Psychosocial Module Contents

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Learning Objectives – *Helping Patients to Have a Good Death*

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

- Describe the elements of a good death from the perspectives of patients, loved ones, and health care clinicians.
- Give examples of how health care clinicians can help to facilitate a good death for patients.
- Explain how culture can impact patients' end-of-life experiences.

Learning Objectives – *Psychiatric Issues in HIV/AIDS Palliative Care*

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

- Distinguish between grief and depression in patients with life-threatening illness.
- List factors involved in diagnosis of depression, anxiety, dementia, and delirium.
- Explain common treatments for each condition.
- List two possible interventions when working with a patient with substance abuse.

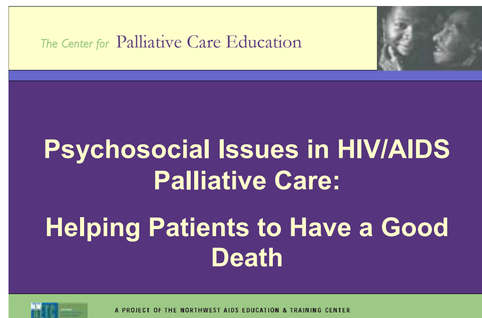
Learning Objectives - *Spiritual Issues in HIV/AIDS Palliative Care*

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

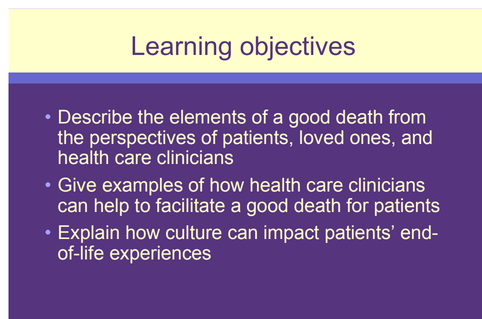
- Define spiritual distress and identify sources that may arise for patients with HIV/AIDS
- Practice skills to assess your own spiritual perspectives as caregivers
- Discuss skills to facilitate patients' assessment of their spiritual needs
- Discuss skills to facilitate addressing patients' spiritual needs

Helping Patients to Have a Good Death

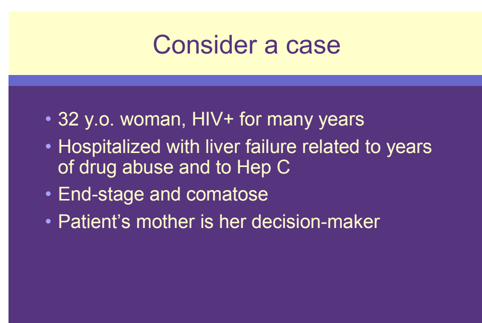
PowerPoint Notes



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.



Slide Note
Today, we are going to focus on the end of the palliative care spectrum—life closure and the last days of life. This is an area where health care clinicians are often the least comfortable because they feel they have so little to offer. In fact, we have a lot to offer patients at this time in their lives. This is also a time where BEING is just as important as doing. We will be discussing what we can offer to patients when treatment options have failed and how we can help them to have a good death. We will be looking at several elements of a good death that we can use as a framework for helping patients to sort out their goals for care at end of life. We will be looking at our own roles in helping patients to have a good death, and we will also be looking at how cultural beliefs, values and perspectives can impact a patient's perception of what is a good death.



Slide Note
I'd like to start with a case…
Pam was 32 years old. She had been HIV+ for many years. She was in the hospital with liver failure related to years of drug abuse and to Hepatitis C. She had been bleeding internally, and had received two blood transfusions, but her bleeding continued, and she had been comatose for two days.
The house staff on the floor were very upset. The clinicians felt that the patient was in pain – they saw her grimacing and moving around uncomfortably, and she moaned whenever she was moved by the nursing staff. Pam's mother, whom Pam had designated as her durable power of attorney for healthcare, had refused to allow the medical team to increase the patient's pain meds. She said she did

not want to jeopardize the patient's sobriety, and she also did not want to jeopardize her chances to recover from this hospitalization. The team had also told Pam's mother that they felt the patient's situation was hopeless, and they recommended stopping all medications, giving no more blood transfusions, and letting the patient die in comfort. Pam's mother would not agree to this, saying she had seen the patient bounce back miraculously in previous hospitalizations.

As clinicians, we are often faced with complex situations such as this. We often find our beliefs, perceptions and recommendations at odds with those of the patient or with a patient's family member. How do we sort it out? What is a good death in this situation – for the patient, for the mom, and for the hospital staff? And how do we help to facilitate this?

Elements of a good death

Pairs or Small Group Exercise:

1. Share briefly with each other examples of both good and not-so-good deaths that you have witnessed.
2. What do you think contributes to a good death? What are elements of a "bad" death?

Slide Note

We'll start by doing an exercise together.

Trainer Suggestion

See "Good Death Exercise" instructions.

In search of a good death: Observations of patients, families & clinicians

- Focus groups & in-depth interviews with 75 participants in North Carolina
- Patients (HIV & cancer), bereaved family members, physicians, nurses, social workers, chaplains, volunteers
- Goal--"to describe the attributes of a good death as understood by various participants in the end-of-life"

Steinhauser, Ann Intern Med, 2000; 132:825-32.

Slide Note

Let's look at what some of the research literature has to say about a good death.

This was a study done at Duke University Medical Center in the HIV and Oncology clinics. Participants were patients, family members, and health care clinicians. The respondents were about 69 percent European-American, 28 percent African-American, and 3 percent Asian-American. Two thirds of the respondents were female. The researchers wanted to find out what were elements of a good death as understood by the various participants in the end of life.

Components of a good death

- Pain and symptom management
- Clear decision making
- Preparation for death
- Completion
- Contributing to others
- Affirmation of the whole person

Slide Note

Here are the elements they came up with. Today, we will be talking about each of these in more detail.

Trainer Suggestion

This would be a good time to compare what's on this list to the list the group made earlier. Give positive feedback for the all contributions, noting similarities and discussing what was missed and what things the group thought of that are not on this list.

Pain & symptom management

- Pain adequately controlled
- Adequate symptom control, particularly shortness of breath
- Intact bodily functions
- Being mentally aware
- Reassurance from clinicians early in the illness

Slide Note

In the literature, most respondents report under treated pain to be the number one issue of concern. Patients have lots of fear and anxiety about being in pain well in advance of the actual experience of pain. Patients and families both felt that it was important for clinicians to give assurance early on and throughout the illness that their pain would be adequately addressed. They wanted to know that their clinician was going to pay attention to it.

The other reported concerns were making sure that all of the most distressing symptoms that people experience, like shortness of breath, were controlled. And people wanted to maintain their dignity by having intact bodily functions. They also wanted to be aware enough to interact with their family and loved ones.

Mental awareness was more important to patients than to clinicians. Clinicians focused on pain control; patients said they wanted more of a balance.

Clear decision-making

For the patient and family:

- Good communication; clinician comfortable discussing death & dying
- Patient participation sought & valued

For the clinician:

- Patient has clear treatment preferences
- Decisions are made before medical crisis

Slide Note

Patients and families wanted good communication with their clinicians, and to have clinicians that weren't afraid to talk about death. They wanted to feel like their participation in the decision-making process was important and valued. Clinicians wanted patients that had clear treatment preferences and they wanted the patients to have made decisions before the medical crisis had occurred, which is a pretty rare thing unfortunately. While clinicians want the decision-making to happen in advance, they usually don't want to facilitate the conversation. It takes training and practice to get comfortable conducting these discussions with patients.

Trainer Suggestion

This might be a good time to have participants discuss their own end-of-life preferences. You might also ask their thoughts on how to facilitate decision-making before a medical crisis.

See *Communication* and *Advance Care Planning* modules.

Preparation for death

For patients and family:
- Knowing what to expect—physical, emotional, spiritual
- Planning for events before, during, and following death-- where to die, who to call, legal issues, memorial plans

For the clinician:
- Clinician training and exploring own issues
- Preparation does not preclude hope; it empowers pts.

Slide Note

In regards to being prepared for death, patients and family members wanted to know what to expect. What does death look and feel like? What will I see my family member doing when they're dying? They also wanted to be reassured that their emotional reactions to what was happening were normal. And they wanted to have help with prior planning for events, like planning for where to die, planning the memorial service, thinking through some of the legal issues. Clinicians in this survey felt that they needed more training in communicating the issues, and also that they couldn't help patients unless they had explored some of their own feelings about death and dying. They also wanted to be able to convey to patients, and even feel this themselves, that preparing someone for the possibility of death did not mean that they could not also convey reasonable hope to the patient. It's the delicate balance of hoping for the best (cure and recovery) and preparing for what patients and families sometimes feel is the worst outcome– death.

Just an interesting aside on the issue of location. In a recent survey, about 90% percent of people in the United States said they would prefer to die at home, but in reality 75 percent of people die in an institution, either a hospital or nursing home. There are many factors involved in this outcome – family ability, convenience, timing, fear, people change their minds. But also, our health care system doesn't really allow for what people say they want.

Completion

- Life review
- Resolving conflicts
- Feeling at peace with self and others
- Spending time with loved ones
- Saying goodbye
- Attention to religious or spiritual beliefs
- Rituals appropriate to culture

Slide Note

In terms of completion, people wanted to feel at peace with themselves and their life. They wanted to say goodbye to their loved ones. They wanted to feel like most of their issues and conflicts had been resolved. And they wanted their religious beliefs attended to, whether that was having last rites, or having a clergy person present, or having whatever ritual they felt would be appropriate for their situation and culture.

Contributing to others

- Need to reciprocate with caregivers
- Sharing time, gifts with loved ones
- Helping others
- Imparting knowledge learned or meaning of life to others
- Leaving a legacy

Slide Note

This element surprised the researchers as it had not appeared in previous studies. People who are dying still want to feel that they're contributing to others. They want to have a reciprocal relationship with their caregivers, so they can still ask, "How are you doing? How was your day?" They want to share meaningful time with loved ones. They want to help others by sharing what they've learned about their dying experience. And they want to leave a legacy; for example, by making a memory book for their children. Or keeping a journal. One patient planned out his whole memorial service, had the speakers lined up, had the invitations printed up. They just didn't have the death date on them. There are many ways that patients can contribute and leave a legacy.

There are also ways that we as clinicians can help patients to feel they have made a contribution. We can share with them what we have learned from working with them or how we will work with patients differently as a result of our experience with them. For example, we can say, "You taught me so much about balancing the different needs of patients and families. I will always keep it in mind whenever I work with other patients."

Affirmation of the whole person

- The patient is not just a "disease"
- Empathy and respect
- Clinician values patient and family lives, beliefs, preferences
- Personal relationship with patient important to clinician

Slide Note

Both patients and clinicians wanted to feel like they are more than just their roles. That the patient isn't a disease, the clinician isn't just a doctor or nurse. That they are humans in this dying process together. That they can have a relationship that values who they are and that values their beliefs and preferences. The caveat for the clinician, of course, is that we still need to maintain our professional boundaries and not burden the patient with our own unresolved issues about death and dying.

Other components from review of "quality of death" literature

Patient:
- Not being a burden—financial, physical, emotional
- Psychological well-being
- Coordination & continuity of care
- Personal dignity

Family: Emotional support, caregiver education, bereavement support

Slide Note

Other studies have had similar results. Other elements that contribute to the sense of having a good death include the desire by patients not to be a burden. Patients also wanted psychological well-being when they died. They wanted their clinician to coordinate their care, and they wanted to maintain their dignity. For family members, they wanted to feel like they had enough emotional support and education to be able to care for their dying loved one.
Some of these elements seem intuitive, but we work in a health care system that can throw up barriers to the possibility of a patient having a good death.

Trainer Suggestion

How have the participants experienced barriers to a good death in our health care system?
Some possible responses are:
The lack of coverage for adequate pain medication, home care, or nursing home care.
The lack of time that clinicians have to spend with patients and family members.
The lack of training clinicians receive in providing good palliative care.
Conflicting perceptions of a "quality death" from different players in the process– hospital administration, each discipline, etc.
How do we as clinicians help to facilitate a good death for patients and their loved ones? See next slide for an exercise about this question.

Role of health care clinicians in a good death

1. Please give an example of an intervention you've witnessed or participated in that helped a patient to have a good death.
2. What do you see as your role in helping patients to achieve a good death?

Trainer Suggestion

See "Good Death Exercise":

Post list of good death elements so participants can refer to them during their discussion. Have people divide in pairs or small groups and generate examples from their own experiences of interventions they've either done themselves or witnessed other people doing that helped people to have some of the things that they wanted at the end of life.
Then ask for participants to share examples and to generate a list of how clinicians can help patients to achieve a good death.

Role of health care clinicians in a good death

- Exploration & support of patient decision-making
- Pain management
- Advocacy for patient's wishes
- Family education & support
- Spiritual support and exploration
- Sorting out grief from depression and treating depression
- Assessment/treatment of psychiatric disorders and/or substance use
- Team support

Trainer Suggestion

Here is an example of a slide that lists some of the possible roles of clinicians at end of life. The trainer might want to create a slide that lists roles specific to the profession of the audience. The trainer should compare this list with the list made by the participants and discuss any missing from their list.

Many of the roles listed above can be covered by different members of the health care TEAM. This might be a good time to talk about multi-disciplinary teams and how to sort out each person's role in the care of the patient before a crisis occurs, how the team will communicate information to the members, how the team will manage conflict or disagreement about patient care, etc.

How HIV/AIDS impacts a good death

- Discrimination
- Fear of contagion
- Isolation/Lack of support
- Estrangement from Family
- Multiple losses
- Disclosure issues
- Mistrust of medical system
- Unpredictable course
- Substance use

Trainer Suggestion

Show the title of the slide first and ask participants: As clinicians, what experiences with HIV/AIDS have you witnessed that have had an impact on the ability of a patient to have a good death. What are some issues that are common or unique to AIDS?

Slide Note

Here are some issues that are common to HIV/AIDS, which are sometimes present with other illnesses as well. These issues may impact a patient's chance of having a good death. The stigma and discrimination associated with HIV/AIDS affects patients' relationships with family and their ability to get the support and services needed at end-of-life. It impacts psychological well-being through its legacy of multiple loss and because of its unpredictable and often roller coaster course. Some of the populations it affects have whole sets of psychosocial concerns such as substance abuse, alienation, bad experiences with the health care system, and other issues that make it hard for them to access care.

Cultural issues that shape our thinking about a good death

Euro-American Principles:
- Patient/Individual Autonomy
- Full disclosure for informed decision-making
- Control over the dying process
- No one should suffer
- Written, formal agreements
- Future orientation

Slide Note

The lists we've made and the research we've just looked at are just one way to help us to think about palliative care and what issues we can address with patients to help them to set goals for how they want to die. In the U.S., our health care system operates from its own cultural perspective. For example, some of the dominant cultural beliefs are: that the patient or the individual has all the decision making power, that we need to tell people everything so they can make informed decisions, that we should have control over the dying process, that nobody should ever suffer, that everything needs to be documented in the chart, and that we should always be thinking and planning towards the future are cultural perspectives rooted in European-American history.

It is important to remember that many cultural perspectives may differ from these that we have mentioned. Most studies have not taken into account the perspectives of people from different cultures.

Trainer Suggestion

You might ask participants, "Does anyone have an example of an experience with a patient that was operating from a different cultural perspective?" If the group is reluctant to volunteer answers, give an example of your own to start the ball rolling.

Alternatives to Euro-American principles

- Family has obligation to shoulder the burden
- The physician is the expert and should decide
- Truth of diagnosis is harmful or burdensome to patient
- We can't control our fate; it's God's will
- All life involves suffering
- A person's word is all that is needed
- Indirect communication
- Emphasis on present orientation

Slide Note

Keeping in mind that while we may know a person's ethnicity, it does not necessarily mean that we know what that individual believes, there are some cultural perspectives which many communities share that will be important to consider. Here are just some alternative perspectives to consider. In many communities, the family and the community are very interdependent. The death of one member affects everybody. And so the family has the obligation to take on the burden of decision making so that the patient can just concentrate on getting better. In some cultures, the physician is considered the expert, and the patient might say, "What should I do?" or "You decide what should happen." And not all of us are very comfortable with being given that level of responsibility. There are some cultures that believe that the truth of diagnosis can actually harm people. For other people, it's God's will what happens, we can't really control it. For some cultures, all life is suffering, and we need to suffer as part of our spiritual commitment. For some people, it's insulting to ask them to sign a paper. Their word should be enough, or a verbal agreement you have should be enough. Other people communicate more indirectly. To do the kind of straight talk that we prefer will seem rude and unhelpful. And for people who are more present-oriented, having a discussion about what might happen in 3 months, just may not work. The main point is not to assume that the patient, the family, or other team members share your health beliefs. We need set time aside for a thoughtful discussion of these issues. See the *Cross Cultural Communication* module.

Cultural issues & pain management

- Pain is under treated in ethnic minorities; less access to pain meds in some communities
- Experience & expression vary by culture
- Belief systems—Pain is to be endured as part of spiritual commitment or test of faith.
- Belief systems—Life is suffering; suffering leads to enlightenment.

Slide Note

Let's look at some of the elements of a good death that we talked about earlier, in relation to culture. There are two points to make about pain. First, people receive different care based on their ethnicity. That is particularly true of pain management. In some African-American communities, for example, there aren't pain medications stocked in the pharmacies near where they live. Or people get less pain treatment when they go to the emergency room. We need to be aware of that reality because it affects how people look at their healthcare clinicians and the level of trust they feel. And then the second thing is that experience and expression of pain vary by culture. As we mentioned earlier, pain can be considered a test of faith, and for many people dealing with their spirituality is more important than dealing with their pain management. A clinician may want to just give the patient pain medication, and the patient may really want to be doing spiritual work.

Culture & clear decision-making

Can discussing death cause Harm?

- Studies have shown that people from many different cultures believe this:
  - –Navajo, other Native-Americans
  - –Immigrants from China, Korea, Mexico

Caresse, JAMA, 1995; 274:86

Slide Note

With decision making, many countries and cultures have different perspectives on disclosure of diagnosis and prognosis. There are studies that have shown that some people believe that if we talk to them about their death, it is actually going to make the situation worse. They could experience irreversible emotional shock, be too depressed to fight the illness, give up hope, and die earlier. This is true with some Native-American populations, and with some people from China, Korea, and Mexico.

Survey of 800 patients in LA assessing cultural differences

Should a patient:

	Be told of 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

This research suggests that people from different cultures will have different preferences regarding truth-telling and decision-making. In this study, 800 patients in Los Angeles were asked the questions, "Should a patient be told of a diagnosis of cancer?" and "Should a patient be the one to decide about life support?" The majority of African-American and European-American respondents felt that being told the diagnosis was important. They also felt that the patient should be the ones to decide about life support. But in Mexican-American and Korean-American respondents, the majority did not want to be told, and they didn't feel like it was the patient's decision alone to make. The results of this study don't mean that we should make assumptions about each member of a particular group, however. We need to try to understand the individual patient's preferences based on both cultural context and on individually held health beliefs. We need to keep in mind that there is a wide range of perspectives. And we need to ask patients these questions ourselves.

Exploring decision-making preferences

- When decisions need to be made about your care, who should be involved?
- If we needed to discuss a serious medical issue, how would you and your family want to handle it? How much would you want to know?

Kagawa-Singer, JAMA 2001; 286:2993

Slide Note

Rather than assume we know what a patient wants, we can ask questions:
"When decisions need to be made about your care, who should be involved? Who should make the decisions?"
"If we needed to discuss a serious medical issue, how would you and your family want to handle it, and how much would you want to know?"
We should ask these questions early on in our relationship with the patient, not when the end-of-life discussion in imminent.

Preparation for death: Culture & death rituals

- Burning sage or incense
- Chanting or wailing
- Family washes & prepares body
- Opposite sex may not touch body
- Body must stay in room for proscribed length of time
- Body must be taken home before burial

Slide Note

In addition to the spiritual and emotional preparations for death, the death rituals that people have may vary. If you look at this list, some of these items are not going to interact well with hospital policies. For example, if after the patient has died, the family gathers around the bed and starts wailing, and there's another person in the bed next to the patient, how will you handle that?

Pause for discussion
You might consider moving the patient to another room, an empty room.

Or if there's burning sage or incense or candles in the room and there's a hospital fire policy, how do we deal with that? Consider the issues around care of the body after death and about autopsies. We need to check these things out ahead of time, and then figure out how we're going to accommodate them. If it is impossible to accommodate them, alternative plans might need to be made, or thoughtful explanations given to the patient and family.

Trainer Suggestion

Invite participants to give some cultural competence advice from their own practice and experience: "How do we build trust with patients so that they will feel free to communicate with us about their needs and preferences? How do we help to ensure that all patients can have a good death?"

Cultural competence in end-of-life care

- Evaluate your own cultural beliefs and practices
- Learn about the specific cultures in your area
- Seek out training in cross-cultural communication

Slide Note

Here are some cultural competence suggestions based on the literature. It's important for us to explore and evaluate our own beliefs and practices first, and then to learn about specific cultures that we're likely to be working with. We may need to seek out training in cross-cultural communication.

And this is just a caveat in terms of learning about specific cultures: Everyone is an individual within their own culture, and so any generalization you read about a specific culture will still need to be checked out with the individual patient. It's not going to be true for everybody.

Cultural competence in end-of-life care

- Inquire about patient's cultural practices and beliefs in advance
- Focus on building trust
- Make accommodations to policy whenever possible
- Address communication barriers
- Consult with a cultural interpreter or broker
- Involve the family

Slide Note

We need to inquire about patients' cultural beliefs and practices, and focus on building trust with people. Figure out how to accommodate peoples' preferences with hospital policy. Use interpreters, if that's necessary. And not just language interpreters but also cultural interpreters that can help you to learn about different cultures, religions, or belief systems. Involve the patient's family with guidance from the patient, and be inclusive – have the patient identify who is family to them.

Reconsider a case

- 32 y.o. woman, HIV+ for many years
- Hospitalized with liver failure related to years of drug abuse and to Hep C
- End-stage and comatose
- Patient's mother is her decision-maker

Slide Note

Let's return to the case and talk about some things we can do to help this patient to have a good death. And to help the patient's mother and the medical team to feel that she did, as well.

A member of the team set up a meeting with Pam's mother. The discussion with Pam's mother included the following:
Aligning with her, "Everyone wants what's in Pam's best interest."
Acknowledging her care of Pam, and Pam's luck in having a loving support system.
Finding out what she knows already about Pam's illness.
Explaining prognosis and diagnosis in plain language.
Asking what her goals are for Pam's care. "Have they ever had a discussion about end of life issues?"
Balancing hope with preparation. "We're all hoping Pam will bounce back again but let's make a plan in case she doesn't. If these are the last days of her life, how do you want them to be?"

Providing education on pain medication and sobriety issues.
Looking for points of agreement and areas where the medical team can compromise.
Helping her prepare for Pam's death with ritual, spiritual support, etc.

The outcome was that Pam's mother allowed the team to increase her pain meds. She still wanted the patient to receive her other medications, and the team agreed to this. They both agreed to stop blood transfusions since they did not seem to be helping the patient. The patient died two days later, and the mother had had a chance to say goodbye.

Conclusions

- No single formula for a good death
- Elements serve as framework of what questions to ask patients about their goals
- Patient views of end-of-life care may be powerfully effected by culture and ethnicity
- Differences between cultural groups can be helpful guide, NOT protocol for care

Slide Note

In conclusion, there is no one right way to die. Everybody is unique in what they need and what they want. The elements of a good death that we talked about are just a framework, a way of thinking about what to ask patients, when you're talking to them about their goals. Patients' needs in end of life care will be affected by their culture, ethnicity, and life experiences. The difference between cultural groups are helpful to know but are not a protocol for care. We still need to ask people individually.

Conclusions

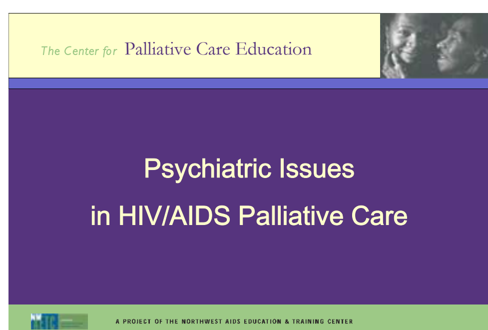
- Develop a protocol for discussing end-of-life care with patients and families
- Patients and loved ones need assurance that all issues will be addressed: Physical, psychological, spiritual, legal, psychosocial
- YOU can have a huge impact on the patient's quality of life and quality of death

Slide Note

It might be good to think about a protocol for yourselves about how to discuss things with patients and families. [Refer participants to the *Communication Module* on the Website] Just reading about communication obviously isn't the way to learn it. We have to practice it, and figure out what works for us in our own style. Patients and loved ones need assurance that we're going to address all their issues, not just their physical issues, but that we're going to help them with psychological and spiritual issues as well. Most importantly, we as clinicians have a huge role to play in helping people to have a good death.

Psychiatric Issues in HIV/AIDS Palliative Care

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

- Distinguish between grief and depression in patients with life-threatening illness
- List factors involved in diagnosis of depression, anxiety, dementia, and delirium
- Explain common treatments for each condition
- List two possible interventions when working with a patient with substance abuse

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What psychiatric issues emerge in HIV palliative care?

- Grief
- Depression
- Anxiety
- HIV Dementia
- Delirium
- Substance Use

Slide Note

These are the topics we will cover today. This will be an overview of the diagnosis and treatment of each of these issues. We won't be able to address all these complex issues thoroughly. A resource list is provided for more information on each topic.

Trainer Suggestion

Hand out copies of the resource lists from www.uwpallcare.org that accompany this module.

Case # 1

- 43 y.o. male, HIV+ x 10 years, no longer able to tolerate HAART, admitted to hospital with pancreatitis, 2nd bout of pneumocystis, fatigue, wasting.
- Patient has stated, "I don't want to go on like this anymore." Partner reports that patient has become more and more withdrawn since his health has declined.

Slide Note

Let's start with a case. The patient is a 43-year-old man with advanced HIV disease. He has been on many HAART regimens in the past few years, and now has developed pancreatitis. He is no longer able to tolerate anti-retrovirals. He is in the hospital with his second bout of PCP, and often feels very fatigued. He has had difficulty eating, as well, and has lost a significant amount of weight. He is being treated for pneumonia, and his fatigue and appetite loss are being evaluated in the hospital.
The patient has stated, "I don't want to go on like this any more." His partner has said that the patient has become more and more withdrawn since his health has declined.

Trainer Suggestion

At this point, you can ask the group to come up with questions that would help in the evaluation of this patient's mental health. What should you ask? What should you look for to determine the patient's psychiatric diagnosis?
Some possible questions might be:
Does the patient endorse any of the following: depressed mood, anhedonia, somatic symptoms, hopelessness?
What does the patient mean by "I can't go on….?" Does the patient have a plan for suicide?
What does the partner have to say? How long has the patient seemed withdrawn? What is the patient's baseline?

Case # 1

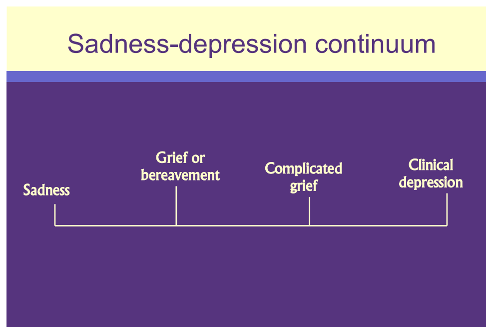
- Patient acknowledges multiple losses – work, health, security, future, body image, role in relationship, many deaths in his community
- Describes tightness in chest, decreased energy, insomnia
- Expresses sadness, anger, confusion
- Looking forward to parents' visit to resolve issues and say goodbye
- Working on memory book for his 2 kids

Slide Note

In talking to the patient, we find out that he has experienced multiple losses. He is no longer able to work; his health has declined significantly, and he is feeling frail. He sees a bleak future if his health does not turn around, and the changes in his body and in his role in his relationship are concerning to him. He also has experienced many deaths in recent years of other members of his community from HIV.
He describes a tightness in his chest, decreased energy, insomnia. He expresses sadness, anger and confusion. When asked about the future and what he is looking forward to, he says that his parents are coming to visit him next week, and he is hoping to resolve some issues with them and say goodbye. Also, he has two children from a previous marriage, and he is working on a memory book for them. He seems excited when he talks about this.

Trainer Suggestion

You might ask the group the following questions:
What are the symptoms the patient endorses? Are they characteristic of a psychiatric disorder? If so, what disorder?
How do you evaluate his symptoms and consider the upcoming events and plans in his life?
How clear cut is his diagnosis? What else might be going on?



Slide Note

This case illustrates how hard it is to sort out grief from depression. We might say that this patient is experiencing grief—a normal response to his illness. We will look at what distinguishes grief from depression in the next few slides. But we would also want to be careful about diagnosis and treatment—we don't want to let a person just "work through" grief on their own—we want to provide evaluation, support, and treatment of psychiatric concerns throughout the patient's illness.

We can look at emotional response to illness as a continuum. On one end is sadness. Then we move up the line to grief, complicated grief, and finally depression. We could insert suicide at the far right end of this line. It's not always easy to say exactly where a person is on the continuum, but there are some indicators that can help us to sort out when a person's response is "normal" and "healthy" and when a person could benefit from aggressive treatment.

Grief

- The affective or emotional response to a significant loss
- Normal & universal
- Expression based on culture

Slide Note

Grief is the affective or emotional response to a significant loss or series of losses. It is a normal and universal response to loss; however; its expression is not universal. How people respond to loss and express grief is often based on culture. We will talk more about that a little bit later.

Tasks of grief

- Realize
- Feel
- Adjust
- Reinvest

Slide Note

There are many different models to describe the grief process; Elizabeth Kubler-Ross' model of the cycle of grief is very popular, for example. The model shown here, based on the work of J. William Worden, is simple—it can be summed up in four words. It also is a non-linear model, much like the grief process itself, and by focusing on tasks, it helps to convey that grief is WORK; it's not a passive state.

The first task in this model is realizing or accepting the reality of the loss. A person may experience numbness, shock, or disbelief, for example, when they've tested positive for HIV, when they're hospitalized with an AIDS-defining illness, or when they realize there are no more HAART options available for them.

That protective numbness eventually goes away as people fully realize what has happened. The next task, then, is feeling or experiencing the emotions or pain around the loss. This is one that many people prefer to skip!

Next is adjusting to the loss and to how life has changed. This might mean quitting your job, changing your activities, accepting your new role in a relationship.
The last task is re-investing. For family members it could be re-investing in a new life without the patient. For patients, it might be finding meaning in your illness, reconnecting with your spiritual beliefs, just being present and experiencing everything, or having resolution with loved ones. It might mean re-investing in the process of dying. One patient really took the reinvestment process far– he planned his whole memorial service, including speakers, music, and location. He had flyers printed up with photos and had the envelopes addressed and stamped. The only thing missing on them was the date. That was his way of re-investing in his new circumstances.

Trainer Suggestion

You might ask the group, "How can we help our patients through the tasks of grief?" The next slide contains some possible answers.

Treatment of grief

- Listen, explore concerns
- Normalize grief responses
- Educate about what to expect
- Reinforce patient's coping strengths
- Enlist support system
- Encourage spirituality, ritual, expression as appropriate

Slide Note

Here are some ideas about helping people to grieve. We can help our patients by active listening and by exploring their concerns. We can help by normalizing the grief response – if your patients says, "I'm so embarrassed because I find myself crying about my situation." or "Sometimes I get so angry!" –you can explain that those are normal responses to loss. Educating people about what to expect through the process and reinforcing their coping strengths are other ways to help. You may suggest that your patient start a journal or write poetry or draw a picture of how they are feeling. You can enlist the patient's support system to check in with the patient and provide meals and activities. Linking your patient to a counselor or a support group will also help. Encourage your patients to utilize their spiritual beliefs and communities and to participate in or develop appropriate rituals and expressions.
All that said, if your patient exhibits any of the symptoms of depression we will discuss later, or if he or she says that this grief experience is not normal for them, or if the grief is protracted and your patient is having difficulty functioning in her or his life, you can treat with an anti-depressant. Stabilizing your patient's mood will allow them to participate in and benefit more from the other interventions you provide, such as counseling or a support group.

Culture & grief

- Patients' expressions of grief will vary by culture
- Family member response may vary by belief system
- Support needs will also vary by culture

Slide Note

Peoples' expressions of grief will vary by culture, anywhere from silent stoicism to very loud wailing. A calm cheerfulness is a socially acceptable response in some Asian cultures. Withdrawal, anger, stomach aches, preoccupation, or loud, demonstrative activity are just some of the varied responses to loss. These are all expressions of grief. To a clinician whose cultural beliefs and practices are different from those of his or her patients, these may seem strange. We might think either that the person is over-reacting or that they are in serious denial! We need to expand our view of appropriate expression of grief, and we need to learn about what is appropriate in the cultures of the patients we treat. The cross-cultural resource section on our website is a good place to start. Family members' responses to the loss of their loved one may also vary based on their belief system. If family members believe that there's life, death, and then heaven and hell, they will be devastated that the patient is gone and they have no more access to them. If family members believe that they will have access to the patient's spirit after death and have a continued relationship with them, maybe the grief won't seem as strong. People's support needs also vary by culture. One woman from Kenya was infected by her husband after he visited a prostitute. She had 2 children, and her husband left her after she was diagnosed HIV positive. She came to the United States to seek treatment. She left her children in Kenya with her mother, got a job in the U.S., and sent money home for her children to go to school. She had had so much sadness and so much loss. Her case manager wanted to help her to express the loss, to deal with the tasks of grief. He suggested that the patient seek counseling. The patient was very upset. "I'm not crazy," she said, and left the office. The case manager consulted a cultural broker and asked how to proceed with the patient. He learned that in Kenya, one only seeks the help of a counselor if one is seriously mentally ill. Mental illness is a serious stigma. The cultural broker recommended a more informal means of support. The case manager was able to find a health care professional from Kenya who was willing to befriend the patient, do activities with her, and accompany her to church. The new friend brought up the patient's issues in the course of conversation, and the patient was able to work through her grief in a way that was appropriate for her.

Trainer Suggestion

You may want to give your own example of working with a patient from a different culture or ask if the participants have examples.

Grief & HIV

- Disenfranchised grief
- Multiple loss – patients, survivors, caregivers
- Stigma, prejudice, discrimination--guilt and shame

Slide Note

These are some grief issues that are common to people with HIV/AIDS. One is the concept of disenfranchised grief. This occurs when society doesn't recognize a person's right to grieve. So if you have an illness that is shameful or has a lot of stigma to it, you won't get a lot of support for grieving. You may be told that you deserve the illness.

Or people may refuse to talk about it. If you are the same-sex partner of someone who has HIV, you may be not recognized as such by the patient's family. You may not be included in the end of-life decision-making or in the planning of the memorial service because your relationship may not be recognized. You may be ostracized from the regular public support and sympathy that a heterosexual partner generally receives. What we mean when we talk about disenfranchised grief is that people with HIV and their partners may not be allowed to openly participate in society's grieving process or may not receive the support they need.

Multiple loss is also common in HIV/AIDS. We saw this with the case we discussed earlier. And here we are not just talking about personal losses, but also community losses. If you're a gay man or an IV drug user, you may have lost 50% of your community to HIV, and if you're a health care provider who works with people who have HIV, you may have experienced multiple losses, as well.

In addition, the stigma, prejudice and discrimination around HIV adds to the burden and the intensity of the grief process. When you internalize guilt and shame around the illness, it can lead to complicated grief and depression.

Complicated grief

- Grieving process is delayed, obstructed, or chronic
- More likely if:
  - –Loss is perceived as preventable
  - –Illness is lengthy
  - –Social stigma makes it hard to share feelings
  - –No support system
- Can become depression if untreated

Slide Note

Complicated grief is the next 'stop' up from grief and bereavement on the continuum we looked at earlier. This is when the grieving process is delayed, or obstructed, or just doesn't stop. It's more likely if, for example, the loss is perceived as preventable. A person with HIV might think, "Oh, I should have practiced safer sex." or "I should have been better about taking my medications." Then the patient starts to feel guilt and low self-worth. They start to feel as if they deserve what is happening to them. If the illness is lengthy, as it often is with HIV, or if social stigma makes it hard to find support, grief can also become more severe and protracted. Complicated grief can easily become a clinical depression if it isn't treated.

Grief vs. depression

Grief:	Depression:
• Distress related to loss – a normal response	• Generalized distress – loss of interest, pleasure
• Some physical symptoms of distress	• Somatic distress plus hopelessness, guilt, suicidal ideation
• Still able to look towards the future	• No sense of positive future

Slide Note

Let's look at elements of grief vs. elements of depression. Grief is a normal response to a specific loss or a set of losses. Depression is more a generalized distress, with decreased or little interest and pleasure in life in general. In grief as in depression, there are physical symptoms. In depression, the physical symptoms are present and can be more severe or debilitating. In addition, hopelessness, guilt, and sometimes suicidal ideation are present. In grief, people are still able to look towards the future. In depression, there really isn't much positive sense of future.

Trainer Suggestion

How do these symptoms relate back to the case?

The patient did not seem to have lost interest in everything—he was still interested in seeing his family and in completing a memory book for his children

He had physical symptoms—insomnia, decreased energy, tightness in chest. Some of these were hard to sort out from the symptoms of his physical illness.

He did have events in the future that he was looking forward to.

Grief vs. depression

Grief:	Depression:
• Associated with disease progression	• Advanced disease and pain
• Retains capacity for pleasure	• Change in capacity to enjoy life or former pleasures
• Still able to express feelings and humor	• Bored, lack of interest and expression

Slide Note

In the scientific literature, grief has been linked with disease progression, whereas depression is associated more with pain that hasn't been adequately treated, or with far advanced disease. People who are grieving still retain some capacity for pleasure, whereas people who are depressed have a marked shift in their enjoyment of life or former pleasures. People who are grieving are able to express their feelings with a range of emotions; they can still laugh. People with depression often have a flat, expressionless affect and lack a full range of emotional response.

Trainer Suggestion

We don't have enough information to relate all these symptoms back to the case, but you could ask the group if any of these apply to our case. The first one about advanced disease does apply to the patient. Also, the patient is physically unable to enjoy former pleasures.

Grief vs. depression

Grief:	Depression:
• Comes in waves	• Constant, unremitting
• Passive wish for death	• Intense and persistent suicidal ideation
• Can cope with distress on own or with supportive listening	• Requires intervention – medication, therapy

Slide Note

Grief is intermittent and often comes in waves, whereas depression is constant. The clinical diagnosis of depression is depressed mood or anhedonia that lasts 2 weeks or more. In grief there can be a passive wish for death, much like the statement made by our patient, "I can't go on like this anymore." We will want to explore such statements with our patients to determine if their wish is more active, i.e., if they have a plan, intent, and the means to carry out the plan. If the suicidal thoughts are persistent and active, the patient has gone beyond a normal grief response. With grief, patients can often cope with the help of a supportive listener or with counseling. However, as mentioned earlier, we might also offer medication to someone experiencing grief, especially if the grief is severe or prolonged, or if it is impairing the patient's functioning and his or her ability to benefit from support and counseling. Depression should always be treated.

Case #2

• 40 y.o. woman, HIV+ x 4 years, very compliant with HAART, in recovery and connected to supportive services. She has just been given a new diagnosis of Hepatitis C, has liver damage, and has had to d/c HAART. She is tearful, and is refusing any further treatment.

Slide Note

Let's look at another case. This is a 40-year-old woman who has been HIV positive for 4 years. She had a T-cell count below 200 and a high viral load upon diagnosis, so has been on HAART since then and has responded well to it. Her HIV diagnosis was a wake-up call for her, and she went into drug treatment soon after her diagnosis. She has been very compliant with her HAART regimen and has connected with support services in the community. Her last liver function tests indicated liver damage, and she was diagnosed with Hepatitis C. She had to discontinue HAART. She now presents very tearful. She states she has not been eating or sleeping well for the past two weeks. She is contemplating stopping all treatment and returning to active drug use.

Trainer Suggestion

At this point, you can ask the group to come up with questions that would help in the evaluation of this patient's mental health. What should you ask? What should you look for to determine the patient's psychiatric diagnosis?
Some possible questions might be:
Does the patient endorse any of the following: depressed mood, anhedonia, somatic symptoms, hopelessness?
Is the patient suicidal? Does she have a plan and means?
How long has she been feeling this way? What is her level of functioning?

Case #2

- Unsupportive family; estrangement from daughter
- Withdrawal from support system
- Sees no future, feels hopeless
- Feelings of guilt and worthlessness
- Memory problems
- Difficulty concentrating
- History of depression, previous suicide attempt

Slide Note

As we talk more to the patient, we find out that she has a very unsupportive family who blames her for her situation and who are abusive. They use separate silverware and dishes when she comes over. She has a 16-year-old daughter from whom she is estranged. She has been active in her recovery, but in the past two weeks since her Hep C diagnosis, she has withdrawn from her support system. She sees no future for herself, feels hopeless, and feels guilt and worthlessness. She endorses memory problems, difficulty concentrating, poor sleep and appetite since her last appointment. And she has a previous history of depression and a previous suicide attempt.

Trainer Suggestion

You might ask the group the following questions:
What are the symptoms the patient endorses? Are they characteristic of a psychiatric disorder? If so, what disorder? How clear cut is her diagnosis? What else might be going on?
What treatment options would you consider?

Diagnosis of depression in terminally ill patients

- Depressed mood
- Lack of pleasure (anhedonia)
- Tearfulness
- Social withdrawal
- Sees no future
- Hopelessness
- Helplessness
- Worthlessness
- Guilt
- Sustained suicidal ideation

Slide Note

The incidence of depression in the terminally ill is anywhere from 9-17%, depending on the study you cite. For those with cancer or HIV, the incidence increases to 17-35%. These figures are dependent on the diagnostic standards used, as well as the stage in disease progression. The main point is that it is common in terminal illness, and more common in patients with HIV/AIDS!
Let's look at how we diagnose depression in patients with life-threatening illness. **For a clinical diagnosis of depression, the patient must be experiencing depressed mood or anhedonia, and the depressed mood and/or anhedonia must be persistent; that is, present for 2 weeks or more.**
It is often difficult to make a diagnosis for people who are terminally and chronically ill by just looking at physical symptoms because often the physical illness manifests those symptoms – fatigue, weight loss, loss of appetite, and insomnia commonly occur with HIV. It might be more useful to focus on psychological symptoms. Depressed mood, tearfulness, lack of interest and pleasure, social withdrawal, isolation, hopelessness, and feelings of worthlessness are all common to depression.

Trainer Suggestion

Ask the group: "Which of these symptoms was endorsed by the patient in the last case?"

Diagnosis of depression
in terminally ill patients

Other indicators:
- Intractable pain or symptoms (dyspnea, fatigue)
- Excessive preoccupation with somatic distress
- Poor cooperation or refusal of treatment
- Previous history of depression
- Family history of a mood disorder

Slide Note

Here are some other indicators of depression in patients with life-threatening illness found in the literature--intractable pain or symptoms, excessive preoccupation with physical symptoms, poor cooperation or refusal of treatment. These symptoms are a little harder to get a handle on, and involve the clinician's judgment of the patient's baseline, history, and even personality! The patient's previous history of depression and a family history of depression are also indicators.

Trainer Suggestion

Ask the group: "Which of these symptoms was endorsed by the patient in the last case?"

Why diagnosis is difficult

- Physical illness produces vegetative symptoms similar to depression
- Psychological distress is normal feature in dying process for many people
- Stigma of psychiatric issues—patient may be reluctant to disclose symptoms
- Provider fear of causing distress by exploring difficult issues

Slide Note

Diagnosis is difficult, as we mentioned earlier, because the neuro-vegetative symptoms of depression are similar to the symptoms of physical illness. Also psychological stress is a normal response to the dying process for many people. It's important to look at a patient's baseline functioning over time and see if their response to this illness is consistent with their usual response to stressful situations. If the depressed mood and anhedonia are pervasive and persistent (2 weeks of more), and if the other psychological symptoms are present, we are looking at depression.

Many patients may be reluctant to disclose psychological symptoms because of the stigma associated with mental illness, and clinicians might be afraid to ask about depression or suicide for fear of causing distress.

One study, by Chocinov, etal, in the American Journal of Psychiatry, found the single screening question, "Are you depressed?", was an accurate indicator of depression in the terminally ill. We can also ask the patient if the symptoms make sense to them – is this how they have responded to loss in the past? Or is it worse now?

Suicide

- Higher in general in patients with medical illness
- Cancer patients 2x more likely than general population
- HIV patients 7-36x more likely

Slide Note

Suicide is our most feared-outcome of untreated depression. Suicide is higher in patients with medical illness, 2 times more likely in patients with cancer, and (depending on the study) 7 to 36 times more likely for people with HIV.

Co-factors in suicide at end-of-life

- New diagnosis (HIV)
- Advanced diagnosis
- Lack of treatment options
- Uncontrolled pain
- Disability
- Number of losses
- Social isolation
- Substance use
- Pre-existing mental illness
- Previous suicide attempt
- Family hx of suicide

Slide Note

Co-factors in suicide for people with life-threatening illness are:

Receiving a new diagnosis of HIV, a new diagnosis of an opportunistic infection or AIDS-defining illness, or, like with the previous case, a diagnosis of hepatitis C. For some patients, it's not just the actual progression of the illness that leads to suicidal ideation, but the fear of its progression as well. If there's a lack of treatment options, if people are in severe pain or severely disabled, if people are isolated, using substances, and have any history of mental illness, suicide attempt, or family history, then they are more at risk for suicide.

Trainer Suggestion

Ask the group: "Which of these co-factors was endorsed by the patient in the last case?"

Depression – Why treat?

Untreated depression:

- Decreases effectiveness of pain meds
- Amplifies other symptoms
- Erodes quality of life
- Impairs capacity for connection, resolution
- Causes emotional distress to loved ones
- Increases risk of suicide

Slide Note

Why would we treat depression in someone who's dying? There are many reasons. Here are just a few:

Untreated depression decreases the effectiveness of pain medication, amplifies other symptoms, and erodes quality of life. Depression makes it hard for people to connect to their loved ones and to have resolution. It causes emotional stress to peoples' loved ones, and it increases the risk of suicide.

The benefits of treating are great, and with proper prescribing, can far outweigh any potential negative side effects of treatment.

Treatment of depression

- If pain is an issue, control the patient's pain
- Use low threshold for initiating treatment
- Be aware of medication interactions
- Be aware of psychotropic medication side effects

Slide Note

Here are some pearls for treating depression in patients with life-threatening illness: If pain is an issue, control the patient's pain. This may address the depression, or you may need to treat the patient's pain in conjunction with the depression. Sometimes, the use of anti-depressants result in lower doses of needed pain medications. Also, we should use a lower threshold for starting the treatment of depression for patients who have only a short period of time left. There is little potential harm in treating people if they seem depressed. You want people to be able to use the time they have left well. That being said, you need to be aware of any potential medication interactions and side effects, monitor closely, and adjust medications and dosages as indicated.

Treatment of depression

Medications:

- SSRIs
- Tricyclics – not as well tolerated
- Psychostimulants – most common in tx at end of life

Slide Note

There aren't many randomized controlled trials with terminally ill people, so these are recommendations based on extrapolations from the literature and on anecdotal evidence. Selective serotonin reuptake inhibitors, like Paxil, Zoloft, and Prozac, are best to use when people are in the earlier terminal stage—the last year or six months--because it takes time to reach a therapeutic dose. If someone is in the last month or less of life, SSRIs would not be your first choice. In those cases, you might treat with psycho-stimulants such as Ritalin, or Dexadrine, because they act quickly.

Tricyclics are never your first choice because they have high side effect profiles. They can even cause mental status changes.

Once again, be aware of what kind of interactions these medications might have with the patient's other medications.

Use of psycho-stimulants at end-of-life

- Fast-acting
- Potentiates opioid analgesia
- Decreases sedation
- Increases cognitive performance

Slide Note

As mentioned previously, psychostimulants are a good choice only at the very end of life, in the last weeks or days. Patients and family members will notice an improvement in mood and energy, often within 24 hours. They can make pain medications work better. Patients are less sedated and can be more cognitively present with their loved ones.

Treatment of depression

Psychotherapy
- Cognitive-behavioral
- Problem-solving
- Supportive counseling
- Interpersonal

Slide Note

Psychotherapy is another effective means of treating depression. However, with clinical depression, patients should be treated with medication first. They will then be better able to engage in therapy once the medications are on board. However, when patients are actively dying or extremely ill, they will not receive much benefit from these types of interventions. In those cases, a supportive presence may be most helpful.

Treatment of depression

Psychosocial
- Team evaluation—psychiatric, social worker, chaplain
- Mobilize social supports
- Encourage activity
- Educate the family and caregivers

Slide Note

Psychosocial interventions, in conjunction with medication and therapy, are also helpful in treating depression. They include interventions by other members of the health care team including social workers and chaplains. Mobilize the patient's support system to check in with the patient, provide activities, provide meals and provide company. Educate the patient, family, and caregivers about depression. Encourage activity as tolerated, even before the patient feels ready for it.

Culture & depression

- Hx of accessing mental health care not positive
- Different mental health treatment for ethnic groups
- Shame/stigma in community – can't handle own problems or not enough faith in God

Slide Note

Patients from racial and ethnic minority groups may have had negative experiences with the mental health system that have made having trust in diagnosis and treatment recommendations difficult. Also, in some ethnic communities, there is a lot of shame and stigma around mental health issues, so patients may be reluctant to talk about them. Being depressed may be seen as being unable to handle one's own problems of as a lack of faith in God or as weakness. We need to focus on building trust with our patients. We also need to probe and explore different belief systems. Using a cultural broker is one way to help us to learn about a patient's beliefs about mental health issues.

Prevalence of anxiety disorders in HIV

• Panic Disorder	10.5%	n=2854
• Generalized Anxiety Disorder	15.8%	n=2864
• PTSD	42% women / 54% pain	
• Acute Stress Disorder	31%	

Bing, 2001, Arch Gen Psychiatry 58: 721-8
Martinez, 2002, AIDS Patient Care STDS 16: 283-91
Koopman 2002, Int J Psychiatry Med 32: 361-78

Slide Note

Anxiety disorders are also common in patients with life-threatening illness. In one study (by Bing, etal, in the Archives of General Psychiatry) of patients with HIV engaged in primary care, approximately 10% of the patients met criteria for panic disorder, and 16% of the patients met criteria for generalized anxiety disorder.

Post Traumatic Stress Disorder and Acute Stress Disorder are increasingly common among individuals living with HIV/AIDS as the epidemic spreads into disenfranchised populations. For many individuals, violence is a daily part of their lives – not something that only occurred in childhood.

Treatment of anxiety

- Antidepressant medications (SSRIs)
- Benzodiazepines
- Psychotherapy
  - –Supportive
  - –CBT
  - –DBT

Slide Note

A common first-line treatment for anxiety disorders is antidepressant medications—specifically SSRIs such as paroxetine or citalopram. As in mood disorders like depression, a family history of benefit from a given medication (or intolerance of a medication) can help guide medication choices.

Benzodiazepines, such as clonezepam, are sometimes used to treat anxiety disorders that do not respond to antidepressant medication. This class of medication is not without risk, however. In addition to concerns regarding addiction and tolerance, benzodiazepines frequently cause mental status changes, especially among medically compromised or frail individuals.

Psychotherapy by itself or as a adjunct to medication is another effective intervention used to treat anxiety disorders. The particular type of psychotherapy used will depend in part on the patient's ability to engage with the treatment provider, including the patient's cognitive functioning. Supportive therapy is less demanding of the patient than the highly-structured and time-consuming expectations of dialectical behavioral therapy, for example.

Case #3

- 29 y.o. man, C3 AIDS, tested positive after hospitalization with PCP 1 year ago, unable to adhere to HAART due to substance use. Now with Hepatitis C and toxoplasmosis. Patient's wife is also HIV+. Parents involved in care and report memory problems, slowed movements, and withdrawal in patient over past few months.

Slide Note

Let's look at one final case. This patient is a 29-year-old man with very advanced AIDS. He has never been able to adhere to HAART because of a long history of substance abuse. Now he has Hepatitis C and a new diagnosis of toxoplasmosis that is not responding to treatment. His wife is also HIV positive and is a partner in his substance abuse. His parents are involved in his care, and they report a cognitive decline in the patient over the past 2 months. They note that he seems more withdrawn, has had problems with memory, and he seems to be moving more slowly and unsteadily.

Trainer Suggestion

At this point, ask the group to describe the symptoms the patient is experiencing and if they are characteristic of any psychiatric diagnoses. If so, what might be the diagnosis of this patient?
Answer: We will need to rule out the effects of toxoplasmosis on the brain as well as the effects of drug toxicity or liver damage. If these are ruled out, patient's symptoms are consistent with HIV dementia.

Diagnosis of HIV dementia

- Diagnosis of exclusion
- Gradual cognitive decline
- Short-term memory loss
- Impaired concentration and attention
- Slowed thought process

Slide Note

The patient's symptoms are suggestive of a diagnosis of HIV dementia.
Dementia is a diagnosis of exclusion. You have to rule out everything else first, such as head injury, previous brain dysfunction, substance use, or depression. What differentiates dementia from delirium or the effects of a drug use episode is its gradual decline over several weeks or months. HIV- associated dementia involves changes in cognitive functioning, typically memory impairment, combined with changes in motor function, and in mood or personality. In the cognitive realm, mental slowing and poor recall are common. In the motor realm, there is also slowing accompanied by weakness. At its most extreme, patients are non-ambulatory and can have seizures. In terms of mood changes, the patient may appear depressed or withdrawn. Personality changes can include an exaggeration of the patient's personality.
Dementia is prevalent in about 15-20% of all HIV+ patients. Although it is a lot less common due to HAART, its prevalence is still high because of the length of time people are living with HIV. Many people with long-term HIV, even on HAART, experience some symptoms of dementia.

Diagnosis of dementia

- Impaired judgment
- Unsteady gait, balance problems
- Personality changes—withdrawn, apathetic, disinhibited
- Hallucinations, delusions (late stage)
- Diagnosis may include LP, CT, MRI

Slide Note

In dementia, judgment is also impaired and balance is unsteady. Patients often undergo a change in personality, anywhere from being withdrawn to being disinhibited. In the later stages, patients may experience psychosis.
In trying to diagnose dementia, clinicians use lumbar punctures, CT scans, and MRI's to rule out other explanations for the mental status changes..

Diagnosis of dementia—conditions to rule out

AIDS-defining conditions:

- Toxoplasmosis
- CNS Lymphoma
- Progressive Multifocal Leukoencephalopathy
- CMV Encephalitis
- Cryptococcal Meningitis

Non-AIDS-defining conditions:

- Viral / Bacterial CNS infection
- Neurosyphilis
- Herpes Simplex Encephalitis

Slide Note

Here are some conditions common to people with AIDS that cause cognitive decline and mental status changes. We need to rule these out before we can diagnosis HIV dementia in a patient.

Treatment of dementia

- Decrease viral load in the brain
- Newer antipsychotic medications—olanzapine, risperidone
- Anti-depressants--SSRIs
- Behavioral management
- Educate family about what to expect and reasonable expectations

Slide Note

How do we treat a patient with dementia? There is limited research on dementia – most treatment recommendations are based on anecdotal evidence. One treatment supported by research is to decrease the viral load in the brain by choosing an antiretroviral treatment regimen that crosses the blood brain barrier.
The newer anti-psychotic medications, such as olanzapine or risperidone, are used because they help with cognitive functioning. They can also help if patients are having delusions or hallucinations. If the patient has depression and dementia, use an SSRI. Behavioral management - lists, calendars, medisets, and a daily routine—can also help. Patients may need to be talked through tasks, and they may need to avoid overstimulating situations and environments. Patients need lots of rest because fatigue makes dementia worse.
Simple, direct communication with people is important, as is educating the patient's family and support system about how to work with the patient. Families (and providers)

often get angry and frustrated with the patient, thinking they're acting differently (slower, forgetful, withdrawn, disinhibited) on purpose! Because language is not affected, family members and providers often miss the other clues for dementia. Educating families on what the dementia is, what happens, and how they can work with and interact with the patient will help.

Continuation of case #3

- Two weeks later, the patient admitted to hospital with decreased level of consciousness, disorientation, and hallucinations for the past two days. Pt. and wife have been continuing to use cocaine intermittently. On admission, the patient has a high fever, and his bloodwork suggests he is dehydrated.

Slide Note

Let's return to the last case. The patient was sent home from his last hospitalization with home care. His wife and parents were given education about how to cope with and help him with his dementia symptoms. Now, the patient and his wife come to the emergency room. His wife reports the patient is experiencing decreased level of consciousness, disorientation, and hallucinations for the last day or two. A toxscreen is positive for cocaine use, and the patient's wife admits that they both got high earlier in the evening. A work-up of the patient reveals he has a high fever and is dehydrated.

Trainer Suggestion

At this point, ask the group to describe the symptoms the patient is experiencing and if they are characteristic of any psychiatric diagnoses. If so, what might be the diagnosis of this patient?

Also ask the group, "Once we've resolved the medical crisis, what do you think the careplan should be for this patient?"

Diagnosis of delirium

- New onset of:
  - –Disturbance of consciousness and attention
  - –Disorientation
  - –Cognitive or perceptual disturbances
- Acute onset, fluctuating course
  - –Waxing and waning levels of consciousness

Slide Note

How do we diagnose delirium? We look for a new onset of impaired consciousness, disorientation, or perceptual disturbances. Other symptoms are memory impairment, sudden behavior changes, and disturbances in the sleep-wake cycle. The patient experiences changes over the course of hours or days. Some parts of the day, the patient may seem clear-headed. At other times, she or he is confused, hallucinating, and agitated. Or the patient may nod off during a conversation. Delirium can present in many ways. It is often misdiagnosed; the key factor in the diagnosis of delirium is its acute or sub-acute onset.

Delirium

- Effects 40-60% of all patients with HIV
- More common at end of life
- Intensely distressing to patient and family
- Requires early diagnosis and aggressive treatment
- Often misdiagnosed as anxiety, depression, dementia, psychosis.

Slide Note
Delirium effects between 40-60% of all HIV patients at some point in their illness. It is most common at end of life. Because the underlying cause of delirium can be life-threatening, it needs to be diagnosed early and treated aggressively.

Common etiologies of delirium

- Medications
- Organ failure
- Infection/fever
- Metabolic changes
- Drug or alcohol use or withdrawal
- Trauma
- May have multiple causes

Slide Note
Medication effects and interactions are the most common cause of delirium. Other common causes include organ failure, infection or fever, and metabolic abnormalities such as increases or decreases in potassium or sodium. Head trauma, for example from falling, can also cause delirium. For the patient in our case, drug use was the cause of his delirium, as well as fever and dehydration.

Treatment of delirium

- Treat the underlying condition, if possible
- Orient patient
- Neuroleptics – halperidol is a good choice
- Benzos may contribute to worsening cognitive impairment

Slide Note
How do we treat delirium? First and foremost, we treat the underlying condition. This might mean treating the patient's withdrawal or treating the infection. It might mean changing or discontinuing the patient's medications.
We also need to try and orient the patient. Give frequent reminders about where she or he is, what the date is, and what is happening and why. Simple things, like opening the blinds during the day or posting a calendar and clock, can help orient the patient to time.
Neuroleptics are often used, and halperidol is the best choice, because it can be given to patients who are unconscious or combative – it can be given IV or IM.
Benzodiazepines are not recommended as randomized clinical trials of hospitalized AIDS patients have show that they can actually make things worse. The only time benzos might be used is if the delirium is caused by alcohol or benzo withdrawal.

Working with multiple diagnoses

- Comprehensive psychosocial history
- Team approach – consistent response and clear roles
- Deal with trust issues – both ways
- Aggressive outreach
- Increase positive social support
- Care conferences

Slide Note

We talked a little in our last case about how we might manage the patient after the medical crisis has resolved. Let's talk briefly about some good practices in working with multiply-diagnosed patients. We define a multiply-diagnosed patient as someone who is HIV+ who also has substance abuse and mental health issues.

First, we need to do a very thorough psychosocial history. In order to do that, we need to build trust with the patient so that they will tell us what they're using. The team approach is important because as we know, some of our really challenging patients can split up a team and play one person off another. We must be consistent in our approach and really clear on what our roles are on the team. We need to communicate regularly with the team to maintain consistency, including having care conferences.

The trust issue goes both ways. Patients with substance use and mental illness are used to being judged by their providers. Often their pain issues are not dealt with because they're perceived as just seeking drugs. They've had a lot of negative interactions with caregivers. At the same time, we clinicians have had many negative interactions with multiply-diagnosed patients. We have our own issues, fears, and judgments that we're bringing to the interaction. We have to work out our own attitudes first, and then have frank discussions with patients about what our limits are, what we're willing to do, and the rationale for doing it this way. We also need to educate our patients about potential drug interactions.

We need to reach out aggressively to these patients, who often are isolated and don't come in for care. And we need to help connect our multiply-diagnosed patients to positive social supports, such as drug treatment, mental health treatment, 12-step programs, support groups, harm reduction programs, and counselors.

Substance Abuse & Pain Management

- Don't under-medicate pain
- Use a written pain contract:
  - One prescriber
  - One pharmacy
  - No refills if lost or stolen
- Use longer-acting, transdermal, generic drugs
- Use home nurse to help with management
- Proactively review regimen, effectiveness of treatment

Slide Note

Let's talk briefly about treating pain in people who have a history of substance abuse because this is a common issue. Clinicians may be nervous about giving pain medications to patients with a history of substance abuse. It is very important, even in people who have a history of ongoing substance abuse, to respect their report of pain. Often people with substance use issues have a lower pain threshold and a higher medication tolerance, so we don't want to under medicate their pain. If a patient has ongoing substance abuse, they need treatment for substance abuse and pain together. Not just one or the other.

It is reasonable to set very clear goals for pain management. With the patient, identify and discuss behaviors that you think are abusive. Use fixed time intervals, and expectations of when the patient will come back in to have their pain reassessed and the prescription refilled. You can use a written contract in which you make notes in the chart that state who the provider is, who the pharmacy is, who's controlling the pain treatment overall, and what the pain

plan is. This makes it difficult for patients with substance abuse issues to come in and get pain medicine from multiple providers.

Using longer acting, transdermal drugs, generic drugs, or drugs that don't have a lot of street value may be more successful. And sometimes a home health nurse can help to monitor and manage the patient's use of medication.

It is also helpful to distinguish between active users and those in recovery, because active users do need much more attention and care than people who are in recovery. Most of the patients that we see in recovery are very wary of their meds, and it's usually hard to talk them into taking enough to adequately treat their pain.

Conclusions

- Important to distinguish between grief, depression, anxiety, dementia and delirium and treat accordingly
- Depression is NOT a normal response to illness and dying
- Consider cultural differences in mental health diagnosis and treatment
- Working effectively with patients with substance abuse is challenging but possible!

Slide Note

In summary, it's important to distinguish between grief, depression, anxiety, dementia and delirium, and treat accordingly. Depression is not a normal response to illness and dying, that is, we shouldn't just accept it as a given; we should treat it. We should also err on the side of treatment when looking at the continuum of sadness to depression. Consider cultural differences when giving a mental health diagnosis and developing a treatment plan. And we CAN work effectively with multiply-diagnosed patients to address both their pain and substance use issues.

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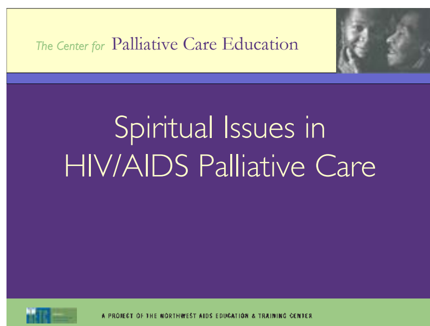
Spiritual Issues in HIV/AIDS Palliative Care

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.

About this module: This module was the work of a number of contributors and reviewers, and it has been through several revisions in its development. Please feel free to use it as you find elements that are useful for your training purposes, and revise as you wish. We would very much appreciate feedback – either on the project website at www.uwpallcare.org, or via email at pallcare@u.washington.edu

Two trigger tapes may be used to accompany this module. Their titles are, "Spirituality and Control Over the Dying Process," and "Respecting the Spiritual Experiences of Dying Patients." Please see the "Resources for Trainers" section of this curriculum for information on using these tapes.

Learning objectives

1. Define spiritual distress and identify sources that may arise for patients with HIV/AIDS
2. Practice skills to assess your own spiritual perspectives as caregivers
3. Discuss skills to facilitate patients' assessment of their spiritual needs
4. Discuss skills to facilitate addressing patients' spiritual needs

Slide Note

We've outlined 4 goals for this session. These include looking at the spiritual issues and spiritual distress that may arise when working with patients with HIV/AIDS, practicing some skills to assess our own spiritual perspectives, and learning skills to facilitate patients' assessment of their spiritual needs. And finally we'll discuss skills, including communicating and accessing community resources, to support patients' spiritual needs.

Introduction: spirituality versus religion

- Concept of spirituality found in all cultures
- Individual's search for meaning
- Relating to transcendent dimension; something greater than self
- In religion, meaning connected with a community
- Religion often includes belief in a deity
- Religion often includes ritual and tradition

Slide Note

A good place to start is to consider the terms we will be using, spirituality and religion. What is the difference between these two?

While there is no single answer to this question, or one definition for these terms, some themes can be found:

While spirituality can be thought of as an individual's relationship with the transcendent and to a sense of something greater than the self, religion is often thought of as a community's common beliefs and practices. In religion, this often includes the belief in a deity. Both spirituality and religion may include ritual and tradition.It may be useful to spend a few minutes going over participants' perspectives on this question. One option is to ask the question, "What is the difference between spirituality and religion?" before putting this slide up, generating responses on a board and then discussing them after putting up the slide.

Why address spirituality?

- Spiritual care is part of comprehensive palliative care
- High prevalence of spiritual belief and practice
- Association with health outcomes
- Spiritual distress – symptoms, facing death

Slide Note

What are the reasons for addressing spirituality today? There is general consensus that spiritual care is an essential component of comprehensive palliative care. For example, the 2002 World Health Organization definition of palliative care states,

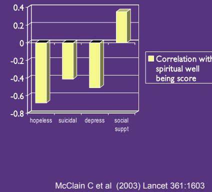
"Palliative care…improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual…"

In the United States as well as globally, there is a very high prevalence of spiritual belief and practice, and belief in the relationship between spirituality and health. Research has recently focused on health outcomes associated with spiritual belief and practice, and we'll look at a couple of those in a few moments.

Finally, we look at spirituality because of the possibility of providing support and easing suffering for our patients who are having spiritual distress.

Religious factors and coping

- 160 cancer patients
- Life expectancy < 3 months
- Surveys suggested spiritual well-being correlated with:
  - lower depression
  - lower hopelessness
  - lower suicidal ideation
  - higher social support



McClain C et al (2003) Lancet 361:1603

Slide Note

Here is one example of the kinds of results that are being seen when researchers look at the links between spirituality and health outcomes.

In this recent study, cancer patients with a life expectancy less than 3 months were interviewed to assess spiritual well being, using a standardized measure, the "Functional assessment of chronic illness therapy – spiritual well-being scale". Assessments of depression, hopelessness, and several other measures were also made. The results were consistent with other studies that suggest spiritual well being may enhance psychological adjustment in terminal illness.

Patients with HIV/AIDS and spiritual well-being

- 117 African American patients who received care at HIV clinics and AIDS service orgs
- Surveyed:
  - Demographics
  - Spiritual Well-Being
  - HIV symptoms
  - Psychological symptoms
- Existential well-being and HIV symptoms were correlated with psychological well-being

Coleman C and Holzemer W. (1999) J. Assn of Nurses in AIDS Care 10(1) 42-50.

Slide Note

In this study, investigators surveyed 117 African American patients who received care at HIV clinics and AIDS service organizations – they looked at measures related to spiritual and existential well-being, HIV symptoms, and psychological symptoms, including depression, anxiety, and hope.

Analysis of the data suggested that existential well-being, one of the measures on the spiritual well-being scale, correlated with psychological well-being. The authors conclude that, "increasing existential well-being, which assesses the extent to which one perceives or has a sense of meaning, purpose, and satisfaction, can be a powerful health benefit to those with HIV/AIDS."

Other positive outcome studies

- Facilitates communication around end of life care
- Enhanced coping, well-being, and increased social support

Slide Note

Other health outcomes which have been associated with spiritual well-being or religious practice have included increased communication about end of life care needs, enhanced coping, well-being, and increased social support.

What is spiritual distress?

- Definition:
  - The state in which an individual or group experiences, or is at risk for experiencing, a disturbance in the belief or value system that provides strength, hope, and meaning to life.

Carpenito-Moyet, L.J. (2004). Handbook of nursing diagnosis.

Slide Note

As we mentioned, one of the reasons palliative care addresses spirituality is to help ease "Spiritual Distress." This is a diagnostic term which is used in the field of nursing, defined here as, "The state in which an individual or group experiences, or is at risk for experiencing, a disturbance in the belief or value system that provides strength, hope, and meaning to life."

How spiritual distress presents

- Rage, Anger
- Hurt
- Guilt, self-blame
- Fear
- Rejection of others

Slide Note

Spiritual distress may be manifest in a number of different ways. There may be hurt directed at family, or guilt, or anger directed at oneself. This distress may be related to experiences with the church, questions directed at God, such as, "Why is God doing this to me, when I've been a good person in my life?" There may be feelings directed at the disease itself, with government, or the health care community for its inability to find a cure, and there may be feelings directed at you.

Trainer Suggestion

This might be a good point to initiate some interaction with the training session participants. Inviting comments about this – do participants have any examples of situations in which they observed any of these issues surfacing for their patients? It may be useful to have them share with a partner for several minutes, and then bring contributions to the whole group.

Common sources of spiritual distress

- Fear
  - Of dying
  - Of what happens after dying
- Beliefs in conflict
  - Changing spiritual orientations
  - Conflict with family's beliefs
  - Loss of community
  - Fledgling religious beliefs

Slide Note

Sources of this distress may derive from experiences, such as fears as a patient faces dying – thoughts about what the experience of dying might be like, about what happens after dying.

Patients may be experiencing conflict in relation to their beliefs. A person may wonder if it is okay to change their spiritual path from the one they were raised with: Is it okay to have become a Buddhist when I was raised a Lutheran? These new beliefs arising from a new religion may be in conflict with those of family. Patients may experience a loss of community stemming from the change in their religion. There may be new, fledgling religious beliefs that the patient is learning about, and maybe struggling with. For example, a newly practicing Buddhist may be experiencing conflict in relating to the concept of re-incarnation.

Some patients may find that approaching death sparks an interest in spirituality which was never part of their life before. This is sometimes jokingly called a death bed

conversion, but it's important to remember not to be judgmental about this experience a patient may be having. Approach all patients' spiritual paths with respect.

HIV/AIDS specific sources of spiritual distress

- Isolation
  - Conflicts with family, church because of homosexuality, drug use, other behavior
  - Disclosure concerns
  - Stigma of HIV/AIDS
  - Society's assignment of guilt for infection
- Issues related to possibly infecting loved ones
- Distress over disappointing others by getting HIV
- Young people not meeting life goals
- Lack of trust in health care system, providers
- Numerous losses of loved ones

Slide Note

There are a number of factors specific to patients with HIV/AIDS that may lead to spiritual distress.
Patients with AIDS remain stigmatized in this society, which can be socially isolating, and because HIV is seen to be associated with sexual behavior and drug use, this can lead to conflicts with family and church, and further social isolation. Guilt and self-recrimination, as mentioned before, may be related to having disappointed others by becoming infected with HIV, or the possibilities of having infected loved ones. One of the biggest sources of distress may be multiple losses – including the losses of life goals, and multiple losses of loved ones due to AIDS.

Addressing spiritual needs or distress

- Preparing yourself
- Communicating about spiritual issues
  - Clarifying patient concerns
  - Providing empathy
  - Identifying goals for care
- Knowing your own beliefs
- Know about resources in your community:
  - People
  - Spiritual or religious communities
  - Information sources

Lo et al (2002), JAMA 287(6) 749-54

Slide Note

Providing support to patients around spiritual needs and spiritual distress will be helped if you prepare yourself. Be ready to take some time to spend with your patient, but remember that conversations about spirituality need not be lengthy, if your time is limited.
We will go over some communication tools for talking with patients about spiritual issues, and for assessing our own spiritual beliefs.
It will also be useful for you to have some information about resources in your community: individuals as well as communities and information sources such as clearinghouses for information about spiritual support. Some communities have HIV/AIDS-specific resources for spiritual needs of patients and families.

Trainer Suggestion

This might be a good point to have participants break into small groups of people working in the same community to share information about local resources for spiritual support.

Addressing spiritual needs: "FICA" format

- Listen
- Follow "FICA" format:
  - Faith, belief, meaning:
    - "Do you consider yourself spiritual or religious?"
    - "Do you have spiritual beliefs that help you cope with stress?"
    - "What gives your life meaning?"

Puchalski CM, Romer AL. Taking a spiritual history allows clinicians to understand patients more fully. J Pall Med 2000;3:129-37.

Slide Note

Listening non-judgmentally is one of the most important skills you can offer to your patient/client. Asking open-ended questions will be important, and a number of people have suggested various formats for these. We've listed the "FICA" format here, a spiritual assessment developed by Puchalski . FICA is an acronym for Faith, Importance, Community, and Addressing the need.
Some suggested questions, both open and closed-ended, are provided here.

Trainer Suggestion

You may want to ask participants to come up with other questions on this and the next several slides which offer possible open-ended questions. It may be useful, also, to explore the difference between open-ended and closed-ended questions.

Helping clients assess their spiritual needs: "FICA"

- Importance and Influence
  - "What importance does your faith or belief have in your life?"
  - "Have your beliefs influenced you in how you handle stress?"
  - "Do you have specific beliefs that might influence your health care decisions?"

Helping clients assess their spiritual needs: "FICA"

- Community
  - "Are you a part of a spiritual or religious community? Is this of support to you and how?"
  - Is there a group of people you really love or who are important to you?"

Helping clients assess their spiritual needs: "FICA"

- Address/Action in Care
  - "How should the health care provider address these issues in your health care?"

Common pitfalls

- Trying to solve problems, resolve unanswerable questions
- Providing premature reassurance
- Imposing own beliefs on patient

Lo et al (2002), JAMA 287(6) 749-54

Slide Note

It may be useful to keep in mind some common pitfalls in communicating with patients about spiritual issues. In an article entitled, " Discussing religious and spiritual issues at the end of life: a practical guide for physicians," Lo and colleagues outlined several things to watch for. Given the focus of biomedical training on "fixing things," a common pitfall may be to try and solve problems. The authors remind readers that simply "walking with" a patient is likely to be comforting.

Other pitfalls to avoid include imposing one's beliefs on patients, and providing reassurance prematurely. For example, the authors remind readers that reassuring a patient that her illness is not a punishment from God may not in fact relieve suffering, which is the desired effect, but may simply deter patients from disclosing other concerns.

Personal awareness

- What are our own spiritual and/or religious beliefs?
- What are your own experiences with death and dying, grief and grieving?
- What have you learned about spirituality and end of life care from your professional training?
- What are your concerns, and what are your hopes related to communicating with patients about spiritual issues?

Slide Note

One of the most important things we can do to help our clients with their spiritual issues is to look at our own issues first

Our own spiritual beliefs and issues may be molded by personal experiences with religious traditions, personal experiences with death and dying, our training in working with patients around spirituality; and working in the framework of a scientific model.

Care must be taken to be sure that we as professionals are clear with ourselves as to what our agendas, our hopes, and our fears are, so that we don't "lay them" on our patients.

Trainer Suggestion

You may want to invite participants to consider these questions and list some answers. Participants may be invited to discuss these with a partner or a small group, if the learning environment in this session is safe for this level of sharing.

Personal awareness exercise

- What is your most hoped-for death?
- What is your most feared death?

Slide Note

A practical exercise to look at our own issues is to ask ourselves, "What is my most hoped-for death? What is my most feared death?"

Trainer Suggestion

At the end of the time period, invite brief feedback on the experience and tell the story below. See instructions accompanying the exercise.

This exercise was developed by Heather Andersen, RN MN Ed.D., of Humansource.net in Seattle. She was the clinical director of Hospice of Seattle, and tells this story of her "enlightenment" related to patient choice and deep listening.

"There was a woman I was helping in her final days at home, I will call her Helen. And I knew, because of her color and her status and everything, that she was probably going to die on this particular night. And so I said, "Well Helen, I'll put up a cot in your room and I'll stay here," and Helen says, "No I want to die alone." And I said, "Well, I'll sleep on the couch then." And Helen says, "No I really want to die alone." And I said, "Well, I think you're probably going to die tonight, Are you sure you don't want me to stay with you?" And Helen says in a very raspy voice, "Heather, you are not listening to me." And at that moment it hit me. I wasn't listening. Even with all my experience, my degrees and my belief in a person's right to die as they wish to, I wasn't able to hear her. What was blocking me was my own fear of dying alone. I so strongly could not imagine dying alone that I failed to see this woman's desire to do what I most feared. I apologized and said that I would need a key to get into her apartment in the morning to take care of her body and I told Helen how brave I thought she was and how much she had taught me this very night. I put the phone by her bed (in case she changed her mind!) And I left. When I returned in the morning, indeed she was dead. And I laughed at myself because I checked to see if she had disturbed her bedding that I had tucked in the night before and to see if she had struggled to get to the phone. She hadn't.

This exercise helps us to take a look at our own issues around death and dying. And how helping may not be help at all but only ways we try to comfort ourselves instead of the patient.

Providing spiritual support

- Establish caring presence
- Include others in care
- Non-judgmental listening
- Explore illness meaning
- Self education about spiritual practices
- Facilitate access to resources in community
- Encourage self-forgiveness

- Reframe self-esteem - changing body image, relationships
- Address guilt, shame:
  - HIV is a medical not moral problem
  - Sometimes bad things happen to good people
- Assist with end-of-life closure
- Facilitate hope, acceptance
- Facilitate spiritual practices

Association of Nurses in AIDS Care (2003)
ANAC's Core Curriculum for HIV/AIDS Nursing

Slide Note

The Association of Nurses in AIDS Care has compiled a list of interventions to address spiritual distress in patients with HIV/AIDS. A number of these are listed above and include some of the skills we have mentioned, as well as some others such as addressing guilt and shame by asserting that HIV is a medical, not a moral, problem.

Trainer Suggestion

Invite participants to review this list and reflect on the interventions that they commonly use and those that they less often use. Are there ones that they might disagree with?

Examples of spiritual and religious practices at end of life

- Rituals
  - Smudging (Native American)
  - Anointing (Catholic)
- Death-specific rituals
  - Washing the body (Islamic)
  - Body remains where death occurred for 3 days (Buddhist)
- Symbols, icons
  - Dream catcher (Native American)
  - Crucifix, rosary (Catholic)
  - Bible (Christian)

Slide Note

One of the interventions mentioned in the previous slide was facilitating spiritual and religious practices at end of life. In working with patients' spirituality, you may come in contact with various rituals that are practiced in different religions. There may be specific rituals which may or may not come in conflict with facility policies or codes. For example, a Native American smudging ceremony entails quite a bit of sage smoke. Some Buddhist traditions require the body not to be moved for 3 days. Islam has some restrictions as to the role of women when a man dies, or the role of a man when a woman dies, in addition to restrictions on the transportation of the body. For some patients, after-death care can be very important, and they may need to feel comfort in knowing that their wishes for after-death care are understood and will be accommodated.

Trainer Suggestion

You may wish to use the trigger tape segment, "Spirituality and Control Over the Dying Process" at this point. See "Resources for Trainers" for information on the use of these tapes.

Spiritual experiences are possible at the very end of life

- Patients may "see" things, people in the room, or say things that seem confused
- There may be important things that are being communicated:
  - Make gentle inquiries, open-ended questions:
    - What is happening? Can you tell me about it?
  - Consider the meaning or possible metaphor of these. They may express patient needs that you can address.

Callanan, M. and Kelley, P. (1997) Final Gifts

Slide Note

At times, patients who are dying may say that they see things or people in the room, or may speak of things that seem confusing or strange.

The suggestions here are gathered from a useful resource called "Final Gifts," a book examining the special awareness, needs, and communications of people who are dying. The authors suggest that the visions and communications from dying people may reflect important experiences that they are having. When we are open to understanding these, we may be better able to support the patient in meeting their needs.

Trainer Suggestion

This is a good point for a facilitator and/or participants to offer a story involving this kind of experience.. You may want to use the trigger tape accompanying these materials entitled, "Respecting the spiritual experiences of dying patients," which includes an interesting anecdote related to this subject. Instructional guidelines for use of this trigger tape can be found in the "Trainer Resources" section of this curriculum.

Summary

- Addressing spirituality is an essential component of palliative care
- Be aware of sources of spiritual distress, both general and specific to patients with HIV/AIDS
- Be aware of our own issues in approaching our patients' spirituality
- Listen non-judgmentally, use "FICA" or other approach to assessment
- Facilitate meeting patients' spiritual needs

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Skill Building & Interactive Exercises

- Elements of a Good Death Exercise
- Discussion Scenarios – Helping Patients to Have a Good Death
- Discussion Exercise – Psychiatric Issues, Case #1: Depression
- Discussion Exercise – Psychiatric Issues, Case #2: Delirium
- Personal Awareness Exercise – Spiritual Issues

Elements of a Good Death Exercise

Type of Activity: Discussion
Time: 30 minutes
Materials: Paper
Pens or pencils
Purpose: To provide participants with the opportunity to consider what constitutes a good death. To consider their own potential role in helping patients to achieve a good death.

Instructions: Divide the class into pairs or into groups of three or four. Have the participants share examples with each other of good and bad deaths they have witnessed. From that sharing, have participants list the things that made a death good or bad. As a large group, come together and make a list of all the elements that constitute a good death. Some other questions for discussion might be:

1. From whose perspective is each element considered part of a good death– from the patient's perspective, the loved one's perspective, or the clinician's perspective?
2. Are the elements of a good death always the same whether you are the patient, the family member, and the clinician? Where might there be differences?
3. How would a clinician consider and balance the differing needs or goals of each part of this good death triad?

After this list is made, divide again into the same groups, and have participants discuss what they see as **their role** in helping patients to have a good death. Use the elements of a good death list generated above, or the six components of a good death from the PowerPoint presentation to focus the discussion. Bring the groups back together for a larger discussion. Answers will vary by type of clinician and can generate more discussion about multidisciplinary teams and role.

Discussion Scenarios – Helping Patients to Have a Good Death

Type of Activity: Discussion
Time: 45-60 minutes
Materials: Case scenarios
Purpose: To give participants an opportunity to evaluate a case and describe solutions based on the elements of a good death discussed in the presentation.

Instructions:
Have the participants divide into small groups of 3-4 people each. Give each group a different case to discuss. Allow 15 minutes for the groups to read and discuss their cases. Come back together in the larger group and have each group report briefly on the case and how they handled it.

Case Scenarios:
1. Your patient is a young woman dying of HIV/AIDS. She is experiencing internal bleeding and is comatose. The patient seems to be in obvious pain to the team. You approach the patient's mother who is the patient's surrogate decision-maker to discuss increasing the patient's pain medications. The patient's mother refuses, stating that the patient is in recovery from substance abuse. She also says that the staff should talk to the patient when she wakes up. She seems unaware of or unwilling to accept the patient's terminal status. How will you approach the patient's mother?

2. Your patient has brain lesions of unknown etiology and is comatose. He appears to be in considerable pain and in your opinion is actively dying. The attending physician feels that he needs a further neurological work-up and thus cannot increase the patient's pain medication as this will cloud the diagnosis. What is your approach?

3. Your patient is an IV drug user who is dying of cancer. The patient has abused pain medications in the past, getting multiple prescriptions from different providers and using different pharmacies. Every visit with the patient brings increasing demands for more pain medication. The patient has been progressively weaker and is homebound. He has a very limited prognosis (<2 months). How will you manage his pain?

4. There is disagreement on your team about the status of your patient and your approach to treating him. Some members feel that further treatment is futile and want to offer comfort measures. Others feel that aggressive measures are still warranted. The patient and family want to meet with the team to discuss care options. How will you approach the patient and her family? How will you manage the conflicting view of the care team?

5. Your patient is being discharged from the hospital and going home to die. He is to be cared for by his family. How can you help both the patient and his family to prepare for what is ahead of them?

6. Your patient has been clear about dying at home and wants no more intervention, just comfort measures. She is hours to days from death. The family is alarmed by her breathing and calls you for advice. They want to call 911. What do you say?

7. You go to visit your patient in the inpatient hospice unit. He is tearful; full of regrets about being estranged from his family; going over and over all the mistakes he has made in his life. He is also questioning

the present purpose of his life. “I feel so useless now. I am not contributing anything to the world.” What do you do?

Discussion Exercise – Psychiatric Issues Case #1: Depression

Type of Activity: Discussion
Time: 30 minutes
Materials: Case scenario
Purpose: To give participants an opportunity to think through and practice diagnosis and treatment of a common psychiatric condition in HIV/AIDS palliative care

Instructions:
Have the participants divide into small groups of 3-4 people each. Give each group the case (without the answers) to discuss. Allow 5 minutes for the groups to read and discuss each part of the case. After each section, lead the small groups in a brief discussion as a large group (in other words, they don't need to move seats!) about each section, just to make sure that everyone is on the right track.

Discussion Question for the Large Group:
Ask participants to share their experiences in working with patients that are similar to this. What did they learn from those experiences about diagnosing and treating depression in patients with life-threatening illness?

Case Scenario – Part 1

Gloria is a 38-year-old woman who has been living with AIDS for the last five years. During that time, she has not seemed to benefit from HAART, being unable to tolerate each of the treatment regimens prescribed by her doctor, and her health has declined steadily. She currently has 0 CD4 cells and a viral load of >100,000. She also has hepatitis C, for which she is receiving interferon treatment.

Today, at her routine clinic appointment, she appears sad and discouraged. What questions should you ask her?

Answer

- How would you describe your mood (spirits, etc.)?
- Are you able to enjoy things you usually like?

Participants may suggest other depression screening questions, and those should be acknowledged. However, they should include these in their lists. We want to establish depressed mood and/or anhedonia, s these are the criteria for diagnosing a clinical depression.

Case Scenario – Part 2

Gloria says she hasn't felt good for a long time. She is tired of fighting her illness and doesn't see much point in going on. She acknowledges feeling down and she says she hasn't enjoyed anything for several weeks.

What further information do you need from Gloria?

Answer

- Has she experienced recent changes in sleep, appetite, energy level, feeling of guilt?
- Is she feeling suicidal or is she pre-occupied with thoughts of death/dying?
- Do you observe psychomotor retardation or agitation (a decline or elevation of mental and motor functioning)?

You established a greater-than-two week history of anhedonia and at least some duration of depressed mood. Now you must establish the other symptoms of major depression and assess her safety/suicidality.

Case Scenario – Part 3

Gloria laughs quietly at the questions being asked of her, stating "I am dying…of course I am thinking about it." She is clear she would never do anything to take her own life, though, because this is against her beliefs.

Her sleep has been poor for many months and so has her appetite. Her energy level gets lower all of the time. She says "What do you mean? Why should I feel guilty?"

Based on your assessment, what would you recommend to Gloria?
Do you need other information from her before deciding what to do?

Answer

Treatment with antidepressants is indicated. You might also consider psychotherapy. If medications are to be used, it is helpful to know if a biological relative has benefited from or not benefited from a given medication. This can guide your choice of antidepressants to use. Given her history of poor tolerance to medications and her hepatitis C, it is important to choose a medication with few side effects and start a relatively low dose. While she does not appear acutely suicidal, it is important to establish her willingness to stay in contact with you (phone, check-in, return appointment within one week, etc.).

Discussion Exercise – Psychiatric Issues Case #2: Delirium

Type of Activity: Discussion
Time: 30 minutes
Materials: Case scenario
Purpose: To give participants an opportunity to think through and practice diagnosis and treatment of a common psychiatric condition in HIV/AIDS palliative care

Instructions:
Have the participants divide into small groups of 3-4 people each. Give each group the case to discuss. Allow 5 minutes for the groups to read and discuss each part of the case. After each section, lead the small groups in a brief discussion as a large group (in other words, they don't need to move seats!) about each section, just to make sure that everyone is on the right track.

Discussion Question for the Large Group:
Ask participants to share their experiences in working with patients that are similar to this. What did they learn from those experiences about diagnosing and treating delirium in patients with life-threatening illness?

Case Scenario – Part 1

Bob is a 45-year -old man living with AIDS who was admitted to the hospital today with a high fever, non-productive cough, and general malaise. According to his admission lab work, he is dehydrated. He is pleasant and cooperative during the admission process. Overnight, he frequently rings his call light. When the nursing staff goes to check on him, he cannot tell them why he called. He keeps saying in an agitated manner, "I need to go home." The nurses are able to calm him down and convince him he is sick and needs to be in the hospital, only to have him call again in 10-15 minutes.

What other information do you need to know about Bob? What questions would you ask?

Answer

- What is his baseline? Is this a change? Over what period of time did the change occur?
- Is there new onset of cognitive impairment or perceptual disturbances?

Based on the limited information provided above, you are trying to determine if Bob is demented (longer term change in mental status) or if he is delirious (acute/subacute change in mental status).

Case Scenario – Part 2

Bob is diagnosed with PCP and started on treatment, and he is given IV fluids. Because of his calling frequently, the nursing staff asks the doctor for an order for lorazepam prn to manage his agitation.

What do you think about the intervention so far?

Answer

Whether this is dementia or delirium, treatment with lorazepam is contraindicated. It will likely exacerbate his change in mental status, in creasing his confusion, agitation, and disorientation.

Case Scenario – Part 3

Bob received a total of 4 mg of lorazepam overnight. Upon waking in the morning, he is obviously agitated, trying to pull out his IV and stating, "I have to go home!" He cannot recall where he is or how he was admitted to the hospital. His fever has gone away. His lab tests this morning show that he is well hydrated. His partner comes to visit and is alarmed at the change in Bob, stating, "This isn't like him at all."

What is your assessment of Bob's condition? What treatment is appropriate at this time?

Answer

Delirium – an acute change in mental status in the setting of a medical condition (PCP, dehydration). Despite improvement in his medical status, the use of lorazepam likely exacerbated Bob's confusion.

The suspected underlying causes of the delirium are being addressed by treating the PCP and dehydration. Since most delirium results from multiple causes, it is prudent to look for other possible causes, e.g. medication effects.

He needs treatment with haloperidol po/IM/IV and reassurance/re-orientation. If his partner is available to stay with him, or if other people well known to him can visit, they can assist with providing reassurance/re-orientation.

Delirium symptoms can outlast the underlying etiology, i.e. even though his medical status is improving, the mental status changes may persist for hours or days (or in extreme cases, weeks). It may be necessary to continue treatment with the haldol until his mental status improves.

Awareness exercise – Spiritual issues
Our hopes and fears about death

Type of Activity: Awareness exercise
Time: 20-30 minutes
Materials: Instruction sheet
Purpose: To explore fears and desires about one's own death. This increased awareness will then help participants keep appropriate boundaries when working with clients who may go through aspects of participants' hoped-for and feared experiences.

Special instructions:

This exercise can be done without significant psychological distress if participants do not probe too deeply. Participants should be instructed to take care not to push themselves beyond an emotional level that is comfortable and feels safe.

Set-up:

Share with the group the purpose of this exercise: "This exercise is designed to assist us in becoming more aware of our hopes and fears related to our own death."

Step 1:

Have each person take about 5 – 7 minutes and describe what type of death they hope for. Be as specific as possible.

Some possible specific elements might be:

- How old you are
- Where your death would take place
- What people would and would not be present
- How much warning you would have
- How alert you would be
- What rituals might be done

Step 2:

Have each person take about 5 – 7 minutes and describe what type of death they most fear. Be as specific as possible.

Some possible specific elements might be:

- How old you are
- Where your death would take place
- What people would and would not be present
- How much warning you would have
- How alert you would be
- What rituals might be done

Step 3:

Debrief. Give participants time to share their feared elements, and then their hoped-for elements.

o Note that for some a hoped-for element might be a feared element for others.

o Note that having control might be a common theme for many.

Discuss an important purpose of this exercise: With the increased awareness of your hopes and fears related to your own death, you can more easily see where you might get hooked or lose your boundaries with a client. If a client is dying in a way that mirrors your hoped-for death, you may push to help them have that scenario. On the other hand, if a person chooses to have elements of your most feared death, you may have a difficult time honoring and supporting their wishes.

Sample Agendas

We've developed some sample agendas for teaching psychosocial issues in HIV/AIDS palliative care. 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*
Good Death Exercise	*10 minutes*
Having a Good Death PowerPoint	*25 minutes*
Discussion Scenarios	*15 minutes*
Wrap Up & Evaluation	*5 minutes*

►*If you have two hours…*

Introductions & Pre-Evaluation	*10 minutes*
Having a Good Death PowerPoint	*30 minutes*
Discussion Scenarios	*15 minutes*
Break	*10 minutes*
Psychiatric Issues PowerPoint	*25 minutes*
Case Discussion – Psychiatric Issues	*20 minutes*
Wrap Up & Evaluation	*10 minutes*

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

Evaluation Forms

We've developed some 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.

Helping Patients to Have a Good Death

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

Psychiatric Issues in HIV/AIDS Palliative Care

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

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

Helping Patients to Have a Good Death

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 with helping patients to have a good death, 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 comfort with helping patients to have a good death:

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

3. Please answer the following:

a. Research suggests that patients at the end of life place a high value on contributing to others. True ☐ False ☐

b. Talking about dying and death with patients can't cause any harm. True ☐ False ☐

c. Research suggests that to patients, the most important element of a good death is pain and symptom management. True ☐ False ☐

d. List 3 elements of a good death which are commonly valued by patients, families and care givers.

Correct Answers: 3a. True, 3b. False, 3c. True, 3d. Correct answers will depend on content discussed in the training session. Examples might include: "resolving conflicts" and "being pain free."

Helping Patients to Have a Good Death

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 easy-to-understand was the information 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 with helping patients to have a good death, 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 comfort with helping patients to have a good death:**

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

7. **Please answer the following:**

a. Research suggests that patients at the end of life place a high value on contributing to others. True ☐ False ☐

b. Talking about dying and death with patients can't cause any harm. True ☐ False ☐

c. Research suggests that to patients, the most important element of a good death is pain and symptom management. True ☐ False ☐

d. List 3 elements of a good death which are commonly valued by patients, families and caregivers.

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!**

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 Helping Patients to Have a Good Death, 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 helping patients to have a good death:
   (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)

3. 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!

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 with psychiatric issues in HIV/AIDS palliative care, 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 comfort with psychiatric issues in HIV/AIDS palliative care:

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

3. Please answer the following:

a. In a patient with delirium, there is a gradual decline in cognitive functioning, whereas in dementia the onset is sudden. True ☐ False ☐

b. Psychostimulants are a good choice of medication for depression only when a patient is in the last weeks or days of life. True ☐ False ☐

c. List 4 elements that help to differentiate grief from depression in a patient at the end of life.

d. List 3 ways to help patients grieve.

Correct Answers: 3a. False, 3b. True, 3c. Correct answers will depend on content discussed in the training session. Examples might include: "attitude toward the future" and "capacity for experiencing pleasure." 3d. Correct answers will depend on content discussed in the training session. Examples might include: "normalize grief response" and "enlist support system."

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 easy-to-understand was the information 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 with psychiatric issues in HIV/AIDS palliative care, 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 comfort with psychiatric issues in HIV/AIDS palliative care:

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

7. **Please answer the following:**

a. In a patient with delirium, there is a gradual decline in cognitive functioning, whereas in dementia the onset is sudden. True ☐ False ☐

b. Psychostimulants are a good choice of medication for depression only when a patient is in the last weeks or days of life. True ☐ False ☐

c. List 4 elements that help to differentiate grief from depression in a patient at the end of life.

d. List 3 ways to help patients grieve.

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: 3a. False, 3b. True, 3c. Correct answers will depend on content discussed in the training session. Examples might include: "attitude toward the future" and "capacity for experiencing pleasure." 3d. Correct answers will depend on content discussed in the training session. Examples might include: "normalize grief response" and "enlist support system."

Psychiatric Issues in HIV/AIDS Palliative 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 Psychiatric Issues in HIV/AIDS Palliative 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 psychiatric issues in HIV/AIDS palliative 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?
   (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

Helping Patients to Have a Good Death

Kagawa-Singer, M. & Blackhall, L. (2001). Negotiating cross-cultural issues at the end of life: "You got to go where he lives".

Pierson, C.M., Curtis, J.R., & Patrick, D.L. (2002). A good death: A qualitative study of patients with advanced AIDS. *AIDS Care* 14(5): 587-98.

Steinhauser, K., Clipp, E., McNeilly, M., Christakis, N., McIntyre, L., & Tulsky, J. (2000). In search of a good death: Observations of patients, families and providers. *Ann Intern Med* 132: 825-32.

Psychiatric Issues in HIV/AIDS Palliative Care

Block, S. for the ACP-ASIM End-of-Life Consensus Panel (2000). Assessing and managing depression in the terminally ill patient. *Ann Intern Med* 132: 209-218.

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Lyketsos, C. & Treisman, G. (2001). Mood disorders in HIV infection. *Psychiatric Annals* 31(1): 45-9.

Resources

Psychiatric Issues in HIV/AIDS Palliative Care

Articles

Bigelow, G. & Hollinger, J. (1996). Grief and AIDS: Surviving catastrophic multiple loss. *Hospice Journal* 11(4): 83-96. PubMed Abstract.

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Byock, I. (1996). The nature of suffering and the nature of opportunity at the end of life. *Clin Ger Med* 12(2): 237-52. PubMed Abstract.

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Lyjetsos, C. & Treisman, G. (2001). Mood disorders in HIV infection. *Psychiatric Annals* 31(1): 45-9.

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Millan, F. & Caban, M. (1996). Issues in psychotherapy with HIV-infected Latinos in New York City. *J Social Distress Homeless* 5(1): 83-98.

Nord, D. (1996). Issues and implications in the counseling of survivors of multiple AIDS-related loss. *Death Studies* 20: 389-413. PubMed Abstract.

Sikkema KJ, Hansen NB, Kochman A, Tate DC and DiFranceisco W (2004). Outcomes from a randomized controlled trial of a group intervention for HIV positive men and women coping with AIDS-related loss and bereavement. *Death Studies* 28: 187-209. PubMed Abstract.

Sikkema, K., Kalichman, S., Hoffman, R., Koob, J., Kelly, J. & Heckman, T. (2000). Coping strategies and emotional well-being among HIV-infected men and women experiencing AIDS-related bereavement. *AIDS Care* 12(5): 613-624. PubMed Abstract.

Silver EJ, Bauman, LJ, Camacho S, and Hudis J (2003). Factors associated with psychological distress in urban mothers with late stage HIV/AIDS. *AIDS and Behavior* 7(4): 421-431.: Report of study of 220 low-income mothers with late-stage HIV/AIDS, examining risk factors for psychological distress. PubMed Abstract.

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Valente S (2003). Depression and HIV disease. *Journal of the Association of Nurses in AIDS Care* 14(2): 41-51. PubMed Abstract.

Books

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