How Do I Tell You? What Words Do I Use?

Communicating the 'Bad News' in a Culturally Respectful Way

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Initiating end of life discussions is difficult even for the most experienced practitioners. Topics this interactive workshop will explore include: assessing for cues, identifying roadblocks, communicating in context, acknowledging the tensions, and how to negotiate culturally acceptable goals of care.

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The Centre for Intercultural Learning provides an understanding of the terms 'low-context' and 'high-context cultures'.

High-Context – Edward Hall describes cultures as either high-context or low-context. High-context cultures rely heavily on the context of an interaction to convey the message. Words are secondary in importance. The responsibility for comprehension lies mainly with the receiver of the message, who should be attuned to the subtle messages conveyed by such markers as silence, tone, the presence or absence of significant people, etc. It is proposed within this framework that, for example, First Nations Canadians and Japanese generally value high-context communication.

Low-Context – Low context communication is explicit, so that all the information is directly contained in the utterances, and there is little or no implied meaning apart from the words that are being said. Within this framework, for example, Scandinavians and Swiss-Germans are generally seen to value low-context communication.

Source: Intercultural Glossary, Centre for Intercultural Learning, Foreign Affairs and International Trade Canada, http://www.dfait-maeci.gc.ca

The following resource material has been adapted from a workshop by Stella Ting-Toomey, author of Communicating Across Cultures (1999).

Low Context Values

- "I" identity
- Individual rights
- Immediate family
- Outcome oriented
- Short/medium-term planning & contract
- Respect for Individuals

High Context Values

- "We" identity
- In-group obligations
- Extended family
- Process-oriented
- Long-term planning & trust-building
- Respect for Elders

Notes: ____

<table>
<tr><th colspan="3">Low-Context Communication
Examples
←-----------------------------</th><th colspan="2">High-Context Communication
Examples
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<tr><td>Germany
Switzerland
Denmark
Sweden</td><td>United States
Canada
Australia
U.K.</td><td>(France)</td><td>Saudi Arabia
Kuwait
Mexico
Nigeria</td><td>Japan
China
S. Korea
Vietnam</td></tr>
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Notes:____

Low-Context Verbal Rituals	**High-Context Verbal Rituals**
Direct style	Indirect Style
Linear logic	Spiral Logic
Individual-based	Status-based – focus on relation to others
Content-focused	Facework talk – focus on politeness and/or the appearance one presents to others
Self-enhancement style	Self-effacement style
Verbal intentions	Nonverbal nuances
Value "talk"	Value "ma" or silence

Low-Context Nonverbal Expressions	**High-Context Nonverbal Expressions**
Face/Gestures – *Complementary*	Face/Gestures – *Disciplined to Animated*
Eye Contact – *Moderate Gaze*	Eye Contact – *Low Gaze-Intense Gaze*
Time – *single external definition of time*	Time – time in relation to many factors e.g. internal signals, seasons, activities
Space – *Medium Space e.g.social conversational distance of roughly 4 – 7'**	Space – *More-Less Space e.g. social conversational distance of 2-31/2'**

Notes:____

* Source – Edward Hall's Theory of Proxemics in The Hidden Dimension (1966)

In Communicating with HCC Individuals, LCC Communicators should learn to…

- Shift direct tone of voice to a more relational tone of voice.
- Use probing questions and be sensitive to face-saving issues.
- Counter HCC verbal indirectness with probing and perception checking questions.
- Develop a "third ear" in listening for nonverbal subtleties and nuances.
- Realize that content interaction goal and relational interaction goal are often intertwined
- Assume a stronger coaching role when in an authority position.

In Interacting with LCC Individuals, HCC Communicators should learn to…

- Shift indirect tone of voice to a clear, direct tone of voice.
- Support their verbal requests with explicit, content goal explanations.
- Describe the specific problematic behaviour or action.
- Work on clarifying content goals with the use of concrete, direct language.
- Use mutual-interest problem-solving statements – be solution-oriented.
- Not take every misunderstanding or problem to the relational level.

Managing Intercultural Differences Effectively: Some Initial Guidelines

- Understand cultural and personal value patterns in-depth
- Increase self-awareness as a multifaceted being
- Increase other-awareness as a multifaceted being
- Understand cultural & ethnic identity complexity issues

Notes:____

Source: Ting-Toomey, Stella (1999). Communicating Across Cultures. New York: Guilford Press.

COMMUNICATION CHALLENGES IN PALLIATIVE CARE

Common Communication Roadblocks in Palliative Care

- Advising, giving solutions
- Persuading with logic, ‘arguing’
- Praising, agreeing
- Reassuring
- Fix-it trap
- Giving your own solution to the problem
- Focusing mostly on tasks at the expense of process
- Not acknowledging a person’s unique communication style and how it affects their way of conveying information to you
- Assuming all clients must engage in significant verbal expression to ‘resolve’ issues prior to death

Listening Obstacles/Roadblocks

1. Not focusing/concentrating
2. Not *appearing* to listen
3. Using jargon, being unclear
4. Talking down to the individual receiving health care
5. Listening only for problems with easy answers

ACKNOWLEDGING THE TENSIONS

Suffering

The essence of suffering is the disparity between the desired and reality, as well as the individual's perceived ability to achieve the desired.

Some forms of suffering for the palliative individual and their family:

- Physical pain
- Emotional, psychological pain
- Anxiety
- Depression
- Fear
- Grief
- Financial burdens
- Sexuality/affection
- Employment
- Self-image
- Isolation
- Relationships
- Spiritual pain and/or religious uncertainty
- Meaning of pain
- Sense of purpose
- Lack of connection
- Cultural meaning of the disease
- Inability to cure
- Lack of control
- Lack of understanding, knowledge
- Dealing with a confusing health care system
- Dealing with some health care professionals

These represent just some of the sources of suffering that individuals may experience when dealing with terminal illness.

The walling of suffering

- False reassurance
- Evasion and denial
- Avoidance and flight
- Blaming the victim
- Intellectual arguments to convince us of the redemptive or corrective value of our anguish.
- The assumption that the control of pain and other physical symptoms is equal to the elimination of suffering.

These are among the most common strategies within medicine and within culture as a whole, for the walling of suffering.

Each is an enemy of intimacy in palliative care, either because it distorts the patient's experience or because it seals that experience off from us completely.

Source: Barnard, David. Journal of Palliative Care 11:4, 1995, 22-26.

Hope in the Dying and their Families

What is 'hope'? For some, it means reaching beyond the present, desiring something better or beyond the current situation or feeling. Others may see it as simply when there is a chance 'greater than zero' of a possibly outcome/ realization. Still others may define it as a feeling of peace, optimism, or acceptance even though their death is on the horizon.

Possible forms of 'hope' for some of the dying:

- Finding meaning, value, and perspective from their life.
- Retaining some capacity for giving and receiving expressions of love, joy, humour.
- Retaining a sense of 'strength' and control in whatever form it may take.
- Retaining a sense of 'control' and self-determination.
- Their personal sense of spirituality.
- Belief of 'life after death' or a different quality of existence.
- Hope for release from existence, or from suffering.
- Hope to live long enough for a particular milestone or event.
- Hope that loved ones will be okay.
- Hope for a peaceful, pain-free death.
- Hope for support.
- Hope for a cure…

Things to remember:

- We do not 'give' a dying person or their family hope; what we can do is try to facilitate their own discovery or reaffirmation of meaning, value, and connection in their life.

- We can assist them in their transition from one form of hope to another, helping them refocus and redefine; e.g. from 'hope of cure' to hope for a good day.

- When a dying person or their family relinquishes a specific hope, they may embark on a process of grieving on multiple levels – for the loss itself and all that it may symbolize.

- We must be careful to avoid ‘projecting’ our own hopes and expectations onto the dying older person and their family.

- We may have to accept that some people die holding onto what we may perceive as a ‘false sense of hope’.

- We may have to accept that some people die *without* a tangible sense of hope.

- We may have to accept that some people die in suffering.

Suggestions for communicating support and hope to the dying and their families:

- Use life review as a valuable tool to help them re-frame or affirm their worth; surround with memories.

- Listen for meaning through the metaphors they may use.

- Do not talk to them as if they were a child; be aware of your tone of voice.

- Listen for the ways they convey their self-image; gently affirm the positive.

- Maintain a compassionate presence: be personal, allow for feelings, react with emotion, be tolerant, be appropriately positive, and avoid conveying judgement.

- Encourage self-determination, sense of control.

- Tailor communication to the person; being sensitive to a person’s capacity and sensibilities.

- Be especially meticulous in your non-verbal communication.

- Acknowledge their losses; ‘normalize’ the experience but do not minimize its impact.

- Encourage important rituals, memorials.

- Discover their passions, their beliefs.

- Be culturally-sensitive (both Inter and Intra-culturally), but avoid making assumptions.

- Encourage sharing of experiences with peers; help them utilize support networks.

- Do not ignore issue of loss faced by cognitively impaired.

- For those limited in verbal communication – smells, fabrics, pictures can act as 'triggers' for memories.

- Remember that you only know a small part of who they are; avoid labelling, see them as a person, not a 'patient'. Be aware of your own biases, assumptions re: the elderly.

- If they express a desire to die for fear of being a burden, we must explore the meaning of this for them.

- Be culturally-sensitive in your interactions.

- Some feelings are seen as more socially acceptable than others. People tend to lean on the more 'acceptable' feelings (e.g., anger is often perceived as more acceptable than fear) even though their true feelings lie underneath.

COMMUNICATING IN CONTEXT:

Steps for Initiating End-Of-Life Conversations and 'Breaking the Bad News'

1. Have the right timing and context. Initiate the conversation at a sensitive time if possible.
2. Find out how much the client knows.
3. Find out how much the client <u>wants</u> to know.
4. Share information – keeping in mind your objectives.
5. Identify and acknowledge the client's reactions.
6. Provide planning and follow-through.
7. Pay attention to the 'emotional signature' and coping styles of patients and families.
8. Avoid common roadblocks to effective communication.

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1. **Have the right timing and context.** Initiate the conversation at a sensitive time, if possible.

    a. Find out how the client is feeling today.

    b. Is it a particularly stressful day for them?

    c. Would the client prefer privacy from others?

    d. Have you had time to establish some rapport with them? Have you conveyed a sense of compassion towards them, in subtle ways?

2. **Find out how much the client knows.** Some possible questions may be:

    a. What have you made of the illness so far?

    b. What have you been thinking about this nausea/unsteadiness?

    c. Have you been very worried about these new symptoms?

    d. What did your doctor/oncologist tell you about the illness/operation? Did that cause you concern or did you find that reassuring?

    e. Have you been worried about yourself?

    f. What are your expectations about this symptom/illness?

During these questions, pay attention to not only the client's overall understanding of their medical condition, but also to the emotional content of the client's statements. What is the client NOT talking about? What non-verbal clues are being given?

3. **Find out how much the client <u>wants</u> to know.** The most critical step in the process. You will have your own style in phrasing questions, but here are some examples.

    a. If your condition gets worse, would you like to know what's going on?

    b. If your condition becomes increasingly serious, how much would you like to know?

    c. Would you like me to tell you the full details you're your condition now – or would you rather have me tell someone else? Who would that be?

d. If the client expresses a preference not to discuss end-of-life matters, try to leave the door open for later. For example "That's okay, if you change your mind or have any questions next time, just as me."

4. **Share information** (aligning and educating). Decide on your objectives (diagnosis, treatment plan, prognosis, support).

    a. Aligning. Start from the clients starting point. Reinforce what the client has said that is correct.

    b. Give information in small chunks – the 'warning shot' e.g., "the situation does appear to be more serious than that…"

    c. Gradually introduce the more serious points, waiting for the client to respond at each stage, acknowledging immediate reactions.

    d. Use simple language; e.g., "would you like to talk about putting together a 'back-up plan' just in case you need some extra support?"

    e. Check reception of your messages frequently.

    f. "Am I making sense?", "Would you like me to clarify anything we've talked about so far?" Repeat your messages.

    g. Listen to your client's concerns throughout. Some people may be so preoccupied with a particular problem that it disables them from focusing on what you're discussing.

5. **Identify and acknowledge the client' reactions.** This may take up a majority of your time spent together, but is vital for continuing an open

dialogue. Be very sensitive to the inherent ‘symbolism’ of what you’re discussing; e.g., No Resuscitation Order.

6. **Planning and follow-through.** Try to pull together what you know of the client’s perspectives/agenda, the medical scenario, and the plan of care. Offer clinical perspective and guidance, demonstrating that you’re on the client’s ‘side’.

    a. Demonstrate an understanding of the client’s problems.

    b. Indicate you can distinguish the fixable from the unfixable.

    c. Make a plan/strategy together, clarify. Often, it is helpful to use such terms as ‘back-up plan’, etc.; essentially, ‘making plans for the worst but hoping for the best”.

    d. Identify client’s positive coping strategies and reinforce them.

    e. Identify and incorporate other sources of support, if possible.

    f. Summarize things for client. Ask if there are any other questions they need answered.

7. **Pay attention to the ‘emotional signature’/coping styles of patients and families.** Some people view the world more logically and others more emotionally. Respect that. If possible, listen for and acknowledge both the emotional and logical/practical aspects of the situation to the patient/family. People are more open and trusting towards those who accept their ‘emotional signature’.

8. **Avoid common roadblocks to effective communication**; the ‘fix-it’ trap:
    - *Advising, giving solutions too quickly*
    - *Always trying to persuade with logic*
    - *Quick praising and reassurance*
    - *Over-analyzing and premature ‘diagnosis’ of emotions*
    - *Talking too much*

    a. These approaches represent only a very basic ‘framework’ to consider when discussing end-of-life issues with clients. In reality, these discussions are a highly dynamic process, with many potential twists and turns. Underlying these discussions is the context of loss that often dominates clients’ experiences.

    b. The most important components you can bring to any discussion in palliative care are compassion, self-awareness, deep listening skills, and a capacity to meet the client ‘where they’re at’. There is no magical formula or ‘script’ for talking with people.

Discussing the ‘No CPR’

Challenging Conversations

- ‘No CPR’ form is highly symbolic for individuals and families.
- For some, signing the form makes their palliative process more ‘real’.
- For some families, No CPR equates with ‘giving up’ on their loved one/’giving in’ to the disease.
- Many individuals/families simply haven’t been told what the form is about.
- Many individuals/families have misperceptions about the relevance and/or effectiveness of CPR; sometimes relating it to TV depictions of miraculous recoveries.

Discussing the No CPR form is a *process* with the individual and families receiving care. Components of this process include:

- Being sensitive to ‘where they are at’; their capacity for understanding and retaining information; acknowledgement of their emotions and the challenge it may represent to actually sign the paper; the ‘meaning’ behind the experience.
- Explaining – and ensuring that the person understands – the **rationale** for the form (it is a physicians order acknowledging the futility of intervention in a terminal disease; the goal is to avoid trauma [physical/emotional] for an individual with a terminal illness who has died of natural causes, and for whom there is no possibility of cure through resuscitation; CPR is not a cure, does not stop the terminal disease process; statistically shown that in advanced cancer CPR is not successful. Cardiac or respiratory arrest will continue to occur.)
- Acknowledging possible **implications** if it’s not signed (undermines possibility of a peaceful, ‘expected’ death; once called, ambulance attendants obligated to carry out the procedure if no form is signed – pounding on the patient’s chest, tubes put in, etc.; physical trauma for patient; emotional trauma for family; Home Support Workers who are in the home are mandated to call 911 if there isn’t a signed form).

- This communication process may take lace over a period of days, weeks, or months, depending upon the circumstances.

- Individual's family physician is expected to be 'lead' person is discussing this issue, but in reality, other health care team members will often engage in the discussion with the individual/family as well.

- Family dynamics, cultural influences, health beliefs, and a palliative person's degree of acceptance, 'avoidance' and/or denial re: prognosis all influence the challenge of discussing the 'No CPR' form, but much rests on the communication skill and sensitivity of the health care professional(s).

- No CPR form does not actually require an individual's or family member's signature to be valid, if it has been signed by the physician.

- Our goal should not be to enforce our 'agenda' on a person just because it fulfills our health care system's 'requirements', i.e. a No CPR form is required while a person stays on the PCU at either VGH or St. Paul's in Vancouver.

- It is possible to have a peaceful, 'planned' home death without a No CPR form, if the individual, family, and health care professionals involved have discussed their anticipated communication process at the time of death (e.g., family calling GP first to pronounce, not 911).

APPENDICES

Appendix A: Journal Article From American Family Physician The End-of-Life Care: Guidelines for Patient-Centered Communication

(American Family Physician. 2008;77(2):167-174. Copyright © 2008 American Academy of Family Physicians.)

When patients are diagnosed with cancer, primary care physicians often must deliver the bad news, discuss the prognosis, and make appropriate referrals. When delivering bad news, it is important to prioritize the key points that the patient should retain. Physicians should assess the patient's emotional state, readiness to engage in the discussion, and level of understanding about the condition. The discussion should be tailored according to these assessments. Often, multiple visits are needed. When discussing prognosis, physicians should be sensitive to variations in how much information patients want to know. The challenge for physicians is to communicate prognosis accurately without giving false hope. All physicians involved in the patient's care should coordinate their key prognosis points to avoid giving the patient mixed messages. As the disease progresses, physicians must reassess treatment effectiveness and discuss the values, goals, and preferences of the patient and family. It is important to initiate conversations about palliative care early in the disease course when the patient is still feeling well. There are innovative hospice programs that allow for simultaneous curative and palliative care. When physicians discuss the transition from curative to palliative care, they should avoid phrases that may convey to the patient a sense of failure or abandonment. Physicians also must be cognizant of how cultural factors may affect end-of-life discussions. Sensitivity to a patient's cultural and individual preferences will help the physician avoid stereotyping and making incorrect assumptions.
(Am Fam Physician. 2008;77(2):167-174. Copyright © 2008 American Academy of Family Physicians.)

Primary care physicians have the opportunity to maintain long-term, trusting relationships with patients and are well positioned to discuss difficult issues such as newly diagnosed cancer or terminal illness.[1] However, primary care physicians may not feel equipped to discuss end-of-life care. The lack of physician training in this area and patient or physician fear may lead to discomfort when communicating bad news.[2] Providing care throughout a patient's illness can be highly gratifying for physicians and may lead to better patient outcomes. Using a systematic approach can help primary care physicians discuss prognosis appropriately, offer realistic hope, provide therapeutic options, coordinate disease transitions, and relieve patient suffering.

SORT: KEY RECOMMENDATIONS FOR PRACTICE

Clinical recommendation	*Evidence rating*	*References*
When preparing to give bad news, it is important for physicians to assess the patient's level of understanding about the disease and expectations for the future.	C	2, 11, 12, 14
When preparing to give bad news, it is important for the physician to assess how much information the patient wants to know and to tailor the discussion appropriately.	C	3, 15
The primary care physician should remain involved with patient care during the early, middle, and late stages of cancer.	C	22
Physicians should initiate discussions about the availability of coordinated, symptom-directed services such as palliative care early in the disease process; as the disease progresses, physicians should transition from curative to palliative therapy.	C	23, 24
Physicians should avoid phrases and words that can be misconstrued by the patient and lead to negative interpretations such as abandonment and failure.	C	12, 14, 27
During end-of-life communication, physicians should assess and be sensitive to the patient's cultural and individual preferences.	C	28-34

A = consistent, good-quality patient-oriented evidence; B = inconsistent or limited-quality patient-oriented evidence; C = consensus, disease-oriented evidence, usual practice, expert opinion, or case series. For information about the SORT evidence rating system, see page 131 or http://www.aafp.org/afpsort.xml.

Communicating Bad News

Illustrative case, part A: *A 57-year-old female schoolteacher recently received a screening colonoscopy. During the procedure, a 2-cm × 2-cm sigmoid mass was biopsied. The mass was diagnosed as a poorly differentiated adenocarcinoma. The patient is waiting at the clinic to see her primary care physician to discuss the results.*

Breaking bad news, particularly discussing prognosis, requires a combination of disease-specific biomedical knowledge and excellent communication skills.[3] When bad news is delivered incorrectly, it can lead to long-term consequences such as poor psychological adjustment for patients.[4,5] Therefore, recommendations have been developed to help physicians appropriately deliver bad news *(Table 1).*[2,5-14]

Table 1. Recommendations for Patient-Centered Communication When Discussing Bad News

Recommendation	*Comments*
Prioritize: Prioritize what you want to accomplish during the discussion	Ask yourself: What are two to four key points that the patient should retain? What decisions should be made during this encounter? What is reasonable to expect from the patient during this encounter?
Practice and prepare: Practice giving bad news; arrange for an environment conducive to delivering the news	Rehearse the discussion; arrange for a private location without interruptions; set cell phones and pagers to vibrate or turn them off; ask the patient if he or she wants to invite family members
Assess patient understanding: Start with opening questions, rather than medical statements, to determine the patient's level of understanding about the situation	Ask the patient: "What do you already know about your condition?" "What does it mean to you?" "What do you think will happen?"
Determine patient preferences: Ask what and how much information the patient wants to know	Assess how the patient wants the information presented; ask the patient, "Some of my patients prefer hearing only the big picture, whereas others want a lot of details. Which do you prefer?"
Present information: Deliver information to the patient using language that is easy to understand (do not use medical jargon); provide a small amount of information at a time; check periodically for patient comprehension	Provide a few pieces of information, and then ask the patient to repeat it back to you
Provide emotional support: Allow the patient to express his or her emotions; respond with empathy	Assess the patient's emotional state directly and often (ask the patient: "How are you doing?" "Is this hard for you?" "You look frustrated/disappointed/angry-is that true?" "Let me know when we should continue"); use nonverbal cues such as eye contact; listen to what the patient says and validate his or her reactions with empathic statements such as "I understand that this is very difficult news."
Discuss options for the future: Devise a plan for subsequent visits and care	Help the patient understand the expected disease course and how the disease may or may not respond to treatment; schedule follow-up visits (ask the patient: "Can we meet next week to discuss treatment options and any questions you may have?")
Offer additional support: Provide information about support services	Bring handouts and pamphlets to the visit; refer the patient to support groups, psychologists, social workers, or chaplains
Consider individual preferences: Assess patient preferences, and tailor the discussion appropriately	Consider the patient's sex, age, health literacy, health status, previous health care experiences, social status, culture, and race/ethnicity; avoid assumptions about what the patient is likely to want; ask the patient directly about values and preferences

Information from references 2 and 5 through 14.

Physicians should customize discussions, especially in situations that are stressful for the patient. Specifically, physicians should assess the patient's understanding ("Tell me what you know about this disease."); emotional state ("This is a lot to take. How are you doing?"); and readiness to engage in the discussion ("Let me know when you're ready to continue."). At each visit, physicians should assess whether patients have physical or psychological symptoms that need to be addressed ("How are you doing/coping?" "Is anything interfering with your quality of life?").[2,6-13]

Discussing Prognosis

Illustrative case, part B: *After surgery, the patient was diagnosed with stage III, two-node-positive colon cancer. Her oncologist discussed the prognosis with her and recommended adjuvant chemotherapy. The patient is still confused about what to do. Distraught, she calls her primary care physician and asks, "What should I do? Will I die soon?"*

It is best to discuss prognosis after accurate cancer staging. In preparation, all physicians involved in the patient's care should coordinate their key prognosis messages to avoid confusing the patient. Physicians should be prepared to discuss the natural history of the disease, treatment and its adverse effects and outcomes, and the patient's probable quality of life. Additionally, physicians should discuss expected five- to 10-year survival rates, with and without treatment, and should address patient fears (e.g., fear of undergoing treatment, suffering, abandonment, or death). Empathic listening can ease and comfort patients.

Physicians should assess the patient's desire and readiness to receive the prognosis.[3,15,16] The desired amount of information varies among patients. Approximately 80 percent of patients want detailed information about their prognosis, whereas 20 percent prefer not to know complete prognostic information.[17,18] Thus, physicians should assess how much information to provide using patient-centered communication *(Figure 1[3,15,16])*.

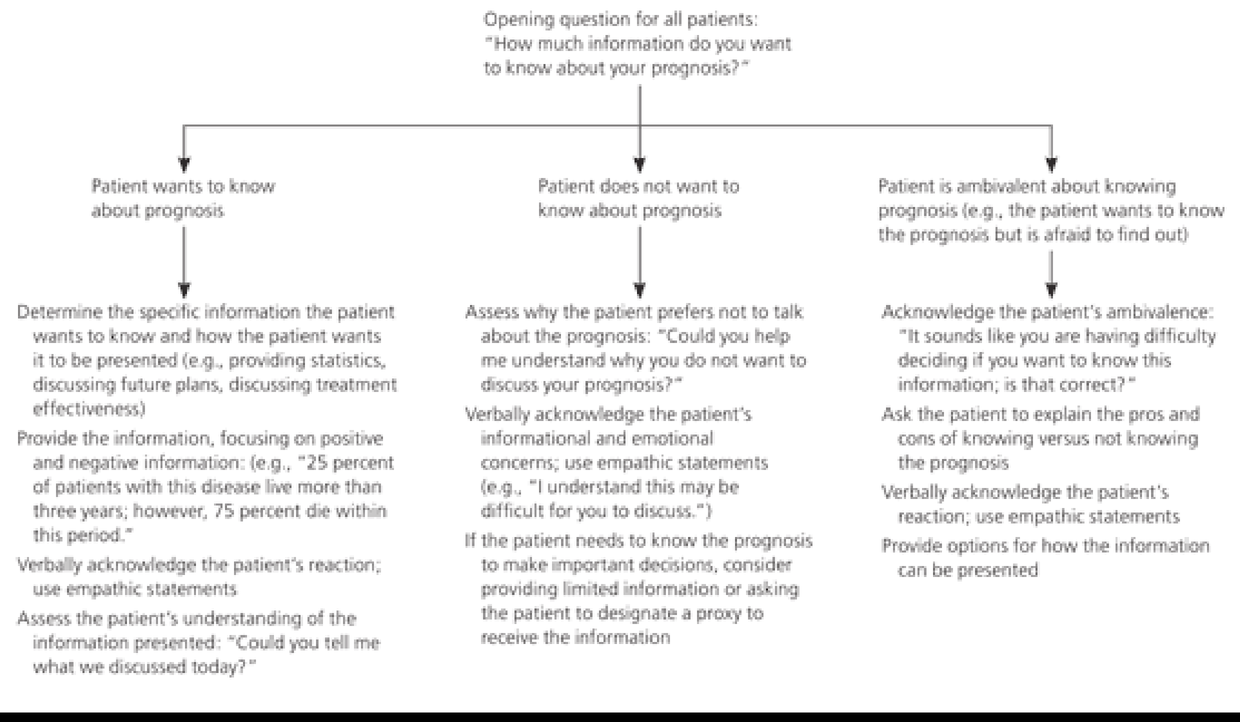

Figure 1. Algorithm for patient-centered communication when discussing a bad prognosis.
Information from references 3, 15, and 16.

After assessing the patient's readiness to receive prognostic information, the physician should focus on communicating the prognosis without giving false hope.[19] One approach focuses on expectations (hoping for the best, planning for the worst), which allows physicians to discuss the worst-case scenario with the patient without taking away the possibility of the best-case scenario. After acknowledging the patient's expression of hope, the physician can ask whether the patient thinks that hope is realistic or probable.

Another approach focuses on providing the patient with a full spectrum of treatment options. A recent study showed that some patients elected to participate in phase I clinical trials of chemotherapy, even though the likelihood of benefit was low. When asked why they chose to participate in these trials, patients reported feeling like they had to do something.[20] Providing options can validate the patient's need to be actively involved in his or her care.

Similarly, another approach focuses on sequential treatment options. In this approach, the physician supports the patient in undergoing a treatment, but also discusses what the next step would be if the initial treatment is unsuccessful. This approach sets practical parameters and allows discussion of alternatives if the goals of care are not attained.

The goals of care change as the disease progresses. At each stage, the physician should help the patient create realistic, achievable goals and hopes. Initially, patients might hope that the cancer responds to chemotherapy or surgery. When disease control is no longer possible, patients might hope to live pain free, achieve closure on personal issues, or die surrounded by friends and family. Focusing on stage-specific goals and hopes can prevent over- and undertreatment while relieving the patient's psychological distress.[21]

The Physician's Role at Different Stages of Disease

Illustrative case, part C: *The patient's functional status has deteriorated rapidly. During chemotherapy, she developed esophagitis and recurrent neutropenic fever. Now, abdominal studies demonstrate early obstruction. Her primary care physician asks himself, "At this stage, what is my role in her care?"*

The primary care physician's role changes at each stage of a patient's illness *(Table 2[2,6,12,16,22])*. Ideally, primary care physicians form the backbone of an integrated team by providing an unbiased medical perspective, providing continuity during a stressful disease course, supporting patients and their families through emotional ups and downs, negotiating or mediating decisions, monitoring for complications, and providing perspective on the illness.[6] This role is tempered by practical considerations such as the physician's practice and relationships with colleagues, available resources, and individual patient needs.

Table 2. The Primary Care Physician's Role in Patient Care During Different Stages of Cancer

Role	*Early stage*	*Middle stage*	*Late stage*
Breaking bad news	Discuss diagnosis, disease course, therapeutic options, patient/family values and goals, and treatment preferences	Discuss treatment effectiveness	Assess patient/family understanding of prognosis and disease course
Communicating prognosis	Discuss expected prognosis	Help the patient understand changes in prognosis and refocus expectations; revisit values and preferences	Objectively discuss the advantages and disadvantages of experimental treatment, if offered by a subspecialist; discuss palliative care options such as hospice
Discussing disease transitions	Focus primarily on medical treatment while assessing palliative needs; the goal is extending life while improving quality of life	Focus on medical treatment and palliative needs	Focus explicitly on palliative care to relieve symptoms (e.g., pain, shortness of breath, fatigue, nausea); the goal is improving quality of life, including treatment of metastatic disease that is causing symptoms (e.g., bowel obstruction, bony metastasis)
Coordinating care	After referring the patient to a subspecialist, request that the patient schedule follow-up visits with you; ask the subspecialist to update you on the patient's care	Monitor the patient for symptoms and adverse effects (physical and psychological); discuss hospice as a therapeutic option; encourage the patient to begin advance care planning (e.g., advance directives, durable power of attorney for health care, living will) in case of deteriorating health	Discuss likely benefits and harms of major therapeutic options; discuss palliative care options
Providing support	Allow the patient to express emotion; answer questions and address concerns; provide emotional support and empathy; refer patient and family to support groups or counseling	Answer questions and address concerns; provide emotional support and empathy	Answer questions and address concerns; provide emotional support and empathy; reassure the patient that he or she will not be abandoned

Information from references 2, 6, 12, 16, and 22.

Negotiating this role to the satisfaction of everyone involved in the patient's care requires open communication. Simple questions can be asked to clarify each participants expectations: (1) to the patient: "Do you understand what is going to happen next? How are you and your family coping with this news?"; (2) to the subspecialist: "What are the expected benefits and harms from this new treatment? How much benefit accrues to the patient?"; and (3) To the health care team: "What additional resources can we mobilize for the patient?"

Primary care physicians may need to be proactive to stay involved in the patient's care.[2] When referring a patient to an oncologist, primary care physicians can communicate their desire to continue caring for the patient. The physician also can ask subspecialists who are caring for the patient to provide periodic updates, and the physician can offer input or advice if the subspecialists have questions. The physician can schedule follow-up visits with the patient, even while the patient is undergoing chemotherapy or radiation.

However, primary care physicians may be uncomfortable with cancer care and may wish to transition the care of the patient to an oncologist or palliative care subspecialist. In this instance, it is important for the physician to communicate to the patient that the physician is still available, but that the subspecialists will be the main caregivers.

During the disease course, the patient's palliative and medical needs intensify. Innovative models can help physicians bridge the gap between traditional curative care and palliative care.[23-25] Physicians assess palliative needs (for relief of suffering) throughout treatment. As the disease progresses, the focus shifts from curative therapy to palliative therapy. During this transition, the primary care physician should offer realistic hope and provide guidance in choosing appropriate treatment and palliative strategies.

Using simultaneous-care models, physicians can provide palliative and curative care at the same time. Newer open-access hospices provide full hospice care while allowing patients to receive disease-directed therapy. In many open-access hospices, patients may receive chemotherapy, radiation, blood transfusions, dialysis, or total parenteral nutrition.

Patients also may receive intense skilled palliative care at home (home-based hospice), often with family members as paid caregivers. A home-based hospice program is a modified version of the traditional home care model and, based on the argument that palliative care is a skilled need, is paid for by most insurance companies. Research shows that, compared with traditional home care, home-based hospice programs can improve patient satisfaction, reduce emergency department and physician office visits, and shorten nursing home and hospital stays while reducing costs by 45 percent.[26]

When discussing the option of hospice or other palliative care, physicians must be careful not to convey to the patient a sense of abandonment. Early in medical training, physicians may learn to use phrases that reflect a singular focus on curative therapy. If physicians see their role as only to cure disease, they may subconsciously convey their sense of failure to the patient if curative treatments are unsuccessful, and that cessation of curative options means the end of the physician's care. The shift from curative to palliative care is merely a change in the type of care that the physician is providing. *Table 3* offers alternatives to commonly misconstrued physician phrases used in end-of-life discussions.[12,14,27]

Table 3. Commonly Misconstrued Physician Phrases Used in End-of-Life Discussions with Patients

Physician phrase	Possible patient interpretation	Alternative phrase
"There's nothing we can do for you"	Abandonment: "My physician doesn't want to see me anymore"	"We can offer many options to control your symptoms and make you feel better"
"It's time to think about withdrawal of care"	Cessation of care: "My physician doesn't want to care for me anymore"	"Do you think that it is time to consider a different type of treatment that focuses on your symptoms? I'll be here with you no matter what you decide"
"Do you want us to do everything that we can to keep you alive (e.g., artificial life support)?"	Cessation of appropriate care: "If I don't have them do everything, I won't get the best medical care"	"If you become extremely ill, would you want to be put on artificial life support, or would you prefer a natural death?"
"You've failed the treatment (e.g., chemotherapy, radiation)"	Personal failure: "I've disappointed my physician"	"The cancer has not responded to the treatment as we had hoped. How are you doing?"
"I think you should consider hospice"	Despair and hopelessness: "I'm going to die soon"	"I want to provide intense, coordinated care with a team of professionals who will treat your symptoms and help you stay comfortable"

Information from references 12, 14, and 27.

Cultural Diversity and Individual Preferences

When a patient and physician enter into end-of-life discussions, each brings individual cultural backgrounds and values, which influence the discussions. Although understanding cultural norms is important, physicians must be careful to avoid stereotyping patients based on their culture.[28]

Individual culture is influenced by the culture of the family, religion and spirituality, education, occupation, social class, friends, and personal preferences. Asking open-ended questions can elicit the patient's preferences for physician frankness, decision making, and direct versus indirect communication *(Table 4[28-34]).* Conflicts may arise when patients and families want care that physicians think is medically futile. Physicians may prevent misunderstanding and promote trust by respectfully listening to patients' beliefs and values and by negotiating mutually acceptable goals.

Table 4. Considerations for Cultural and Individual Patient Preferences in End-of-Life Discussions

Considerations	*Questions for patients*	*Potential consequences*
Physician frankness (indirect or direct communication)	"How much do you want to know about your medical condition at this time?" If the patient prefers not to know everything: "Do you want to talk about this again at another time?"	Physician may be regarded as rude, cruel, and uncaring if the physician is frank about the patient's condition when the patient is not ready to hear it or prefers to learn the information indirectly from a family member The patient may experience feelings of hopelessness, depression, or anxiety if not psychologically ready to hear a bad prognosis or if he or she prefers to remain hopeful about the condition
Involvement of family members or preference for autonomy	"Would you prefer that I discuss your medical condition with you directly, or would you prefer that I discuss it with a family member?" If the patient prefers that you discuss it with a family member: "Would you like to be present during the discussions about your medical condition?"	Disagreements between the family or patient and the physician may occur when the physician does not assess whether the patient or family prefers family members to be involved The patient may feel isolated if the family is not involved in discussions
Decision making	"How do you want to make decisions regarding your health care?" "Do you want to make a decision yourself after I have given you all of the options?" (nondirective counseling) "Do you want me to suggest what I think is the best option?" (directive counseling) "Do you want to discuss the pros and cons of treatment and then make a decision together?" (shared decision making)	Unwelcome decisions may be made for the patient, and there can be a lack of collaboration between physician and patient (and family) if the physician uses directive counseling when the patient prefers nondirective counseling The patient can lose confidence in the physician if the physician uses nondirective counseling when the patient prefers directive counseling
Advance care planning	"What are your goals for your life, right now?" "How do you feel about prolonging your life with artificial life support, even if there was no chance that you'd be able to live independent of the machines?" "If you became unable to make your own health care decisions, who would you want to make them for you?"	Overuse of potentially futile, aggressive care at the end of life and underuse of hospice services may occur if the patient does not endorse or understand available advance care planning options
Social, educational, and family factors	"Tell me about your family" "Have you or your family had significant experience with someone with a serious illness?" "If so, how did that experience affect you?"	The physician may offend or stereotype the patient because of incorrect assumptions if the physician does not ask about the patient's background Misunderstandings between physician and patient may occur if the physician does not assess social, educational, and family preferences
Religious and spiritual factors	"Is there anything I should know about your religious or spiritual views before we discuss your medical condition?"	The physician may be regarded as disrespectful if the patient's religious and spiritual preferences are not addressed The patient may reject medical advice if the physician does not understand how the patient views the physician's role and advice in the context of religion or spirituality

Information from references 28 through 34.

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Source: Ngo-Metzger Q, August K, Srinivasan M, Liao S, End-of-Life Care: Guidelines for Patient-Centered Communication, American Family Physician Journal, January 15 2008.

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Appendix B: DEEP LISTENING

"The caregiver's real work is to establish *connection* so the patient can reveal what needs to be shared. Deep, empathetic listening helps others articulate difficult feelings. It opens to dying people a path through anger and fear to a place of safety and security – our listening presence. If they feel very secure they may tell us, and thus put in order, their unfinished business."

"The good listener does not coolly observe but rather warmly resonates. This sympathetic vibration is the interpersonal experience we call empathy. Listening is the heart of our work as caregivers, and empathy is the hear of our listening."

"Empathetic listening comes from an open heart, but keeping the heart open to dying people can be difficult. The swirl of feelings set off by their suffering can overcome and exhaust the listener who is "all heart". One common strategy is to escape from our strong feelings by fleeing up into our minds. Looking down from the safety of our thoughts can disconnect us from threatening emotion, but it also elevates us to a place of watching rather than listening. This is the place that medical professionals can go when they distance themselves from their patients."

- Merrill Collett

The Heart of Listening

Do stay focused

Do be mostly silent

Do follow

Do be receptive

Do be aware of your body language

Do ask open-ended questions, when appropriate:

- How does that make you feel?
- What is that like for you?
- Can you tell me more about that?
- What do you think that means?
- How are you handling that?
- Can you explain that to me?
- How were things different before?

NOTES: