics: Disparities in information-giving and affective behaviors. *Patient Education and Counseling*. 2006;62:355-360.
- <sup>25</sup> Tay LH, Hegney D, Ang E. Factors affecting effective communication between registered nurses and adult cancer patients in an inpatient setting: a systematic review. *Int J Evid Based Healthc*. 2011;9(2):151-164.
- <sup>26</sup> Epstein RM, Street RL. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD, 2007.
- <sup>27</sup> Street RL, O'Malley KJ, Cooper LA, Haider P. Understanding concordance in patient-physician relationships: Personal and ethnic dimensions of shared identity. *Annals of Family Medicine*. 2008;6(3):198-205.
- <sup>28</sup> Green A. A person-centered approach to palliative care nursing. *Journal of Hospice and Palliative Nursing*. 2006;8(5):294-301.
- <sup>29</sup> Johnston B, Smith LN. Nurses' and patients' perceptions of expert palliative nursing care. *Issues and Innovations in Nursing Practice*. 2006:700-709.
- <sup>30</sup> Bushinski RL, Cummings KM. Practices of effective end-of-life communication between nurses and patients/families in two care settings. *Creative Nursing*. 2007;3:9-12.
- <sup>31</sup> 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 doi:10.1186/1471-2458-4-62.
- <sup>32</sup> Rodin G, Mackay JA, Zimmermann C, et al. Clinician-patient communication: a systematic review. *Support Care Cancer*. 2009;17:627-644.
- <sup>33</sup> Williams SW, Hanson LC, Boyd C, et al. Communication, decision making, and cancer: What African Americans want physicians to know. *J Palliat Med*. 2008;11(8):1221-1226.
- <sup>34</sup> Betancourt JR, Green AR, Carillo JE, Ananeh-Firempong O. Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports*. 2003;118:293-302.

- 
- <sup>35</sup> Cooper-Patrick L, Gallo JJ, Gonzales JJ, et al. Race, gender, and partnership in the patient-physician relationship. *JAMA*. 1999;282(6):583-589.
- <sup>36</sup> Matthews AK, Sellergren SA, Manfredi C, Williams M. Factors influencing medical information seeking among African American cancer patients. *Journal of Health Communication*. 2002;7:205-219.
- <sup>37</sup> Tucker CM, Herman KC, Pedersen TR, et al. Cultural sensitivity in physician-patient relationships: Perspectives of an ethnically diverse sample of low-income primary care patients. *Med Care*. 2003;41:859-870.
- <sup>38</sup> Field MJ, Cassel CK, eds. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997:59-64. ISBN:0309063728.
- <sup>39</sup> Sekimoto M, Asai A, Ohnishi M, Nishigaki E, et al. Patients' preferences for involvement in treatment decision making in Japan. *BMC Fam Pract*. 2004;5(1):1. PMID: 15053839.
- <sup>40</sup> Jadalla A, Sharaya H. A Jordanian view about cancer knowledge and attitudes. *Cancer Nurs*. 1998;21(4):269-273.
- <sup>41</sup> 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.
- <sup>42</sup> Steinhauser KE, Clipp EC, McNeilly M, et al. In search of a good death: Observations of patients, families, and providers. *Ann Intern Med*. 2000;132:825-832.
- <sup>43</sup> 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(19):2476-2482.
- <sup>44</sup> Greisinger AJ, Lorimar RJ, Aday LA, et al. Terminally ill cancer patients. Their most important concerns. *Cancer Pract*. 1997;5(3):147-154.
- <sup>45</sup> Cutcliffe JR. How do nurses inspire and instill hope in terminally ill HIV patients? *J Adv Nurs*. 1995;22(5):888-895.
- <sup>46</sup> Wittenberg-Lyles E, Goldsmith J, Ragan SL. The COMFORT Initiative: Palliative nursing and the centrality of communication. *J Hospice and Palliative Nursing*. 2010;12(5):282-292.
- <sup>47</sup> Taylor SL, Lurie N. The role of culturally competent communication in reducing ethnic and racial healthcare disparities. *Am J Manag Care*. 2004;10:SP1-SP4.
- <sup>48</sup> Cené CW, Roter D, Carson KA, et al. The effect of patient race and blood pressure control on patient-physician communication. *J Gen Intern Med*. 2009;24(9):1057-1064
- <sup>49</sup> Stewart MA. Effective physician-patient communication and health outcomes: A review. *Can Med Assoc J*. 1995;152(9):1423-1433.

- 
- <sup>50</sup> Bertakis KD, Roter D, Putnam SM. The relationship of physician medical interview style to patient satisfaction. *J Fam Pract.* 1991;32:175-181.
- <sup>51</sup> Levinson W, Roter DL, Mullooly JP, et al. Physician-patient communication: the relationship with malpractice claims among primary care physicians and surgeons. *JAMA.* 1997;277:553-559.
- <sup>52</sup> Moore RJ, Spiegel D, eds. *Cancer, Culture and Communication.* ©2004. Kluwer Academic /Plenum Publishers. New York, NY.
- <sup>53</sup> Mack JW, Weeks JC, Wright AA, et al. End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol.* 2010;28 10.1200/JCO.2009.25.4672.
- <sup>54</sup> Mack JW, Paulk ME, Kasisomayajula V, Prigerson HG. Racial disparities in the outcomes of communication on medical care received near death. *Arch Intern Med.* 2010;170(17):1-8.
- <sup>55</sup> Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA.* 2008;300(14):1665-1673.
- <sup>56</sup> Rhodes RL, Teno JM, Welch LC. Access to hospice for African Americans: Are they informed about the option of hospice? *J Palliat Med.* 2006;9(2):268-272.
- <sup>57</sup> Zapka JG, Carter CL, Hennessy W, et al. Care at the end of life: Focus on communication and race. *J Aging Health.* 2006;18:791-813.
- <sup>58</sup> van Ryn M, Burke J. The effect of patient race and socio-economic status on physicians' perceptions of patients. *Soc Sci Med.* 2000;50(6):813-828.
- <sup>59</sup> Tessler Lindau S, Basu A, Leitsch SA. Health literacy as a predictor of follow-up after an abnormal pap smear: A prospective study. *J Gen Intern Med.* 2006;21:829-834.
- <sup>60</sup> Cooper LA, Roter DL, Johnson RL, et al. Patient-centered communication, ratings of care, and concordance of patient and physician race. *Ann Intern Med.* 2003;139:907-915.
- <sup>61</sup> Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient-physician communication during medical visits. *Am J Public Health.* 2004;94:2084-2090.
- <sup>62</sup> Welch LC, Teno JM, Mor V. End-of-life care in Black and White: Race matters for medical care of dying patients and their families. *JAGS.* 2005;53:1145-1153.
- <sup>63</sup> Piette JD, Schillinger D, Potter MB, Heisler M. Dimensions of patient-provider communication and diabetes self-care in an ethnically diverse population. *J Gen Intern Med.* 2003;18:624-633.
- <sup>64</sup> Glasgow RE, Emont S, Miller DC. Assessing delivery of the five 'As' for patient-centered counseling. *Health Promotion International.* 2006;21(3):245-255.

- 
- <sup>65</sup> Whitlock EP, Orleans CT, Pender N, Allan J. Evaluating primary care behavioral counseling interventions. An evidence-based approach. *American Journal of Preventive Medicine*. 2002;22:267-284.
- <sup>66</sup> Glassman P. Health literacy. *National Network of Libraries of Medicine*. Last updated 6/29/12 <http://nmlm.gov/outreach/consumer/hlthlit.html>
- <sup>67</sup> Kutner M, Greenberg E, Jin Y, Paulsen C. (2006). The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy (NCES 2006-483). U.S. Department of Education. Washington, DC: National Center for Education Statistics.
- <sup>68</sup> Davis TC, Berkel HJ, Arnold CL, et al. Intervention to increase mammography utilization in a public hospital. *J Gen Intern Med*. 1998;13:230-233.
- <sup>69</sup> Kim SP, Knight SJ, Tomori C, et al. Health literacy and shared decision making for prostate cancer patients with low socioeconomic status. *Cancer Investigation*. 2001;19(7):684-691.
- <sup>70</sup> 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(7):1484-1488.
- <sup>71</sup> Sharma RK, Sydney MDy. Cross-cultural communication and use of the family meeting in palliative care. *Am J Hospice & Palliat Med*. 2011;28(6):437-444.
- <sup>72</sup> Gries CJ, Curtis JR, Wall RJ, Engelberg RA. Family member satisfaction with end-of-life decision making in the ICU. *Chest*. 2008;133(3):704-712.
- <sup>73</sup> Buckman R. *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore, MD: The Johns Hopkins University Press; 1992:65-97.
- <sup>74</sup> Garg A, Buckman R, Kason Y. Teaching medical students how to break bad news. *CMAJ*. 1997;156(8):1159-1164.
- <sup>75</sup> Baile WF, Buckman R, Lenzi R, et al. SPIKES-A six-step protocol for delivering bad news: Application to the patient with cancer. *Oncologist*. 2000;5(4):302-311.
- <sup>76</sup> Faulkner A, Maguire P. *Talking to Cancer Patients and Their Relatives*. Oxford, England: Oxford University Press;1996:58-70.
- <sup>77</sup> Quill TE, Townsend P. Bad news: Delivery, dialogue, and dilemmas. *Arch Intern Med*. 1991;151:463-468.
- <sup>78</sup> Quill TE, Arnold RM, Platt F. "I wish things were different": Expressing wishes in response to loss, futility, and unrealistic hopes. *Ann Intern Med*. 2001;135:551-555.
- <sup>79</sup> Clever SL, Tulsky JA. Dreaded conversations: Moving beyond discomfort in patient-physician communication. *J Gen Intern Med*. 2002;17:884-885.

---

<sup>80</sup> Roter DL, Larson S, Fischer GS, et al. Experts practice what they preach: A descriptive study of best and normative practices in end-of-life decisions. *Arch Intern Med.* 2000;160:3477-3485.

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## Self-Assessment Questions

### Module 7AA: Communicating Effectively

1. Mr. Petty is a 58-year-old fast-food worker who had unresectable rectal cancer. The cancer initially disappeared from CT scans after combination chemotherapy and radiotherapy. He has always indicated he has faith in God and the doctor, and has never demonstrated much interest in the details of therapy. Yet, he has always made decisions by himself. At the present office visit, he complains of abdominal discomfort and poor appetite; physical examination shows a large nodular liver. After establishing an appropriate setting, you would next:
  - a). tell him cancer has spread to the liver
  - b). tell him he's in God's hands now
  - c). determine what he understands
  - d). determine who he relies on for support
  
2. Mrs. Johnson is a 62-year-old former cleaning woman with Rai Stage IV chronic lymphocytic leukemia, poorly controlled diabetes mellitus and consequent peripheral neuropathy, renal insufficiency, and coronary artery disease. She has advanced congestive heart failure that is not responding well to medical therapy. Her daughter asks you not to talk to her about the cancer because it "would take away all hope." She wants you to give chemotherapy, but tell the patient it is "strong antibiotics." Your best next response is to:
  - a). ask the daughter more about what kind of hope she would like her mother to have
  - b). agree and wait for a future opportune time
  - c). disagree and tell the patient the truth
  - d). tell the daughter you have to tell the patient the truth
  
3. Mr. Oliver is a 53-year-old farmer with non-small cell lung cancer metastatic to liver and bone. In talking about the future course of his illness, he begins to cry. His wife is also tearful. Besides having facial tissues available, the next best approach is to:
  - a). continue with the discussion
  - b). reassure him
  - c). be silent
  - d). tell them to stop crying
  
4. You are completing a family meeting for Mrs. Gordon, who has moderately advanced Alzheimer's-type dementia and newly diagnosed unresectable pancreatic cancer, in

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which you have been describing the nature and likely course of the disease. The patient is unable to participate. In concluding the meeting, it is most important to:

- a). summarize the plan of care
- b). reassure the family that all will be well
- c). tell them to be strong
- d). summarize their decisions about code status

## Self-Assessment Answers

### Question 1. The correct answer is: c)

This question is aimed at understanding the steps of information giving. It is best to ascertain the patient's understanding of his situation as well as how much information he wants to know before giving the new medical information. Euphemisms, even well intentioned, won't build a therapeutic relationship for the future. They may be interpreted as abandonment. Finding out his support system is important, but not the best answer to the question.

### Question 2. The correct answer is: a)

This question is aimed at the healthcare provider's response when the family says "don't tell." The best next step is to assess why the family member is making the request. Confronting the family by insisting you will tell or going around them will only create mistrust and likely endanger the therapeutic relationship. Not telling is also inappropriate without ascertaining that is the patient's desire. After talking with the family member, the next aim may be to have a family meeting to ask the patient how she wants medical information handled.

### Question 3. The correct answer is: c)

This question is aimed at the healthcare provider's response to strong emotion. Silence usually is best at first. Telling them to stop crying directly or providing premature reassurance gives them the same message—that you are not acknowledging or interested in supporting them through their emotional response to the news. Continuing with the discussion in spite of tears can also give the same unfortunate message.

### Question 4. The correct answer is: a)

This question is aimed at understanding how to finish the interview. It is best to conclude with a summary of the plan for the next steps. Reassurance that "all will be well" may not, in fact, be true. Avoid unintentional messages to not complain. Although a decision about code status may

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be part of the plan, it should generally not be a single focus of care and should only be summarized in the context of the total plan of care, including what will be done.