Communicating with Patients & Families Module Contents

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Learning Objectives

Communicating with Patients & Families about End-of-Life Care

At the end of this presentation, participants will be able to:

- Explain the value of good patient-provider communication about end-of-life care.
- Describe several competencies in communicating with patients and families.
- Explain how HIV/AIDS impacts this communication.
- Identify barriers to communication and actions to take that can improve communication with patients and families.

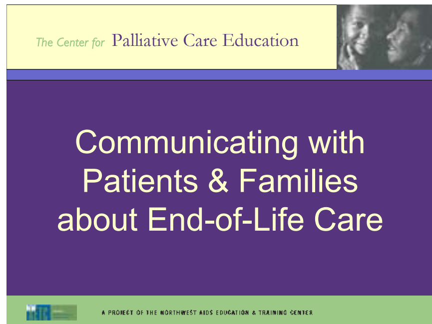
Learning Objectives – *Giving Bad News*

At the end of this presentation, participants will be able to:

- List the 6 steps in giving bad news.
- Adapt the bad news protocol to their work setting.
- Explain how the manner in which bad news is given can impact patient outcome and patient care.
- Explain how culture impacts patient information needs and decision-making.

Communicating with Patients & Families about End-of-Life Care

PowerPoint Notes



NOTE TO TRAINER: This module contains a great deal of data from research studies that you may wish to cut and paste to fit the needs of your group and your own sense of what is important to cover.]

Trainer Suggestion

Introduce yourself and go over the agenda for the session. If there is time in the session and a small enough group, invite participants to introduce themselves and talk about what they are hoping to learn.

Invite questions and comments throughout the presentation.

Learning objectives

- Explain the value of good patient-provider communication about end of life care
- Describe several competencies in communicating with patients and families.
- Explain how HIV/AIDS impacts this communication
- Identify barriers to communication and actions to take that can improve communication with patients and families

Slide Note

Workshop goals for participants include learning about issues and research related to patient perspectives, clinician competencies, and strategies to enhance clinician-patient communication in end of life care. Specific information about HIV/AIDS and clinician-patient communication will also be covered. It is hoped that participants will explore their own perspectives regarding these issues and will consider ways to improve their communication with patients and families in their own work.

Trainer Suggestion

If there is time for it, another possible learning objective could be: Develop a communication protocol that you can apply in your work setting.

Outline

- The challenge of communicating about end-of-life care
- Patients' and families' perspectives
- Issues specific to HIV/AIDS
- Recommendations for clinical practice

Consider a case

- 48-year-old man with C3 AIDS comes to clinic after initial chemotherapy treatment for new lymphoma diagnosis:
  - –File indicates history of injection drug use
  - –He hands the clinician a POA document and says "Here, this is for your files."
  - –When asked, says he doesn't want to discuss it.

Slide Note

To begin thinking about this topic, we'll start with a case and we'll return to it later after we've considered a number of these issues.

This was a 48-year-old man with advanced AIDS and a new diagnosis of lymphoma. He came into the clinic for a follow-up after his initial chemotherapy treatment.

At the end of the appointment, he handed the clinician a document which identified a friend to have durable power of attorney for health care. He said he'd gotten the form when he was in the hospital for his chemotherapy treatment.

When he was asked about the document, he said his partner had told him to complete the document because he might die soon.

Trainer Suggestion

You may want to invite participants to suggest ideas about how to proceed in this situation, and to explore what might be communication issues brought up by this case.

Why is communication important?

- Because we can't predict patients' wishes
- Because advance directives are often not helpful
- Because patients and their family members say it's very important

Slide Note

One of the most important skills we have to help patients at the end of life is our ability to communicate. Good communication provides clarity, increases the patient's sense of power and dignity, and strengthens our relationships by building trust.

Trainer Suggestion

Consider having this slide begin with the title only, while facilitating a discussion about why communication might be important. The bullet points can be brought in once participants have had a chance to brainstorm on this issue.

Why is communication important?

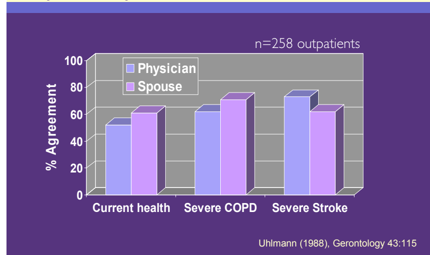
- Because doctors with good communication skills identify patients' problems more accurately
- Because their patients are more satisfied with care and better adjusted psychologically
- Because doctors with good communication skills have greater job satisfaction

Maguire P (2002) BMJ 325:697

Slide Note

Peter Maguire and colleagues studied doctor-patient communication and found that good communication skills offered physicians a number of benefits, including improved ability to identify patients' problems, better job satisfaction, reduced work stress, and more satisfied patients.

Can physicians and spouses predict patients' wishes for CPR?



Slide Note

One reason communication is vital is because patients' wishes are often difficult for clinicians to predict. For example, this study asked 258 elderly outpatients what their preferences were for CPR in their current health, if they had severe COPD and were unable to walk across a room without limiting dyspnea, or severe stroke with hemiparesis and aplasia. They then asked the patients' spouses and their primary care physicians what they thought the patient would want. The results show that spouse and physician predictions were about the same as chance for current health and not much better than chance for severely disabled health states. This and studies like this, indicating that physicians and spouses can not accurately predict patients' wishes for end of life care, gave rise to the advance directive movement.

Elements of communicating about end-of-life care

- Advance Directives
  - –Living will
  - –Durable Power of Attorney for Health Care
- Advance Care Planning
  - –Communication with family and doctors about goals, values, and treatment preferences

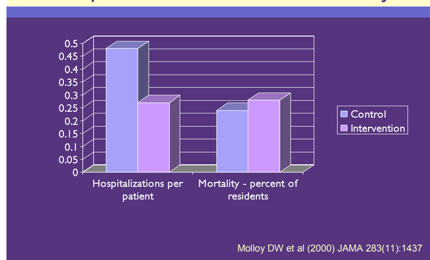
Slide Note

Communicating with patients and families about end of life care may involve several things, including the development of advance directives such as the legal will and durable power of attorney for health care. Advance care planning can be seen as the larger process of communicating about end-of-life care – eliciting and understanding the patient's values and goals so as to ensure that the patient receives care that is congruent with those values.

Trainer Suggestion

See Advance Care Planning module.

Advance directives reduced hospitalizations but not mortality



Slide Note

In this randomized controlled trial of nursing home patients in Canada, an intervention involving educating staff, residents and families about advance directives and offering advance directives to patients resulted in reduced hospitalizations, without a reduction in mortality. In addition, measures of patient and family satisfaction were not reduced after the advance directive intervention was implemented.
This study had a number of limitations, including no information on patient symptoms or quality of life. The study does suggest that excessive hospitalizations may be averted with an advance directive program.

Benefits of Advance Directives

- Good for some specific situations:
  - If there is a specific treatment a patient clearly doesn't want
  - If the patient does not want his or her legal next of kin to be making decisions
- A tool for raising the discussion
- Advance directives can ease the burden on the family

Slide Note

As we saw from the Canada study, advance directives have some benefits.

The documents can be useful in specific situations. For example, if there is a specific treatment a patient doesn't want, or if the patient does not want his or her legal next of kin to be making medical decisions.

The process of creating advance directives can be important for raising the discussions that need to happen, and finally advance directives can ease the burden of decision making that may otherwise fall on a patient's family.

Do advance directives facilitate communication of patient wishes?

- Controlled trials of advance directives show no change in care
- PSDA has had no effect on end-of-life care
- SUPPORT study found advance directives had no effect on:
  - End-of-life communication or decision-making
  - Aggressiveness or costs of care

Schneiderman, Ann Int Med, 1992; Teno, JAGS, 1997

Slide Note

But advance directives on their own do not solve all the problems of provider-patient communication. Advance directives have been seen in the past as a way to solve the problem of facilitating decision making for patients at the end of life. The idea was that people could fill out a document ahead of time, and make their wishes for end of life care clear in advance. Although advance directives have not fulfilled the hopes that people had for them, it is still important to communicate with patients about end-of life care, including engaging in advance care planning discussions. The PSDA, or Patient Self Determination Act, was a law passed by U.S. Congress in 1990, which mandated that health providers ask patients about advance directives upon admission to a hospital.

There have been 2 studies looking at advance directives and whether they influence the care that patients receive, and these have shown no difference. Living wills and durable power of attorney for healthcare did not change the care that patients received, and did not make the care more likely to match what patients wanted.

One of the largest studies which had these findings had the acronym of SUPPORT, which stands for, "The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments." We'll talk about this study next.

Trainer Suggestion

See Advance Care Planning module for more information on advance directives.

Can communication be facilitated?
Results of SUPPORT study

- Nurse:
  - Provided prognostic information
  - Elicited patient preferences
  - Facilitated advance care planning
- No effect on:
  - Patient-physician communication
  - Physician knowledge of patient preferences
  - Level of reported pain
  - Resource utilization

SUPPORT, JAMA, 1995

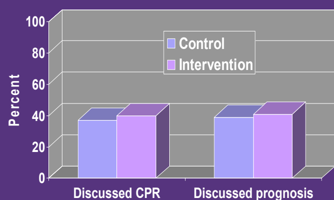
Slide Note

The SUPPORT study was a randomized controlled trial involving seriously ill patients in the hospital. The intervention involved having a specially trained nurse who facilitated communication among the patient, the family and the clinician. The nurse provided prognostic information and elicited from the patients what their preferences were for end of life care, and for resuscitation. They gave that information to the clinicians, and then they scheduled a meeting between the patients' families and the physicians, to facilitate advanced care planning.
The results of the study indicated that this intervention had no effect on patient – physician communication, no effect on physician knowledge of patient preferences, no effect on levels of reported pain, and no effect on resource utilization.

Trainer Suggestion

This may be a point for discussion – why do participants think this may not have been effective? One possible conclusion: Improving this kind of communication is very difficult. Providing a nurse to facilitate communication may have not been effective because the nurse was not part of the care team.

Communication with physicians:
Seriously-ill hospitalized patients



SUPPORT, JAMA, 1995

Slide Note

This slide is also from the SUPPORT study. It shows the proportion of patients who said that their physician had discussed CPR with them while they were seriously ill and in the hospital, and it was a little less than 40%. This was also not affected by the intervention. The proportion that said their physician had discussed prognosis with them was again less than 50%, and no difference was seen with the intervention.
The data from this study suggest that clinicians don't communicate about important end-of-life topics very often. When clinicians do communicate with their patients about these topics, how well is it done?

Quality of communication about DNR orders & advance directives

- In audiotapes of 87 patient-physician discussions, physicians:
  - –Spend 73% of the time talking
  - –Initiate discussion about patients' values or goals in < 33% of the time
  - –Rarely:
    - ~Explore reasons for preferences
    - ~Ask patients to define quality of life

Tulsky, J Gen Int Med, 1995; Annals Int Med, 1998

Slide Note

This slide is from a study by James Tulsky and colleagues, who audio taped 87 patient-physician discussions about do not resuscitate orders and advance directives.

They found that physicians spent ¾ of that time talking, and only a quarter of the time listening. These doctors also very rarely initiated discussions about what was important to the patients, what their values were, what their goals of therapy were, and even less often, explored the reasons for the preferences that they give.

Trainer Suggestion

There is a good opportunity to initiate a discussion, with some humor, regarding the data showing 73% of time was spent talking! Some possible discussion starters might be: As a clinician, how much time do you think you spend talking versus listening? What has been your experience as a patient in terms of a clinician listening and talking to you?

Benefits of a communication skills course

- 160 oncologists videotaped with 6-10 patients, 3 months after course, improved:
  - –Use of focused and open questions
  - –Expression of empathy
  - –Appropriate response to patient cues

Fallowfield, Lancet 2002: 359;650

Slide Note

Is there a way to teach clinicians to communicate better? This is a randomized controlled trial which was done in England. The investigators developed a 3-day communication skills course for physicians. 160 oncologists were randomized to one of these four conditions: receive the 3-day course, receive written feedback based on videotapes of them with their patients, both the course and the written feedback, or neither.

Physician-patient communication was videotaped 3 months after the course. Evaluation of these communications suggested that the written feedback had no effect, but the in-person skills course improved physician skills at talking with patients. The investigators saw an increase in clinician use of open-ended questions, improved expression of empathy, and an increase in appropriate responses to patient emotions.

Outline

- The challenge of communicating about end-of-life care
- Patients' and families perspectives
- Issues specific to HIV/AIDS
- Recommendations for clinical practice

Physician skill at end-of-life care

- Goal of study: To identify components of physician skill at end-of-life care
- Used focus groups of:
  - –Patients with terminal illness
  - –Families who lost a loved one
  - –Physicians, nurses, and social workers

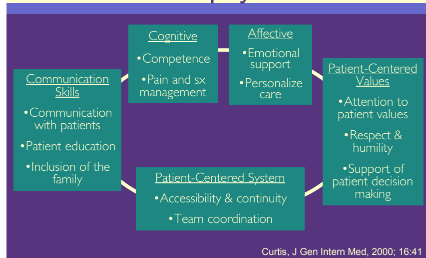
Curtis, J Gen Intern Med, 2000; 16:41

Slide Note

The goal of this study by Randy Curtis and colleagues at the University of Washington was to identify components of physician skill at providing end of life care, from the perspective of patients with terminal illnesses, families who had lost a loved one, and nurses, physicians, and social workers who had experience with end of life care.

This study used qualitative methods. There were 11 different focus groups of patients, 3 groups of family members who had lost a loved one, and groups of nurses, social workers and physicians.

Conceptual model of the domains of physician skill



Slide Note

The patients were asked questions about palliative care, end of life care, and the physicians who were providing care to them. Their responses were audio taped, and the research team used a qualitative method called grounded theory to devise a framework for understanding what was important to them.

The analysis of patient responses revealed these 5 domains related to physician skill. Communication skills included educating patients about their disease and including the family. Cognitive skills included medical competence and pain and symptom management. Affective skills included providing emotional support and personalizing the care to the individual, as opposed to treating them like a disease or an organ system.

Patient-centered values were very important to patients and their families, as well as patient-centered systems of care.

Communication with patients: Competencies

- Listens to patients
- Encourages questions from the patient
- Talks with patients in an honest and straightforward way
- Gives bad news in a sensitive way
- Willing to talk about dying
- Sensitive to when patients are ready to talk about death

Curtis, J Gen Intern Med, 2000; 16:41

Slide Note

When they looked at what about communication was most important to patients and families, at the top of the list was being able to listen, encourage questions from them, and talk with them in an honest and straightforward way about their disease, their prognosis, and what they have to look forward to. They wanted providers to give bad news honestly, obviously, but also in a sensitive way.

It was very important to them that the person cared about them as an individual. Patients and families preferred that providers be willing to talk about dying with patients, but also be sensitive to when patients are ready to talk about death.

Communication with patients

"Like when I had my first PCP outbreak, I didn't want to have a certain thing done to me because it terrified me. And I had a lot of doctors yelling at me 'You have to do this, you have to do that' but then there was one who really listened to me… he was just there to observe and he was the only one who listened to me."

- Patient with AIDS

Slide Note

Here is an example from a patient with AIDS.

It is easy for clinicians to find themselves in positions of not having the time to listen to people, but this study suggests that listening is a very important part of communication with patients in end of life care.

Trainer Suggestion

The quotes from this study may be good for stimulating discussion about these topics. A discussion starter here might be: Describe an experience you've had in which a clinician listened well, either to you or to another patient.

Communication with patients

"My experience… is that doctors don't really like to talk about death… or know how to talk about death. And that was very difficult for us, because this was our first experience with a family member dying… every time we got the truth, mostly from the hospice nurses, we really appreciated that… it focused us on the issues so we could have some quality time with my dad at the end."

- Family member

Slide Note

This is another quote from a patient's family member.

Trainer Suggestion

A discussion starter here might be: Why might this person have the perception that doctors don't really like to talk about death? Do you think this is true, from your experience?

Patient education: Competencies

- Gives enough detailed information to understand their illness and treatments
- Tells patients how this illness may affect their life
- Guides patient and family to helpful resources
- Talks with patients about what their dying might be like

Curtis, J Gen Intern Med, 2000; 16:41

Slide Note

Regarding patient education, these are the elements that patients reported were important in their communication with their clinicians.

For some patients, it can be a real source of relief to be able to talk about what the last day or week might be like, to hear that their pain will be controlled, and to hear that their clinicians will be available to help them.

Patient education

"It is good to get a little technical. I don't like it when the doctor says, 'Oh, your tests are good.' So what does that mean? I like him to say 'Your blood count is this and your hematocrit is this.' I have lung cancer, so I've had a jillion chest x-rays and the first doctor I had would show me them and say this and that and put it in layman's terms… it gave me a good idea of what was happening."

- Patient with cancer

Slide Note
Here's a quote from a patient with cancer, about the importance of patient education.

Trainer Suggestion
A discussion starting point here might be: What are the challenges of explaining technical information to patients? How can you know how much technical information to share?

Inclusion of the family: Competencies

- Openly and willingly communicates with family.
- Includes family in decision-making.
- Helps family understand what the dying might be like.

Curtis, J Gen Intern Med, 2000; 16:41

Slide Note
Patients reported that they want their clinicians to be open and inclusive of their family, so that family members can be helped in decision making and in preparing for the patient's death.

Inclusion of the family

"My doctor involved my family in my care when I was in the doctor's office, when I was in the hospital, all along the way. Your family is a very important part of your care and your support system. His involving them made a big difference."

- Patient with AIDS

Slide Note
Here is an example from a patient with AIDS emphasizing the importance of inclusion of the family.

Trainer Suggestion
A discussion starter for this slide might be: Why might it be important to include the family in discussions? When and when is it not appropriate to include family members in discussions about end of life care?

Outline

- The challenge of communicating about end-of-life care
- Patients' and families' perspectives
- Issues specific to HIV/AIDS
- Recommendations for clinical practice

Trainer Suggestion

Before moving on to the next section, this might be a time to stop and have participants break into pairs to discuss their own comfort level and experiences talking with patients about death.

AIDS-specific communication issues

- Continued uncertainty about prognosis
- Benefits vs. burdens of HAART
- Unresolved issues with families, estrangement
- Substance abuse:
  - –Misuse of medications
  - –Decreased social support
  - –Decreased coping skills

Slide Note

These are some of the issues that may arise when working with patients who have AIDS. Keep in mind that not all patients with AIDS will have these issues.
Sometimes, for patients and for providers, the continued uncertainty about prognosis makes it hard to know when to have a conversation about EOL issues. Because the course of the illness is so variable, a good guideline might be to have these conversations more frequently as the patient's status waxes and wanes. An ongoing discussion about the benefits vs the burdens of HAART at EOL should be a part of the conversations. This might include discussing the balance of any palliative benefits of the HAART regimen on HIV symptoms vs. the burden of uncomfortable and sometimes toxic side effects.
The psychosocial issues listed here, while not specific to HIV/AIDS, are more frequent. Many people with HIV/AIDS are estranged from their families, either due to their sexual orientation, history of substance abuse, legal issues, or mental health concerns to name a few. Substance use and HIV/AIDS is a complex topic that won't be covered today, but it's important to keep in mind how substance use can impact communication with and care of patients at end-of-life. Issues around medication use and pain control, little social support which impacts the patient's ability to receive care at home, and decreased coping skills are just a few issues you as a provider might face.

Barriers to communication about palliative care: Patients

- I don't like to talk about getting sick
- I have concerns about bringing up assisted suicide
- I would rather concentrate on staying alive
- I have not been very sick
- I don't know what kind of care I want if I get very sick

Curtis, Arch Intern Med, 2000; 160:1690

Slide Note

Randy Curtis and his colleagues conducted a study involving patients with advanced AIDS. Interviews were conducted with 57 patients and their physicians, to identify barriers and facilitators to communication about end-of-life care.
These are what patients identified as being the most important barriers to their communication with their providers.

Barriers ranked most important by clinicians

- I have too little time during appointments
- I worry that discussion will take away hope
- My patient isn't ready to talk about EOL
- My patient's ideas about care change over time
- My patient has not been very sick yet

Curtis, Arch Intern Med, 2000; 160:1690

Slide Note

Their clinicians cited these barriers, with the most important barrier being insufficient time during appointments.

Trainer Suggestion

Some possible discussion starters would be, "From your experience, are there additional barriers to communicating with patients about palliative care? Which of these barriers would you say have been the most important? What might you suggest as ways to overcome these barriers?"

Examples of interventions to address barriers

- Educational intervention:
  - –Patient doesn't know what care he/she wants
  - –Patient has not been very sick
- Counseling intervention:
  - –Patient, clinician discomfort talking about death
  - –Patient concern bringing up assisted suicide
- Systems changes:
  - –Too little time during appointments

Curtis, Arch Intern Med, 2000; 160:1690

Slide Note

After identifying barriers to communication, the authors recommended types of interventions which might address some of these concerns. They suggested 3 categories of interventions: Educational, Counseling, and Systems-level. Examples of barriers which might be addressed in each of these 3 ways are listed here.

Trainer Suggestion

If you initiated a discussion during the previous slide about how to overcome barriers, you can use this slide to compare and consider the participants' suggestions and the authors' recommendations.

Outline

- The challenge of communicating about end-of-life care
- Patients' and families' perspectives
- Issues specific to HIV/AIDS
- Recommendations for clinical practice

Slide Note

Based on the research and our experience, here are some recommendations for clinical practice.

Preparing for a discussion about end-of-life care

- Advance preparations:
  - –Knowledge of patient/family and disease
  - –Review goals of discussion
- Plan timing, location, and setting:
  - –As early as possible in course of illness
  - –Quiet and private room
- Appropriate people present:
  - –Family, friends, staff, interpreter

Slide Note

It's important to make some advance preparation for discussions about end of life care. Holding a discussion about end of life care as early as possible in the course of the illness allows for a trusting relationship to build between you and the patient, and gives the patient time to really consider their values and needs.

Think about what you know about the patient and the family. Read the patient's chart and have information about the disease process itself. Patients may have a lot of questions about treatment options, or prognosis, and it's important to have as much information as possible. And to give them the same information as they are receiving from their other care team members.

It's important to think about what we're trying to accomplish. For example, do we want the patient to reach a decision or do we just want to provide information for them to think about? Consider the timing and location of the discussion and make sure you know who should be there.

Holding a discussion about end-of-life care

- Elicit patient/family's understanding and values
- Use language appropriate to the patient
- Align patient and clinician views
- Use repetition to show you are listening
- Acknowledge emotions, difficulty
- Use reflection to show empathy
- Tolerate silences

Slide Note

One goal of these conversations is to align patient and clinician views. This doesn't mean, "Get them to think about it our way." If there are differences between patient and clinician perspectives, the goal is to come to a shared understanding and form an alliance with the patient. Eliciting the patient's values and goals will help facilitate aligning your views. Asking about past experiences can be a good way of starting a discussion. Another way to facilitate this communication is to describe potential situations the patient might face as the disease progresses. There are workbooks with values exercises such as those found in *Your Life Your Choices* that can help to facilitate a discussion with the patient about values and goals.

In terms of language, sometimes the patient is very knowledgeable and you can use medical terminology. Other times you will need to explain things simply.

When emotions come up, it's important that we acknowledge them and let the patient talk more about them. Use reflection to show caring and empathy. If a patient seems really sad, it can be really helpful to say, "You know this seems really hard for you. You seem really sad. Do you want to talk about it?" It is also important to tolerate silence, and not to fill all the space with words. Sometimes, after a particularly long silence, a patient will say something that's important to them, and having that information can make a big difference in providing better care.

Trainer Suggestion

Refer to the module on Advance Care Planning for more detail on communicating with patients about values and goals.

Finishing a discussion about end-of-life care

- Achieve a common understanding
- Make recommendations:
  - –Don't leave a patient/family feeling deserted
- Ask if there are any questions
- Develop a plan for follow up:
  - –When you will meet again?
  - –How to reach you in the meantime?

Slide Note

Think ahead about how to finish the discussion, to achieve a common understanding.

It is important that we make recommendations, using the expertise and training we have to help patients and families. Ask if there are any questions, and develop a plan for follow-up, when to meet again, and how the patient and family can reach someone in the meantime, if other issues come up.

In terms of talking with families about withdrawing life support, focus the family on what the patient would want, not what the family wants for the patient. Family members may have a difficult time thinking about withdrawing life support from grandma. But when asked what would your grandmother want, it becomes clear: "No way would she want this."

Additional suggestions for discussing end-of-life care

- Discussing goals of care:
  - "What are your biggest concerns?"
  - "What is the hardest part of this for you and your family right now?"
- Hoping and preparing:
  - "I am *hoping for the best.* I think that, at the same time, we need to *prepare for the worst* in case the treatment is not effective."

Slide Note

The patient's goals of care are an important part of this discussion, and some of these questions can be addressed at this time. Often, the biggest concern is being a burden, so one thing we can discuss with patients is how to address this concern.

Framing the conversation in terms of hoping for the best while preparing for all possibilities aligns you with the patient.

Exploring cultural beliefs

"What do you think might be going on?"

"If we needed to discuss a serious medical issue, how would you and your family want to handle it?"

"Some people find it hard to trust clinicians who are not from their culture. Have you felt that?"

Kagawa-Singer, JAMA 2001; 286:2993

Slide Note

Keep in mind that culture and ethnicity play a large role in our values and attitudes about end of life care. For example, studies comparing ethnic groups, including African American, European American, Korean American, and Mexican American patients have shown dramatic cultural differences in attitudes about end-of-life care.

It is important to remember that just because we know someone's race or ethnicity doesn't mean we know their attitudes. We need to communicate with our patients to know what they want.

Some ways to address cross-cultural communication in end of life care include: Exploring cultural attitudes, building trust, addressing communication barriers, addressing religion and spirituality, and involving the family.

The questions here are some suggestions for exploring cultural beliefs with your patients. Make it explicit that you're going to work with the patient and the family to build trust, and to understand and accommodate differences in treatment preferences that may have cultural roots.

Trainer Suggestion

See Cross-Cultural Communication module for further detail on exploring cultural beliefs related to end-of-life care.

Reconsider the case

- 48-year-old man with C3 AIDS comes to clinic after initial chemotherapy treatment for new lymphoma diagnosis:
  - –File indicates history of injection drug use
  - –He hands the clinician a POA document and says “Here, this is for your files.”
  - –When asked, says his partner told him he had to make this because “I might die soon.”

Slide Note

We come back to the case, a man with advanced AIDS and a new diagnosis of lymphoma. He had come into the clinic for a follow-up after his initial chemotherapy treatment.

At the end of the appointment, he handed the clinician a document which identified a friend to have durable power of attorney for health care. When he was asked about the document, he said his partner told him to do it because he might die soon. He seemed somewhat reluctant to talk about it, but as his clinician spent time to build a relationship with him, important discussions about end-of-life care began to take place.

Trainer Suggestion

This might be an opportunity for brainstorming: Now that we’ve had a chance to think about these issues, what might be ways to proceed with this patient?

Case: Discussing palliative care

- Know when patient is ready to talk about death:
  - –Introduce topic in a non-threatening way
  - –Let him help direct when to readdress it
- Communicate the importance of discussion among patient, clinician, and person designed as power of attorney

Slide Note

It may take several visits, building a trusting relationship, before he is willing to come back to this issue and start making plans for what might happen as his disease progresses.

As you can see from this case, we need to balance caring and honesty. It is important to make it clear to the patient that you’re available to talk when he is ready. Follow his lead, and be attentive to the cues he gives when he is ready.

You can educate him on the importance of having his friend present so that if he becomes unable to speak for himself, his friend will know his wishes and be able to make the best decisions possible.

Understanding the clinician’s discomfort

- Discomfort discussing death is universal:
  - –Patient/family fears
  - –Clinician inadequacy
- Recognize discomfort to minimize:
  - –Giving mixed messages about prognosis
  - –Avoiding patient or family
  - –Using euphemisms for dying and death

Slide Note

Discomfort talking about death is universal. It involves confronting patients’ and families’ fears, and our own feelings of inadequacy at not being able to offer a cure to the patient. We did not go into medicine to cause people distress, and often we do not know how to have discussions about death.

Recognizing our discomfort helps us avoid giving mixed messages about prognosis when we talk to patients and families. If we try to soften the message too much, patients won’t understand what we are trying to say.

It is important to avoid using euphemisms for dying and death. One of the great stories on this subject was of a doctor who had come into a family conference and said to the family, “Well, this is like the bottom of the 9th, with 2 outs, nobody on, and we’re down by 8 runs.” And the family did not understand baseball and had no clue what he was talking about. We need to not do that.

Trainer Suggestion

This might be good spot for an exercise such as a role play, with participants checking in with their own comfort levels as they practice talking about end of life care. *See also Giving Bad News Module.

Summary: Communicating about end-of-life care

- Prior research identifies problems and hope for solutions
- Patients' and families' perspectives provide some guidance
- Develop a protocol for discussing end-of-life care with patients and families:
  - –Preparations and goals
  - –Checklist of things to accomplish

Slide Note

To summarize, prior research identifies a lot of problems related to communicating with patients and families about end of life care, and also offers some solutions.
Culture and ethnicity play a very important role, and we need to address these issues explicitly in our discussions with patients and families.
It can be helpful to think about developing a protocol that works for each of us individually for discussing end of life care with patients and families.

Trainer Suggestion

If the participants are co-workers, this may be an opportunity for them to discuss their own protocols and possibilities for change. They may want to schedule a follow-up meeting among themselves to discuss their next steps in developing or changing their protocols.

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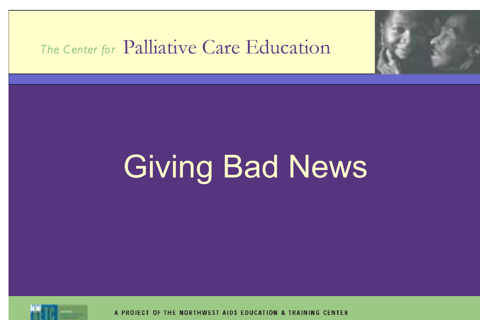
This project is funded by Health Resources and Services Administration (HRSA) and the Robert Wood Johnson Foundation (RWJF).

Giving Bad News

PowerPoint Notes



Trainer Suggestion
Introduce yourself and go over the agenda for the session. If there is time in the session and a small enough group, invite participants to introduce themselves and talk about what they are hoping to learn. Invite questions and comments throughout the presentation.

Learning objectives

- List the 6 steps in giving bad news
- Adapt the bad news protocol to your work setting
- Explain how the manner in which bad news is given can impact patient outcome and patient care
- Explain how culture impacts patient information needs and decision-making

Consider a case

- 24-year-old F; HIV+ for 3 years; current IVDU
- Unstable living situation
- Estranged from family
- On HAART, but questionable adherence
- Recent abnormal LFTs
- You are meeting with her to give her a Hep C diagnosis

Slide Note
To begin thinking about these issues, we'll start with a case. The patient is a 24-year-old female who has been HIV+ for 3 years. She is currently using intravenous drugs. She has no permanent living situation. She stays with friends or off and on with her boyfriend. She is estranged from her family. Her boyfriend has been an inconsistent source of support. She has been on her current HAART regimen for over a year, but her adherence is questionable. She has been on other HAART regimens in the past and has developed some resistance. In her most recent blood work, she had an abnormal liver function test, and further testing has shown that she has Hepatitis C. You are meeting with her to give her this diagnosis.

We will be revisiting this case during this talk, but let's just talk for a moment about what sorts of things you might think about as you prepare for your discussion with this patient.

Do physicians give bad news?

- 1961 Oken in JAMA
- Survey of 219 physicians
- 88% generally DID NOT inform patients of a cancer diagnosis

- 1979 Novak in JAMA
- Survey of 264 physicians
- 98% generally DID inform patients of a cancer diagnosis

Slide Note
This slide shows the results of two studies, 18 years apart. In the first study done in the early sixties, physicians did not inform the majority of their patients of a cancer diagnosis. As our culture has embraced patient autonomy and self-determination, the practice of physicians has changed, as well. In this later study, done in 1979, physicians informed their patients of a cancer diagnosis almost 100% of the time.

Giving bad news

- Reviewing the evidence
- Recommendations for clinicians
- Cultural considerations

Slide Note
Giving bad news is stressful for clinicians and hearing bad news is difficult for patients. Yet it is possible to give bad news in a way that creates trust and strengthens the clinician-patient relationship.

There are three parts to this presentation. First, we will look at research that describes how health care providers give and how patients receive bad news. In the second part of the talk, we will go over an approach for giving bad news to patients. And finally, we will look at cultural issues and how they might impact both the giving and receiving of bad news.

Reviewing the evidence

- What do patients want to know?
- How do patients experience bad news?
- How competent are physicians in giving bad news?
- How should physicians give bad news?
- Does how bad news is given make a difference?
- Do cultural differences matter?

Slide Note
Here are the questions we will be addressing.

What do patients want to know?

- 2,331 patients at UK cancer centers:
  - –98% wanted to know if the illness was cancer
  - –87% patients preferred "as much information as possible"
- Need to individualize delivery to patient needs

Jenkins, Br J Cancer 2001;84:48-51

Slide Note

A variety of studies indicate that most American and European patients want a full discussion of their medical condition. For example, in this study of over two thousand patients at British cancer centers, most patients reported wanting as much information as possible, but they also emphasized the importance of individualizing the information based on each patient's needs.

How do patients experience bad news?

- Bad news results in a cognitive, behavioral, or emotional deficit in the person receiving the news that persists
- Clinicians can't change the news
- Clinicians can make the news worse, or they can help give realistic hopes

Slide Note

First let's define bad news: what is it? The definition most often used in the medical literature is that bad news results in a cognitive, behavioral or emotional deficit in the person receiving the news and that these deficits persist.

An important thing to remember in giving bad news is that clinicians can't change the news itself, but the way they give it can shape the experience for the patient. They can make the news worse by adding to patient confusion or anxiety, or they can help give patients realistic hopes.

A variety of responses to bad news

100 patients diagnosed with cancer:

– Shock	54%
– Fright	46%
– Accept	40%
– Sadness	24%
– Not worried	15%

Lobb, Med J Aust 1999: 290-4

Slide Note

When patients are given bad news, they have a wide variety of reactions. There is no single reaction to expect. In this study of 100 patients receiving a diagnosis of cancer, their self-reported reactions were shock, fear, acceptance, and sadness. 15% said they were not worried.

Trainer Suggestion

This may be a good time for a discussion question: In your experience, how have patients with cancer or other life-threatening illnesses reacted to their initial diagnosis?

Responses to bad news

4,527 patients tested for Huntington disease
- <1% experienced "catastrophic event"
  - –Including suicide, attempted suicide, psychiatric hospitalization
- Increased risk associated with
  - –those with manifestations of Huntington's
  - –those with previous psychiatric illness
  - –those who were unemployed

Almqvist, Am J Hum Genet 1999: 1293-1304

Slide Note

This study followed people who had undergone genetic testing for Huntington's disease. Although physicians have expressed concern that giving bad news will lead patients to do drastic things, this study shows that the actual numbers, even for a disease with no treatments, are very small. The study found that those at increased risk of "catastrophic events," including completed or attempted suicide or psychiatric hospitalization, were those already manifesting Huntington's, those with histories of psychiatric illness, and those who were unemployed.

(Of note, those who did test positive had a higher rate of catastrophic events than those who tested negative, but the rates were low - 0.02% of those with positive testing versus 0.002% in those who tested negative. The catastrophic events occurred over the 4 years after testing was done.)

People receiving bad news may not remember much

- Three months after parents received bad news
- 12 of 23 sets took in "little or none of the information given"
- 4 of 23 sets denied that a separate information session had occurred
- 10 of 19 sets remembered the information session, but didn't understand the content

Eden, Pall Med 1994: 105-114

Slide Note

This study showed that people who receive bad news may not remember much about the conversation. Parents who had received bad news about their child were interviewed three months later. Half of the parents admitted that they took in "little or none" of the information from the initial conversation. Four sets of parents didn't remember that a longer information session had occurred a few days after the initial bad news session. 10 other sets of parents remembered the information session, but didn't understand the content. The results of this study indicate that we may need to have more than one conversation with the patients or family member before the bad news "sinks in." One way to check on the patient's understanding of the news is to ask them to reflect back what they have heard or what their interpretation of the news is.

Medical jargon can make bad news worse

- Technical language frequently unclear
- 100 women with breast cancer:
  - –73% misunderstood "median survival"
  - –No agreement on what a "good" chance of survival meant numerically

Ford, Soc Sci Med 1996: 1511-9

Slide Note

A common complicating factor is when doctors use medical terminology and technical language that patients don't understand. This confuses patients and increases their distress. In a study of 100 women with breast cancer, 73% did not understand the term "median survival," and there was no agreement among clinicians on what a "good" chance of survival meant in terms of weeks, months, or years.

Physicians are inaccurate in detecting distress

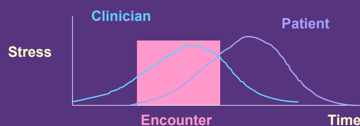
- 5 oncologists studied intensively
- None predicted patient distress better than chance
- One had negative predictive behavior
- All very satisfied with their performance
- Little probing about patient emotional state

Ford, Br J Cancer 1994: 767-70

Slide Note

It turns out physicians are very inaccurate in detecting distress. Here is a study where anthropologists observed oncologists. They were present at all interviews and spoke with the patients afterwards. They asked the patients if they were distressed, then asked the oncologists to rate their patients' distress. The oncologists weren't very good at matching their patients' answers. In fact it's surprising how bad they were.

Patient and clinician stress related to bad news



Ptacek, JAMA 1996: 496-502

Slide Note

One reason that physicians may not be great at detecting distress when they give bad news is that they are themselves stressed during the encounter. About 20% of physicians in one study said that they experienced strong emotions when they had to tell a patient that their medical condition would lead to death. And since this study is based on self-report and doctors are socialized to not be 'emotional,' this is probably an underestimate.

The stress clinicians experience when they give bad news has a different trajectory than the distress patients experience. The clinician's stress peaks during the encounter, when the bad news is delivered. The patient's stress peaks after the encounter, when the ramifications of the bad news are being felt. This mismatch in stress and distress is important to be aware of in being with a patient who receives bad news.

Trainer Suggestion

This might be an opportunity to do an exercise using the participants own experiences. When did they have a stressful time talking with a patient?

Gaps in what patients want and what they receive

- Most patients are highly 'satisfied' yet:
  - –57% wanted to discuss life expectancy, but only 27% actually did
  - –63% wanted to discuss the effects of cancer on other aspects of life, but only 35% actually did

Lobb, Med J Aust 1999: 290-4

Slide Note

Physicians, who have been studied the most on this topic, and other clinicians, often feel that they do a reasonable job and don't need training. This study involved patients who were receiving bad news about their cancer. Most of the participants, when asked in general how the encounter went with their clinician, said they were "highly satisfied." However, when asked for specifics about the encounter, almost a quarter rated their doctor as nervous or uncomfortable, and many felt they did not have the conversation they wished to have with their clinician.

An explanatory note: In this study, patients were interviewed after a bad news conversation initiated by their physician. The study does not identify reasons why the discussion of life expectancy and the effects of cancer on patient life did not come up.

Pitfalls in giving bad news

- 79 patients, 68 family said bad news encounter was suboptimal because:
  - –Physician was too blunt
  - –Place or time was inappropriate
  - –Patient got the sense that there was no hope, they wanted physicians to balance sensitivity and honesty

Curtis, J Gen Intern Med 2001: 41-9

Slide Note

What are the pitfalls in giving bad news that a clinician should watch for? In a study of patients and family members who were asked about getting bad news, they said the encounter was suboptimal for these three major reasons.

The patients wanted their physicians to balance sensitivity and honesty. They were not asking physicians to lie, sugar coat, or evade the actual news, but they wanted to feel like there was some hope in their situation.

How bad news is given makes a difference

- 100 patients with breast cancer, adjustment to illness correlated with:
  - –Physician behavior during cancer diagnostic interview
  - –History of psychiatric issues
  - –Premorbid life stressors
- Patients dissatisfied with how physicians provided information were 2x more likely to be depressed or anxious

Roberts, Cancer 1994, 74 (1 supp): 336-41

Slide Note

Does how bad news is given actually make a difference? In this study, patients with breast cancer were interviewed after a doctor's appointment. They were followed after the bad news encounter to see how they adjusted to the news. Their adjustment correlated with three factors: first, the physician's behavior during the diagnostic interview; second, a history of psychiatric illness; and third, other life stressors. The important finding is that patients who were dissatisfied with how they were given the diagnosis were twice as likely to become depressed or anxious. How we give bad news will impact patient mental health and adjustment to illness.

A recommended protocol for giving bad news

1. Prepare info, location, setting
2. Find out what they already know
3. Ask how much they want to know
4. Share the information
5. Respond to the patient's emotion
6. Negotiate a concrete follow-up step

Buckman, *How to Break Bad News*, 1992

Slide Note

Here is an overview of the process on giving bad news. It is based on the work of Robert Buckman, whose book is cited here. We will go through the protocol step-by-step.

Bad news protocol

1. Prepare
   - Know the facts
   - Find time
   - A quiet space
   - The right people

Nonverbal cues: distance, posture, eye level

Slide Note

Let's revisit the case we opened with, regarding the young woman whom you are about to give a new diagnosis of Hepatitis C. How do you start?

You need to prepare for the meeting. First, make sure you have the correct information. Be careful not to give people bad news based on preliminary results of a test. For example, a radiology resident may read an x-ray differently than his/her attending. Make sure you are confident of the information – consider reviewing the primary data yourself. Check out with the patient that this is a good time to talk. Make sure you have adequate time and a private space. Make sure that the right people are there for support– perhaps her boyfriend, maybe a social worker or some other professional that she has a good relationship with. When you do sit down –and I recommend sitting down for any serious conversation– be aware of your eye contact, the level of your chair relative to hers, how close you sit – too close may feel intrusive to her, but too far away may seem unconnected.

Bad news protocol

2. Find out what the patient already knows:

   "I want to make sure we're on the same page; what have other doctors told you?"

   "When you first had (<u>symptom</u>), what did you think it might be?"

Slide Note

Next, find out what her perception of the issue is. For instance, you could ask "What have you heard from other doctors or nurses about your liver tests?"

Her answer will give you information about how much she understands and about how concerned she is about this problem – or unconcerned. This will guide your approach and help you decide on what level you should discuss the news.

Bad news protocol

3. Ask how much the patient wants to know:

   "Would you like me to tell you the full details of your condition or is there someone else you would like me to talk to?"

Slide Note

The next step is to ask how much the patient wants to know. This step can seem awkward, but can be very helpful if you are concerned about cultural beliefs. A helpful way to ask is: "Are you the kind of person who would rather focus on the big picture, or are you the kind of person who wants to know all the details?"

Trainer Suggestion

A possible discussion question here is: Have you found other effective ways of finding out how much the patient wants to know? What has worked well, in your experience?

Bad news protocol

4. Share the information:
   - Warning shot
   - "I have some bad news about the results of your blood test."

Slide Note
Firing a warning shot gives the patient a chance to prepare herself to receive bad news: "I have some bad news about the results of your blood test that we need to discuss."

Trainer Suggestion
You may want to solicit other suggestions for warning shots from the audience.

Bad news protocol

4. Share the information:
   - Use language at the same level as the patient's:
   - "Did you get that? Did that make sense to you?"

Slide Note
When you give the news, use language at the same level as the patient's, and be straight forward. You might say something like "I have a new blood test result to discuss. Your blood tests show that you have a kind of virus that affects the liver, called Hepatitis C."
You want to give her time to absorb this information and ask questions, and you may want to check her understanding by saying, "Did that make sense to you?" or by asking her to repeat the news back to you in her own words.
This is a good time, if the patient is ready, to go over treatment options, prognosis, etc. Remember to balance honesty with sensitivity.

Bad news protocol: Final steps

5. Respond to the patient's emotions:
   - –Acknowledge, name, empathize
     - "I can see that this wasn't something you expected to hear."
   - –You don't have to agree with the emotion or share it.

Slide Note
After sharing the news, be prepared to respond to her emotions. She may be shocked and speechless, or very matter of fact and unconcerned. Showing that you are sensitive to her response demonstrates that you are paying attention to how the news is affecting her.

Trainer Suggestion
A possible discussion question: What are some other ways you could respond to the patient's emotions in a sensitive manner?

Bad news protocol: Final steps

6. Negotiate a concrete follow-up step:
"Let's talk next week after you see the GI specialist."

Slide Note

It is important to make a follow-up plan after the conversation. As we saw in an earlier slide, sometimes people go into shock when they hear bad news and don't start processing it until after they have left the appointment. They might have lots of questions or concerns that they did not think to bring up during the conversation. Giving patients permission to call you or providing another resource for information is one way to deal with this. Or you can make an appointment with the patient in the near future.

Trainer Suggestion

This might be a good place to stop and do a demonstration of the protocol, either with trainers or participants playing the parts of clinician and patient. See Role Plays Section for suggestions on how to do this.

Dealing with the fallout

- Walk through the bad news encounter
- Use case-specific knowledge
- Know usual clinician pitfalls:
  - –Failure to assess understanding
  - –Failure to acknowledge emotion

Slide Note

Sometimes we are not the one to give the actual bad news but find ourselves in the position of dealing with the aftermath of someone else's attempts. We can follow the bad news protocol in a modified way in this situation– researching the patient's situation in advance, finding a good place to talk and asking the patient to explain their understanding of the bad news they already received. We can also perform the step clinicians often skip or avoid in their own discomfort– addressing the patient's emotional response to the bad news.

Survey of 800 patients in LA: Assessing cultural differences

Should a patient:

	Be told of a diagnosis of cancer	Decide about life-support
African American	88%	60%
European American	87%	65%
Mexican American	43%	41%
Korean American	35%	28%

Blackhall, JAMA, 1995; 274:820

Slide Note

An important point to remember is that patient ethnicity can influence how and even if patients want to know about bad news. This was a study looking at 800 patients in the Los Angeles area; 200 each in these four ethnic groups. One of the questions the researchers asked was: "Should a patient be told of a diagnosis of cancer?" The African American and European American respondents both felt that being told the diagnosis was important. But in Mexican American and Korean American populations, the majority of respondents did not want to be told.

Can discussing death cause harm?

- Studies have shown that people from many different cultures are more likely to believe discussing death can bring death closer:
  - –African Americans
  - –Some Native Americans
  - –Immigrants from China, Korea, Mexico

Curtis, Arch Intern Med, 2000; 60:1690
Caralis, J Clin Ethics, 1992; 4:155
Caresse, JAMA, 1995; 274:86

Slide Note

Furthermore, in some cultures, people believe that just discussing death can make it more likely to happen or can cause emotional harm. Some feel that if a patient is told they are dying, they will give up hope and will not fight their illness. In some cultures, one of the roles of a clinician or healer is to speak in a positive way. This does not mean these patients are "in denial" about the finiteness of life. They just have a different perspective on dealing with illness.
A useful question to ask all patients, one that may help to get at this issue is: "If someone in your family were to be seriously ill, how would you want the doctors to handle it? Would you want to be told?" It can also be helpful to provide information in an indirect way, as if discussing someone else. For example, "Some people who have this illness like to prepare for the worst by getting their affairs in order."

Trainer Suggestion

See the Culture module for more background information on this issue.

Exploring cultural beliefs

- What do you think might be going on?
- If we needed to discuss a serious medical issue, how would you and your family want to handle it?
- Would you want to handle the information and decision-making, or should that be done by someone else in the family?

Kagawa-Singer, JAMA 2001; 286:2993

Slide Note

Even though we have research to guide us in understanding different cultural reactions to bad news, it is important to not make assumptions about people based on their ethnicity or culture. Here are some questions we can ask to ascertain an individual patient's view of their illness and their preferred way of receiving news and making medical decisions.

Summary

- Giving bad news is a fundamental communication skill
- How bad news is delivered can affect how patients adjust to the illness
- Exploring cultural beliefs is important in adapting the bad news communication to each patient

Slide Note

In summary, we've covered three main points:
Giving bad news is a fundamental communication skill.
How bad news is delivered can affect how patients adjust to the illness.
Exploring cultural beliefs can help clinicians adapt the giving of bad news to the needs of each patient.

Skill Building & Interactive Exercises

- Communication Case Examples Exercise
- *Communicating with Patients & Families* – Sample Role Play Scenarios
- *Giving Bad News* – Sample Role Play Scenarios
- *The Doctor* Video Exercise
- EPEC Trigger Tape Exercise – *Giving Bad News*

Communication Case Examples Exercise

Type of Activity: Discussion
Time: 20 minutes
Materials: Overheads or handouts of cases (minus the discussion examples)
Purpose: For participants to recognize helpful and unhelpful communication behaviors when discussing end-of-life care with patients.

Instructions for Using the Case Scenarios: One way of presenting these cases is to make each case into an overhead that can be projected in front of the class. They can also be printed out as handouts after removing the discussion examples.

Read the case aloud to the participants, or have the participants read the case aloud, with two people each reading a part. Then ask the group to identify examples of good communication by the clinician in each scenario. Summarize the participants' list, and then refer to the lists provided with each case to make sure all examples are noted. Then ask the group to state where there could be room for improvement in the communication. Once again, refer to the lists provided with each case.

Discussion Questions:

1. What did you like about this encounter?
2. In each case, how would you feel if you were in the patient's or family member's role?
3. How might you approach the patient or family member in each case?
4. How might you reword some of the clinician's comments?

Case 1: Patient Visit to Clinic

A 43-year-old man with advanced HIV infection is on his third HAART regimen after having had increasing viral load on one regimen and severe side effects with the second regimen. He is a retired fire fighter. He comes back for follow up for neuropathy from the HAART and depression.

Clinician: Hello Mr. K. How have you been doing?

Mr. K: I don't know. I guess I'm wondering why all this is happening to me.

Clinician: I know this has been really hard on you. We talked about this before. These medications do have the tendency to make people sick and can also make them feel quite down. Tell me, how much have you been able to walk around? Last time we met you could only walk about 10 yards.

Mr. K: I can walk to the mailbox and back – about 30 yards. It is just so terribly hard.

Clinician: Sounds like you are doing better than last time. I'm really happy to hear that you can walk farther. I was very worried about how this neuropathy was going to affect your life. Do you feel like the homecare nurse is providing you the support that you need?

Communications Examples to Discuss

Good communication behavior:

- Starts with an open question
- Makes statement of concern and caring for the patient
- Asks about and attempts to provide practical support with activities of daily life
- Remembers information from previous visit
- Acknowledges patient's emotion – "I know this has been hard for you."

Communication behaviors that could be improved:

- Doesn't explore patient's meaning with "why is this happening to me?"
- Makes premature reassurance with "sounds like you are doing better" that doesn't validate or explore patient's emotions

Case 2: Family Conference in the ICU

A 32-year-old man with a advanced HIV infection and cirrhosis from hepatitis C develops community-acquired pneumonia followed by multiple organ failure. After seven days in the ICU without improvement, clinicians are meeting with the wife to discuss withdrawal of life support. After an update on his condition, the patient's wife and son say they think he would want life support withdrawn.

Physician: We could continue to keep him alive with the life support that we have discussed. However, it seems clear to me from what you have said that his wishes would be not to have that done. I think you have made a very reasonable decision, and a brave decision, to put aside your personal feelings of wanting to have him around and honor him by honoring his wishes.

Wife: (crying) He would do the same thing for me.

Physician: And that's to be commended. This is not necessarily your deciding, but you are being his surrogate and trying to tell us what he can't tell us now. So our primary goal now will be to keep him comfortable. We will increase the pain medicine as needed to make sure he is not having pain or feelings of suffocating, and, as we discussed, we will take away the life support. I suspect, once we do that, he will not survive very long.

Wife: We have done our tough job, now the tough job is up to you.

Physician: Do you have any more questions for us?

Communications Examples to Discuss

Good communication behavior:

- Good description of surrogate decision-making
- Reassures wife that she has made the best decision
- Reassures wife that the medical team will address pain and other symptoms
- Prepares wife for the amount of time from withdrawal of life-support and death

Communication behaviors that could be improved:

- No acknowledgement of wife's crying
- Does not explore what wife means by "the tough job"

Sample Role Play Scenario #1

Type of Activity: Simulation/Discussion
Time: 30-60 minutes (depending on role play format)
Materials: Role play scripts for each character in the scenario
Purpose: To provide participants with the opportunity to practice the communication protocol. To develop empathy for patients and their situations.

Instructions: Divide the class into groups of three. Roles for each participant are listed below:

1. **You are the clinician.** You are meeting with your patient, Joe Rodriguez, to discuss his wishes for further treatment and care. Joe is a fairly new patient to your clinic. He is a 35-year-old man who has been HIV+ for 8 years. He has been on four different HAART regimens. Despite his current regimen, he has a climbing viral load and has recently been in the hospital with PCP. His social worker has told you that she thinks he has had problems with adherence to his regimen. This is your first discussion with him about his declining health status and goals for care. How will you determine the patient's wishes for future care? How will you determine who will be involved in future decision-making? Use the protocol outlined in the presentation as a guide to having this discussion.

2. **You are the patient.** Your name is Joe Rodriguez, and you have been HIV+ for 8 years. You have tried quite a few different HAART regimens, but have had trouble adhering to any of them for long. You have had some side effects with your current regimen and feel discouraged as your viral load continues to climb. You were recently in the hospital with PCP. You had suspected something was wrong for quite some time, but were afraid to go to the doctor. You have not had very good experiences with the health care system in the past, and are not sure how you feel about your new doctor. Your usual way of coping is to avoid the situation for as long as possible, but when someone talks to you in a sympathetic manner, you can open up. You are going to meet with your clinician to discuss your health status and care options.

3. **You are the observer.** Your job is to observe the interaction between the clinician and the patient and to offer feedback and suggestions afterwards. Remember that in a role play, most clinicians feel self conscious and vulnerable. Be supportive! Provide **positive** feedback first, and then make just one or two suggestions for improvement. Don't flood the clinician with a list of recommendation. Be sensitive to how the clinician reacts to your comments. Frame your feedback as observations of behavior, not as judgment about the clinician's skill. As you watch the role play, keep in mind the following questions:

Discussion Questions:

1. In what ways does the clinician do any of the following:
   - Elicit the patient's goals and values?
   - Encourage questions from the patient?
   - Acknowledge and respond to the patient's emotions?
   - Provide education in language that is appropriate to the patient?
   - Explore cultural beliefs?
   - Make recommendations and develop a plan for follow-up?

2. Do you have one or two suggestions for the clinician to help her/him work more effectively with this patient?

* See Role Playing as a Teaching Technique for information on how to include role play into your training.

Sample Role Play Scenario #2

Type of Activity: Simulation/Discussion
Time: 30-60 minutes (depending on role play format)
Materials: Role play scripts for each character in the scenario
Purpose: To provide participants with the opportunity to practice the communication protocol. To develop empathy for patients and their situations.
Instructions: Divide the class into groups of four. The roles for each participant are listed below:

1. **You are the clinician.** You are about to meet with Ted Jones and his family to discuss future care plans. Mr. Jones is HIV+ with end-stage liver disease. You met with the patient yesterday to tell him of his poor prognosis. He has told you privately that he would like to go home to die, but he has not discussed this yet with his wife. You have met his wife in the clinic where she has been a strong advocate for aggressive treatment. How will you approach this discussion? Assuming his wife agrees to homecare, you will want to discuss with her homecare arrangements and what to expect in the dying process.

2. **You are the patient.** Your name is Ted Jones. You are 55 years old, and you have been HIV+ for 7 years. Your health has been poor for the past year, and you are now hospitalized with end-stage liver disease. You are tired of fighting your illness and now just want to go home and die peacefully. You live with your wife and your 19-year-old daughter. You are worried that your care will be too big of a burden on your family. You are also worried about how your wife will take your decision as she has been a strong advocate for aggressive care throughout your illness. Your wife, Mary, is also HIV+, but has been asymptomatic.

3. **You are the family member.** Your name is Mary Jones and you are Ted's wife. You are HIV+, but have been very healthy on a HAART regimen for the past few years. You have watched your husband's health decline, and you are afraid of what lies ahead. You have a strong belief system that if Ted really wants to fight his HIV, he can live. You have encouraged him throughout his illness to seek aggressive treatment and feel that he should consider any and all treatment options now, including ICU care. You are worried about how your daughter will be affected by her father's declining health and the impact of watching him die.

4. **You are the observer.** Your job is to observe the interaction between the clinician, patient, and family member and to offer feedback and suggestions afterwards. Remember that in a role play, most clinicians feel self conscious and vulnerable. Be supportive! Provide **positive** feedback first, and then make just one or two suggestions for improvement. Don't flood the clinician with a list of recommendation. Be sensitive to how the clinician reacts to your comments. Frame your feedback as observations of behavior, not as judgment about the clinician's skill. As you watch the role play, keep in mind the following questions.

Discussion Questions:

1. In what ways does the clinician do any of the following:
   - Elicit the values and goals of the patient and his wife?
   - Listen to their concerns and encourage questions?
   - Acknowledge and respond to their emotions?
   - Provide education in appropriate language?
   - Explore cultural beliefs?
   - Make recommendations and develop a plan for follow-up?
2. How does the clinician handle the different end-of-life philosophies of the patient and his wife?

3. How does the clinician explain different homecare options? How does the clinician prepare the patient and wife for what lies ahead?

4. Do you have one or two suggestions for the clinician to help her/him work more effectively with this patient and family?

* See Role Playing as a Teaching Technique for information on how to include role play into your training.

Sample Role Play Scenario

Type of Activity: Simulation/Discussion
Time: 30-60 minutes (depending on role play format)
Materials: Role play scripts for each character in the scenario
Purpose: To provide participants with the opportunity to practice the bad news protocol. To develop empathy for patients and their situations.

Instructions: Divide the class into groups of three. The roles for each participant are listed below:

1. **You are the clinician.** April Davis is coming in for a clinic appointment today. She is a 3-year-old woman who has been HIV+ for 5 years. She has been on various HAART regimens over that entire time, but adherence has been an ongoing issue. Lately her viral load has been increasing and her T-cell count is down. You did resistance testing to see what might be going on. It looks like she might be out of options for HAART. Follow the bad news protocol to tell the patient this news.

2. **You are the patient.** Your name is April Davis and you are 33 years old. You have been HIV+ for 5 years and have been on many HAART regimens in that time. Adherence has been a problem for you, and at your last visit, your T-cell count had dropped and viral load had increased. Your doctor did resistance testing at that visit. Now you are coming in to hear the results of the tests.

3. **You are the observer.** Your job is to observe the interaction between the clinician and the patient and to offer feedback and suggestions afterwards. Remember that in a role play, most clinicians feel self conscious and vulnerable. Be supportive! Provide **positive** feedback first, and then make just one or two suggestions for improvement. Don't flood the clinician with a list of recommendation. Be sensitive to how the clinician reacts to your comments. Frame your feedback as observations of behavior, not as judgment about the clinician's skill. As you watch the role play, keep in mind the following questions:

Discussion Questions:

1. In what ways does the clinician follow each of the six steps of the Bad News Protocol:
   - Prepare for the meeting?
   - Determine what the patient already knows?
   - Find out what the patient wants to know?
   - Share the news with the patient?
   - Respond to the patient's emotion?
   - Plan for follow-up?

2. Do you have one or two suggestions for the clinician to help her/him work more effectively with this patient?

* See Role Playing as a Teaching Technique for information on how to include role play into your training.

Scene from *The Doctor* or

How Not to Give Bad News

Type of Activity: Observation/Discussion
Time: 20-30 minutes
Materials: *The Doctor* video
VCR and television
Purpose: For participants to observe and name good and not-so-good elements of a bad news discussion.

Set-up: *The Doctor* is a movie starring William Hurt in which he plays a surgeon who is diagnosed with cancer of the voice box. His experience in the role of an ordinary patient helps him in becoming a better surgeon (and a better person). In the scene we are about to see, Dr. Jack McKee has a first appointment with an ENT doctor who gives him his initial diagnosis. Please watch for the ways in which Dr. Abbott, the ENT doctor, interacts with Jack and shares with him his diagnosis.

[The scene occurs at approximately 9 minutes and 40 seconds into the film.]

Discussion Questions:

1. What body language does Dr. Abbott display? What messages are conveyed by her body language?
2. What does Dr. Abbott do well in her appointment with Jack? What things are not done well?
3. How does Dr. Abbott convey Jack's diagnosis? Is this effective?
4. How do you think Jack feels during his appointment with Dr. Abbott?
5. How does Dr. Abbott explain the procedures she performs during the appointment?
6. How does Dr. Abbott explain the diagnosis and next steps?
7. What would you recommend to Dr. Abbott to improve her communication with Jack?
8. What might be some consequences of her communication with Jack?

Some possible things to point out in the film:

- No eye contact.
- Body turned away, washing hands, etc.
- Brisk, in an obvious hurry.
- Does not try to establish any sort of connection.
- No explanation of the procedures as she does them.
- No real empathy for the discomfort she is causing.
- "Doctor, you have a growth."
- No explanation of what she is thinking in terms of diagnosis.
- Rattles off a list of future tests and then quickly leaves.
- No attention to emotional reaction.
- No inviting of questions at the appointment or in the future.

EPEC Trigger Tape Exercise – *Giving Bad News*

Type of Activity: Observation/Discussion
Time: 20-30 minutes
Materials: EPEC Trigger Tape #2 – *Giving Bad News*
VCR and television
Purpose: For participants to observe and name good and not-so-good elements of a bad news discussion.

This exercise is to be done using the Module #2 Trigger Tape from the EPEC Curriculum. EPEC (Education for Physicians on End-of-Life Care) developed a curriculum to provide physicians with the basic knowledge and skills needed to appropriately care for dying patients. In addition to 12 training modules on palliative care topics, EPEC developed accompanying trigger tapes that provide examples of end-of-life communication skills and are used to stimulate discussion. The curriculum and trigger tapes can be ordered from their Website at http://www.epec.net/content/products.html.

Emanuel LL, von Gunten CF, Ferris FF, eds. "Module 2: Giving Bad News," *The Education for Physicians on End-of-Life Care (EPEC) Curriculum:* © The EPEC Project, The Robert Wood Johnson Foundation, 1999.

Set-up: The patient is Mr. Gonzales, a 67-year-old mechanic who immigrated to the U.S. from Mexico 10 years ago. The doctor is Dr. O'Brien. He has been caring for the family for 3 years. Mr. Gonzales had a colonoscopy last week, and the biopsy results confirm a diagnosis of adenocarcinoma. The video shows a scene in which Dr. O'Brien gives him the news of his colon cancer.

Discussion Questions:

1. What body language does Dr. O'Brien display? What messages are conveyed by his body language?
2. How does Dr. O'Brien set up the telling of the bad news?
3. What things does Dr. O'Brien do well? What things could he do differently?
4. In what ways does Dr. O'Brien follow the bad news protocol?
5. How does Dr. O'Brien deal with the reluctance of Mr. Gonzales to talk any further?
6. How does Dr. O'Brien handle the patient's emotions?
7. What cultural issues might be operating in this situation? How should Dr. O'Brien handle them?
8. How does Dr. O'Brien address the patient's family involvement?
9. What plans does he make for follow-up with the patient, if any?

Sample Agendas

We've developed some sample agendas for teaching communication skills. These agendas are adapted from trainings conducted by the Center for Palliative Care Education. The training module components are designed to work flexibly with each other. We encourage your experimentation in combining different components to find a training program that works for you and your audience.

►*If you have one hour…*

Introductions & Pre-Evaluation	*5 minutes*
Bad News Trigger Tape	*5 minutes showing* *5 minutes audience reaction*
Giving Bad News PowerPoint	*30 minutes*
Discussion (solicit case examples)	*10 minutes*
Wrap Up & Evaluation	*5 minutes*

►*If you have two hours…*

Introductions & Pre-Evaluation	*10 minutes*
The Doctor Video	*5 minutes showing* *10 minutes audience reaction*
Communicating with Patients & Families PowerPoint	*40 minutes*
Break	*10 minutes*
Role Play Communication Skills Discussion/Process	*30 minutes* *10 minutes discussion*
Wrap Up & Evaluation	*10 minutes*

* Please refer to Tips for Developing a Training Agenda for more information.

Evaluation Forms

We've developed evaluation forms to use with our training modules. They consist of unique identifier information about the participant, and questions aimed at gaining information about participant satisfaction and program effectiveness. You may want to adapt these forms and questions to your own evaluation needs.

Communicating with Patients & Families about End-of-Life Care

- ▶ Pre-Training Survey
- ▶ Post-Training Survey
- ▶ Follow-Up Survey

Giving Bad News

- ▶ Pre-Training Survey
- ▶ Post-Training Survey
- ▶ Follow-Up Survey

* Please refer to Evaluating Your Training Session for more information.

Communicating with Patients & Families about End-of-Life Care

Pre-Training Survey

Thank you for completing this survey. Your input will help us improve our training program and will provide information about its effectiveness to guide future planning. Please answer these questions as best you can – if you're not sure of an answer, just give it your best try.

Date:___/___/___ ID: Birth month:____ Day:____ Last 4 digits of SSN:_______________

1. Please rank your current level of skill in the area of communicating about end-of-life care with patients and families, by checking one of the following numbers from 1 to 5:

Need more skill for basic competency		Adequate skill		Highly skilled
1	2	3	4	5
☐	☐	☐	☐	☐

2. Please rank your current level of personal comfort in the area of communicating about end-of-life care with patients and families:

Extremely uncomfortable		Somewhat comfortable		Extremely comfortable
1	2	3	4	5
☐	☐	☐	☐	☐

3. Please answer the following by checking the True or False box:

	True	False
a. Regardless of a patient's ethnicity, full disclosure is the best approach for physicians and health care providers when discussing end-of-life care with patients.	☐	☐
b. Physicians spend about the same amount of time *talking* to their patients as they spend *listening* to their patients when communicating about end-of-life care.	☐	☐
c. Research suggests that to patients with life-threatening illness, provider communication is more important than medical competence.	☐	☐

Correct Answers: 3a. False, 3b. False, 3c. True

Communicating with Patients & Families about End-of-Life Care

Post-Training Survey

Thank you again for your input to help us improve our training program and guide future planning. As before, please answer these questions as best you can – if you're not sure of an answer, just give it your best try.

Date:___/___/___ ID: Birth month:____ Day:____ Last 4 digits of SSN:______________

1. Please respond to the following questions using the scale below:

	Not at all		Somewhat		Very much
Did the training hold your interest?	☐	☐	☐	☐	☐
Did you learn things in the training that will be useful for your work?	☐	☐	☐	☐	☐
How understandable was the material presented to you?	☐	☐	☐	☐	☐
Were the educational materials, such as slides or handouts, useful?	☐	☐	☐	☐	☐
How responsive was the trainer to the audience's questions?	☐	☐	☐	☐	☐
Did you feel the trainer's presentation was culturally sensitive?	☐	☐	☐	☐	☐

2. What were the strengths of this presentation?

3. How could we improve this presentation?

4. Would you recommend this training to someone else? Yes ☐ No ☐

5. Please rank your current level of skill in the area of communicating about end-of-life care with patients and families, by checking one of the following numbers from 1 to 5:

Need more skill for basic competency		Adequate skill		Highly skilled
1	2	3	4	5
☐	☐	☐	☐	☐

6. **Please rank your current level of personal comfort in the area of communicating about end-of-life care with patients and families:**

Extremely uncomfortable		Somewhat comfortable		Extremely comfortable
1	2	3	4	5
☐	☐	☐	☐	☐

7. **Please answer the following by checking the True or False box:**

	True	False
a. Regardless of a patient's ethnicity, full disclosure is the best approach for physicians and health care providers when discussing end-of-life care with patients.	☐	☐
b. Physicians spend about the same amount of time talking to their patients as they spend listening to their patients when communicating about end-of-life care.	☐	☐
c. Research suggests that to patients with life-threatening illness, provider communication is more important than medical competence.	☐	☐

8. **What do you anticipate doing differently in your work as a result of this training?**

9. **How much did this training help prepare you to do the following:**

	Not at all		Somewhat		Very much
Provide primary end-of-life care for patients with HIV/AIDS?	☐	☐	☐	☐	☐
Provide education and training to other clinicians on end-of-life care issues?	☐	☐	☐	☐	☐
Advocate for better palliative care in your workplace?	☐	☐	☐	☐	☐
Other ________________________________	☐	☐	☐	☐	☐

10. **Would you be willing to be contacted in one month for a brief follow-up?** Yes ☐ No ☐
    If yes, what is your email address? ____

11. **Please write any additional comments, thoughts, or suggestions here. We appreciate your taking the time to complete these surveys. Thank you very much!**

Correct Answers: 3a. False, 3b. False, 3c. True

Communicating with Patients & Families about End-of-Life Care

Follow-Up Survey

[This is a sample of a letter to send out to your training participants 4-6 weeks after the training.]

Hello!

About a month ago, you attended a presentation on Communicating with Patients & Families About End-of-Life Care, given by [presenter].

Thank you for participating in our evaluation. Your survey responses have been very helpful for planning the next steps in our training program. Thanks also for agreeing to answer some follow up questions for our evaluation. If you have a few minutes to answer the following questions, it would be very helpful.

Now that a month has gone by...

1. What changes, if any, do you feel you have made in your work as a result of this training session?

2. Please rank your current level of skill in communicating with patients & families about end-of-life care:
   (1=Need more skill for basic competency; 3=Adequate skill; 5=Highly skilled)

3. What is your overall rating of the quality of the session you attended?
   (1=Poor; 3=Average; 5=Excellent)

4. Please write any additional comments, thoughts, or suggestions here.

Please contact me [your contact information here] if you have any questions about our project or if you'd like us to keep you informed of any upcoming training sessions. Thanks again!

Giving Bad News

Pre-Training Survey

Thank you for completing this survey. Your input will help us improve our training program and will provide information about its effectiveness to guide future planning. Please answer these questions as best you can – if you're not sure of an answer, just give it your best try.

Date:___/___/___ ID: Birth month:____ Day:____ Last 4 digits of SSN:______________

1. Please rank your current level of skill in the area of giving bad news to a patient/client by checking one of the following numbers from 1 to 5:

Need more skill for basic competency		Adequate skill		Highly skilled
1	2	3	4	5
☐	☐	☐	☐	☐

2. Please rank your current level of personal comfort in the area of giving bad news to a patient/client:

Extremely uncomfortable		Somewhat comfortable		Extremely comfortable
1	2	3	4	5
☐	☐	☐	☐	☐

3. Please answer the following by checking the True or False box:

	True	False
a. Giving a 'warning shot' before communicating bad news- e.g., "I have something serious to tell you," only contributes to the patient's anxiety by beating around the bush.	☐	☐
b. You should always have family members present when you give bad news.	☐	☐
c. Asking open-ended questions encourages patients to give more irrelevant details than closed-ended questions.	☐	☐
d. Asking patients what they know before giving the bad news generally increases distress.	☐	☐

Correct Answers: 3a. False, 3b. False, 3c. False, 3d. False

Giving Bad News

Post-Training Survey

Thank you again for your input to help us improve our training program and guide future planning. As before, please answer these questions as best you can– if you're not sure of an answer, just give it your best try.

Date:___/___/___ ID: Birth month:____ Day:____ Last 4 digits of SSN:______________

1. Please respond to the following questions regarding this training using the scale below:

	Not at all		Somewhat		Very much
Did the training hold your interest?	☐	☐	☐	☐	☐
Did you learn things in the training that will be useful for your work?	☐	☐	☐	☐	☐
How understandable was the material presented to you?	☐	☐	☐	☐	☐
Were the educational materials, such as slides or handouts, useful?	☐	☐	☐	☐	☐
How responsive was the trainer to the audience's questions?	☐	☐	☐	☐	☐
Did you feel the trainer's presentation was culturally sensitive?	☐	☐	☐	☐	☐

2. What were the strengths of this presentation?

3. How could we improve this presentation?

4. Would you recommend this training to someone else? Yes ☐ No ☐

5. Please rank your current level of skill in the area of giving bad news to a patient/client by checking one of the following numbers from 1 to 5:

Need more skill for basic competency		Adequate skill		Highly skilled
1	2	3	4	5
☐	☐	☐	☐	☐

6. **Please rank your current level of personal comfort in the area of communicating bad news to a patient/client:**

Extremely uncomfortable		Somewhat comfortable		Extremely comfortable
1	2	3	4	5
☐	☐	☐	☐	☐

7. **Please answer the following by checking the True or False box:**

	True	False
a. Giving a 'warning shot' before communicating bad news- e.g., "I have something serious to tell you," only contributes to the patient's anxiety by beating around the bush.	☐	☐
b. You should always have family members present when you give bad news.	☐	☐
c. Asking open-ended questions encourages patients to give more irrelevant details than closed-ended questions.	☐	☐
d. Asking patients what they know before giving the bad news generally increases distress.	☐	☐

8. **What do you anticipate doing differently in your work as a result of this training?**

9. **How much did this training help prepare you to do the following:**

	Not at all		Somewhat		Very much
Provide primary end-of-life care for patients with HIV?	☐	☐	☐	☐	☐
Provide education and training to other clinicians on end-of-life care issues?	☐	☐	☐	☐	☐
Advocate for better palliative care in your workplace?	☐	☐	☐	☐	☐
Any other roles or activities related to palliative care: (*please list here*) ________________________________	☐	☐	☐	☐	☐

10. **Would you be willing to be contacted in one month for a brief follow-up?** Yes ☐ No ☐

If yes, what is your email address? ____

11. **Please write any additional comments, thoughts, or suggestions here. We appreciate your taking the time to complete these surveys. Thank you very much!**

Correct Answers: 7a. False, 7b. False, 7c. False, 7d. False

Giving Bad News

Follow-Up Survey

[This is a sample of a letter to send out to your training participants 4-6 weeks after the training.]

Hello!

About a month ago, you attended a presentation on Giving Bad News, given by [presenter].

Thank you for participating in our evaluation. Your survey responses have been very helpful for planning the next steps in our training program. Thanks also for agreeing to answer some follow up questions for our evaluation. If you have a few minutes to answer the following questions, it would be very helpful.

Now that a month has gone by...

1. What changes, if any, do you feel you have made in your work as a result of this training session?

2. Please rank your current level of skill in giving bad news:
   (1=Need more skill for basic competency; 3=Adequate skill; 5=Highly skilled)

3. What is your overall rating of the quality of the session?
   (1=Poor; 3=Average; 5=Excellent)

4. Please write any additional comments, thoughts, or suggestions here.

Please contact me [your contact information here] if you have any questions about our project or if you'd like us to keep you informed of any upcoming training sessions. Thanks again!

Suggested Handouts

1. Back, A. (1998). *Breaking bad new: Ethical topics in medicine.* Available at University of Washington Department of Medicine Ethics in Medicine Web site at http://eduserv.hscer.washington.edu/bioethics/topics/badnws.html

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Communicating with Patients and Family

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Websites

National Family Caregivers Association - www.nfcacares.org. They have available for order a brochure entitled, *Improving Doctor/Caregiver Communication: A Guide for Family Caregivers* .

University of Washington School of Medical Ethics in Medicine - eduserv.hscer.washington.edu/bioethics/. *Breaking Bad News*, a short case-based tutorial based on Robert Buckman's work, is available on this website.

Resources

Cross-Cultural Communication

Articles

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Samovar, L. & Porter, R. (1994). 7th ed., (Eds.). *Intercultural communication: A reader*. Belmont, CA: Wordsworth Publishing Company.

Videos

Cross-Cultural Health Care Program
www.xculture.org.
Seattle, WA
Available for order on their website at www.xculture.org.
1. Communicating effectively through an interpreter: an instructional video for health care providers.
2. East Africans and mental health: Delivering bad news.