

EPEEC for Veterans

Education in Palliative and End-of-life Care for Veterans

Trainer's Guide

Module 7

**Comprehensive
Whole Patient
Assessment**

Emanuel LL, Hauser JM, Bailey FA, Ferris FD, von Gunten CF, Von Roenn J, eds. EPEC for Veterans: Education in Palliative and End-of-life Care for Veterans. Chicago, IL, and Washington, DC, 2012..

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Module 7 trainer's notes

Principal message

To relieve a patient's suffering, the clinician will want to learn about the patient's physical, psychological, social, spiritual, practical, and loss/grief needs and expectations. A comprehensive history and physical examination provides that information and strengthens the patient-clinician relationship.

Module overview

Comprehensive end-of-life care aims to treat both the underlying disease process(es) and the experience of living with life-limiting illness. Veterans suffer as whole persons: persons with relationships to others, a past, and an anticipated future. Suffering can be the result of direct manifestations of the disease process, predicaments created by it, or the process or therapies used to provide care.

A comprehensive assessment sheds light on characteristics of the Veteran, any physical, psychological, social, spiritual, practical, end-of-life, or loss/grief issues that are a concern to the Veteran or family, and the critical steps in the process of providing care, including information sharing, decision-making, care planning and delivery, and confirmation of the quality of the care.

This broad assessment is manageable if the functional inquiry starts by using screening questions to highlight domains of issues that are of concern. Then, based on the answers, the clinician performs a more in-depth evaluation of specific issues. While it may initially seem to be an overwhelming task, a full evaluation can be completed over several encounters. All members of the palliative care team can assist with multiple components of the detailed assessment.

Comprehensive assessments not only start the therapeutic relationship; they recur through the course of the illness. The focus shifts depending on the illness stage, individual needs, and changing goals of care. Even a clinician who is familiar with a Veteran should expect to conduct periodic assessments of all domains of potential suffering from diagnosis until the end of the therapeutic relationship.

Preparing for a presentation

1. Assess the needs of your audience

Choose from the material provided in the syllabus according to the needs of your expected participants. It is better for participants to come away with a few new pieces of information, well learned, than to come away with a deluge of information, but remembering nothing.

2. Presentation timing

Allow sufficient time to have participants introduce themselves.

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Trigger tape & discussion	5-7 minutes
Presentation	40 minutes
<u>Summary</u>	<u>2-3 minutes</u>
Total	49-53 minutes

3. Number of slides: 27

4. Preparing your presentation

The text in the syllabus was not designed to be used as a prepared speech. Instead, the slides have been designed to trigger your presentation. Although the slides closely follow the text of the syllabus, they do not contain all of the content. Their use presumes that you have mastered the content. You may want to make notes on the slide summary pages to help you prepare your talk in more detail and provide you with notes to follow during your presentation.

Practice your presentation using the slides you have chosen, and speaking to yourself in the kind of language you expect to use, until it is smooth and interesting and takes the right amount of time.

5. Preparing a handout for participants

The syllabus text and slides in the **Trainer's Guide** were designed to be reproduced and provided to participants as a handout, either in its entirety, or module by module. If the entire curriculum is not being offered, please include the following in each handout:

- **EPEC for Veterans Front Cover Page**
- **EPEC for Veterans Acknowledgment Pages** (to acknowledge the source of the material)
- Syllabus and slides for **Module 7**
- Additionally, you may wish to provide copies of the **Brief Pain Inventory** and the **Memorial Symptom Assessment Scale** which are included in the Appendix to Module 7.

6. Equipment needs

- computer with DVD capability or separate DVD player
- flipchart and markers for recording discussion points

Making the presentation

1. Introduce yourself

If you have not already done so, introduce yourself. Include your name, title, and the organization(s) you work for. Briefly describe your clinical experience related to the information you will be presenting.

2. Introduce the topic

Show the title slide for the module. To establish the context for the session, make a few broad statements about the importance of whole patient assessment as a clinical skill. Tell participants the format and time you will take to present the session. Identify any teaching styles other than lecture that you intend to use.

3. Review the session objectives

Show the slide with the session objectives listed. Read each objective and indicate those that you are planning to emphasize.

4. Show the trigger tape or present the clinical case

After reviewing the objectives for the session, show the trigger tape or present the clinical case below. It has been designed to engage the audience and provide an appropriate clinical context for the session. It was not designed to demonstrate an ideal interaction, but to ‘trigger’ discussion.

Clinical case

K.M is a 54-year-old woman who is Veteran of Desert Storm/Shield. While in Iraq, K.M. had a chest x-ray ordered due to a relatively minor shrapnel injury from an improvised explosive device (IED). The chest x-ray results were abnormal and eventually led to a diagnosis of adenocarcinoma of unknown origin. The lesion was initially found in her lung and excised as a suspected primary tumor, but then presented in her axillary nodes, behaving more like breast cancer. After separation from the army due to her medical condition, K.M. has scheduled an appointment at VAMC to establish a new primary care provider near her new home. A medical student greets her and asks to carry out a comprehensive assessment prior to the attending physician’s arrival.

An additional case can be found in the accompanying trigger tape.

Discussion

If the discussion is slow to start, you may want to ask more direct questions, like:

- Have they had similar patients?
- How did the patient react to the clinician's questions?
- How did the clinician start? What was well done? What was missing?
- What did the clinician do to foster a comfortable atmosphere?
- How did the physician address the patient's concerns?

Use the discussion to set the stage for the material to follow. Don't let the discussion focus on a critique of the technical quality of the trigger tape or how 'real' the players seemed. If the participants don't like something that was said or done in the trigger tape, ask them how they would do it themselves.

Setting limits to discussion time

Limit discussion of each scene of the trigger tape to no more than 5 minutes, then move on to the presentation. To help move on if the discussion is very engaged, try saying something like:

- Let's hear two last points before we move on.
- Now that you have raised many of the tough questions, let's see how many practical answers we can find.

5. Present the material

Recommended style: Interactive lecture

An interactive lecture will permit you to engage your audience, yet cover the material within 45 to 60 minutes. First, provide an overview of the domains and elements of a comprehensive assessment. Then, use the case of K.M. to illustrate each of elements and how they tie together in the process to both provide the information to guide care and strengthen the clinician-patient relationship.

Alternative style 1: Case-based

If you have mastered the material and the method, a case-based approach to teaching this module can be very effective. Start by presenting an overview of the domains and elements of a comprehensive 'whole patient' assessment and why it is important in end-of-life care.

Then, use and expand on the case of K.M. to discuss the assessment of each of the elements with each assessment domain. Use a flipchart or overhead projector to capture

the major discussion points. Use the discussion to interweave the key take-home points from the syllabus.

Alternative style 2: Role-play

If you feel comfortable directing a role-play exercise and leading the subsequent discussion, this technique can be a valuable way to illustrate to participants the complexity, yet importance, of a comprehensive ‘whole-patient’ assessment.

Start the session by summarizing the overall approach and goals of a ‘whole-patient’ assessment either by using a few slides or by listing the main issues on a flipchart or overhead projector.

Then, introduce the role-play exercise. Develop your own scenario for the small groups to use, or use the one from the trigger tape. Ensure that all participants are clear about the nature and stage of the patient’s cancer.

Ask participants to divide into clinician, patient, and observer groups. One way to do this is to ask them to ‘count off’ from 1 to 3. Then, tell the ‘1s’ they are clinicians, ‘2s’ they are patients, and ‘3s’ they are observers.

Ask the clinicians to take 10 to 15 minutes to conduct an organized assessment that covers several of the elements in at least 5 of the domains. More time may be needed if participants are relatively unskilled in general assessment technique.

After 10 to 15 minutes, stop the assessment and invite the small groups to discuss their experience. Ask the patient to comment on the questions and how they made him or her feel. Ask the clinician to comment on the substance of the answers and on his or her feelings. Ask the observer to comment on the substance and the nature of the interaction.

After the small group discussion, lead the larger group in a discussion of the results. Ask for feedback first from the clinicians, then from the patients, then from the observers. Use the flipchart or overhead projector to capture the important discussion points. Use the discussion to interweave the key take-home points from the syllabus.

6. Key take-home points

1. Veterans’ suffering has a context; consider Veterans and families together.
2. Bodies do not suffer, only persons do. Personhood means having a past, present, and future. Facing a life-threatening illness challenges and often redefines usual sources of meaning. Loss of meaning is a form of suffering.
3. Conceptual frameworks, approaches for investigating and understanding suffering, and approaches for intervention to relieve suffering have been neglected in the training of physicians.
4. Whenever possible, quantify the severity of an issue.

5. Minimize the burden of laboratory and radiological investigations. Only order tests when the results will have a specific use or add to well-being.

7. Summarize the discussion

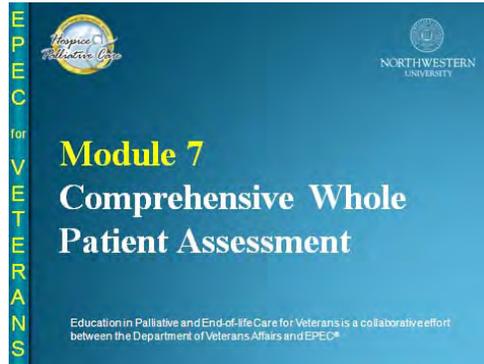
Briefly review each part of the presentation. Recap 2 or 3 of the most important points that were discussed.

8. Post-test/evaluation

Ask the participants to evaluate the session.

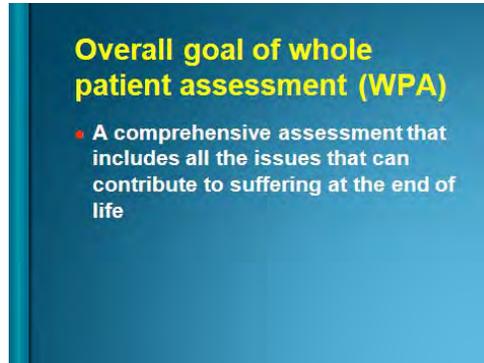
Abstract

Slide 1



Palliative care aims to treat both the underlying disease process(es) and the experience of living with life-limiting illness. Veterans suffer as whole persons: persons with relationships to others, a past, and an anticipated future. Suffering can be the result of direct manifestations of the disease process, predicaments created by it, or the therapies used to provide care. A comprehensive assessment sheds light on characteristics of the Veteran; any physical, psychological, social, spiritual, practical, end-of-life, or loss/grief issues that are a concern to the Veteran or family; and the critical steps in the process of providing care including information sharing, decision-making, care planning and delivery.

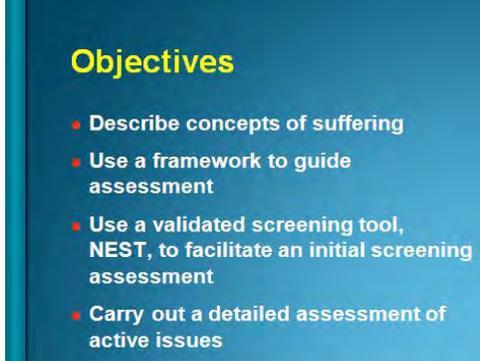
Slide 2



This broad assessment is manageable if the functional inquiry starts by using screening questions to highlight domains of issues that are of concern. Then, based on the answers, the clinician performs a more in-depth evaluation of specific issues. While it may initially seem to be an overwhelming task, a full evaluation can be completed over several encounters. All members of the palliative care team can assist with multiple components of the detailed assessment. Even a clinician who is familiar with a Veteran should expect to conduct periodic assessments of all domains of potential suffering from diagnosis until the end of the therapeutic relationship.

Objectives

Slide 3



Objectives

- Describe concepts of suffering
- Use a framework to guide assessment
- Use a validated screening tool, NEST, to facilitate an initial screening assessment
- Carry out a detailed assessment of active issues

After studying this module, clinicians will be able to:

- describe concepts of suffering;
- describe a framework to guide assessment of the multiple issues that frequently cause Veterans and families suffering;
- use a validated screening tool to facilitate an initial assessment; and
- carry out a detailed assessment of active issues.

Clinical case

Slide 4



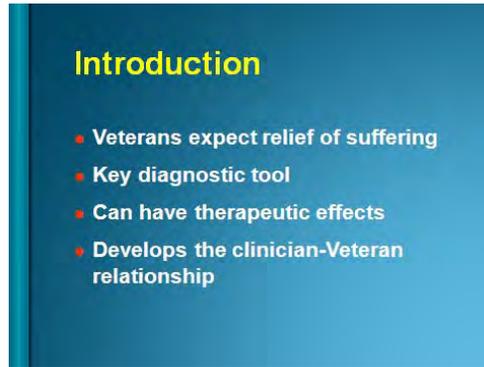
Clinical case

K.M is a 54-year-old woman who is Veteran of Desert Storm/Shield. While in Iraq, K.M. had a chest x-ray ordered due to a relatively minor shrapnel injury from an improvised explosive device (IED). The chest x-ray results were abnormal and eventually led to a diagnosis of adenocarcinoma of unknown origin. The lesion was initially found in her lung and excised as a suspected primary tumor, but then presented in her axillary nodes, behaving more like breast cancer. After separation from the army due to her medical condition, K.M. has scheduled an appointment at VAMC to establish a new primary care provider near her new home. A medical student greets her and asks to carry out a comprehensive assessment prior to the attending physician's arrival.

An additional case can be found in the accompanying trigger video.

Introduction

Slide 5



Introduction

- Veterans expect relief of suffering
- Key diagnostic tool
- Can have therapeutic effects
- Develops the clinician-Veteran relationship

Slide 6



The clinician's role

- Listen
- Acknowledge
- Analyze
- Offer information, practical suggestions
- Introduce sources of support

Assessment, *the process of evaluating a specific issue to gather data*, is a core skill of all clinicians. Comprehensive palliative care includes disease management as well as a thorough assessment of the multiple issues that impact Veterans and their families. In particular, the comprehensive assessment can highlight areas of current and potential suffering for the Veteran.

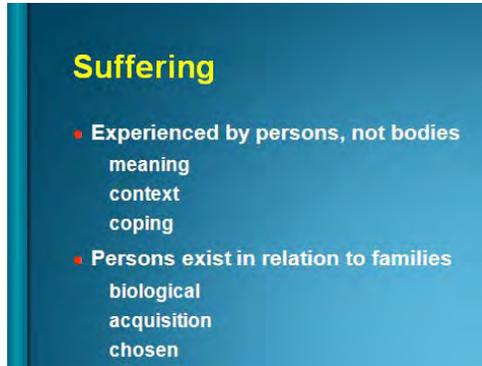
The successful integration of information gathered by several different team members takes effort and coordination. Interdisciplinary team conferences provide an opportunity to synthesize the data that has been collected, discuss possible therapies and plan the process to facilitate decision-making with the Veteran and family. At the same time, individual clinicians are key in providing assessments of different aspects of patients and families.

Besides providing information, each episode of assessment offers an opportunity for discussion with the Veteran, proxy, and/or family about the context of the Veteran's disease, prognosis, the multiple issues that may be causing suffering, and the process of providing care. It is a time to emphasize the need for advance planning and personal preparation, particularly when the clinician anticipates that the Veteran may experience physical and cognitive decline in the not-too-distant future. By offering information and practical advice, introducing sources of support, attending to details and providing enough time 'to be heard,' the clinician, Veteran and family have the chance to build trust and a therapeutic relationship.

This module focuses on the essential elements of assessment for each major dimension of the Veteran’s experience with their illness and the health care system.

Concepts of suffering

Slide 7



Suffering

- Experienced by persons, not bodies
 - meaning
 - context
 - coping
- Persons exist in relation to families
 - biological
 - acquisition
 - chosen

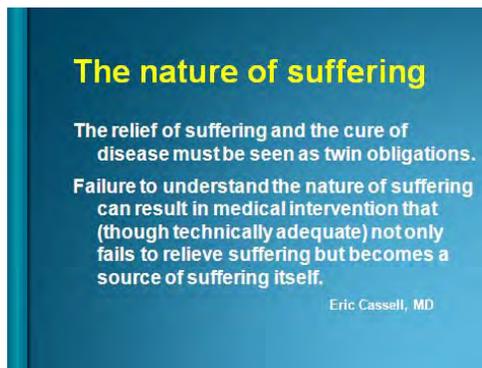
Slide 8



Concepts of suffering

- Fragmentation of personhood – Cassell
- Broken stories – Brody
- Challenge to meaning – Byock
- Total pain – Saunders
- Relational distress- Ferrell and Coyle

Slide 9



The nature of suffering

The relief of suffering and the cure of disease must be seen as twin obligations.

Failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

Eric Cassell, MD

What does it mean to suffer? Every one of us will have a very personal sense of what brings meaning and value to our lives. We will also have a very personal sense of what causes suffering.

In an attempt to understand suffering in a way that would permit further study and understanding and inform clinical care, Eric Cassell outlined a conceptual framework for suffering.¹ He pointed out that “bodies do not suffer, only persons do.” Persons are unique and do not experience a disease in the same way. Persons suffer when their personhood is threatened. Elements of what it means to be a person include having a past, a present, an anticipated future, a private life, a role, and a transcendent dimension.

Howard Brody has built on the concept that personhood requires a past, present, and future by noting that human lives are, in a sense, stories.² Our story is our sense of self, and as we face a life-limiting illness, our story takes an unexpected turn. In this conceptual framework, our story transforms into our legacy. Often, when the Veteran comes to a clinician, the emotional subtext of the Veteran’s complaint can be heard as, “Doctor, my story is broken. Can you fix it?” Much suffering by Veterans facing the end of life can be understood in this perspective. The Veteran’s private life is challenged by unanticipated and unwelcome transitions and practical needs. The transcendent dimension may take on a new meaning, play a more active role in decision making, or become a source for coping or additional distress in significant life changes.

Facing a life-threatening illness may challenge or threaten our usual sources of meaning. The loss of purpose, the threat to role and social function, and the impairment of leisure and enjoyment may all contribute to suffering. The sense of self, life significance and thus meaning usually must be redefined when a serious illness intervenes. The clinician can gain insight by considering the activities and things that give personal meaning and value in life, and reflecting on how the prospect of a life-limiting illness might impact those. Ira Byock, using a Jungian theoretical model, has described opportunity and the possibility of growth as a person in response to suffering.³

While the experience of illness and suffering may be unique to each individual, the domains of suffering may be more generalizable. In listening to patients describe their needs and expectations for care Cicely Saunders, founder of the modern hospice movement, conceptualized suffering as having four elements. She termed it ‘total pain’ and identified the elements of physical, psychological (emotional), social (including practical), and spiritual pain.⁴

In *The Nature of Suffering and the Goals of Nursing*, Betty Ferrell and Nessa Coyle describe some of the relational aspects of suffering for nurses caring for dying patients and some of the moral distress they feel when they are unable to relieve suffering. They also describe the importance of presence - for patients, families and each other - in the presence of suffering.⁵

The broad perspective

Slide 10



The broad perspective

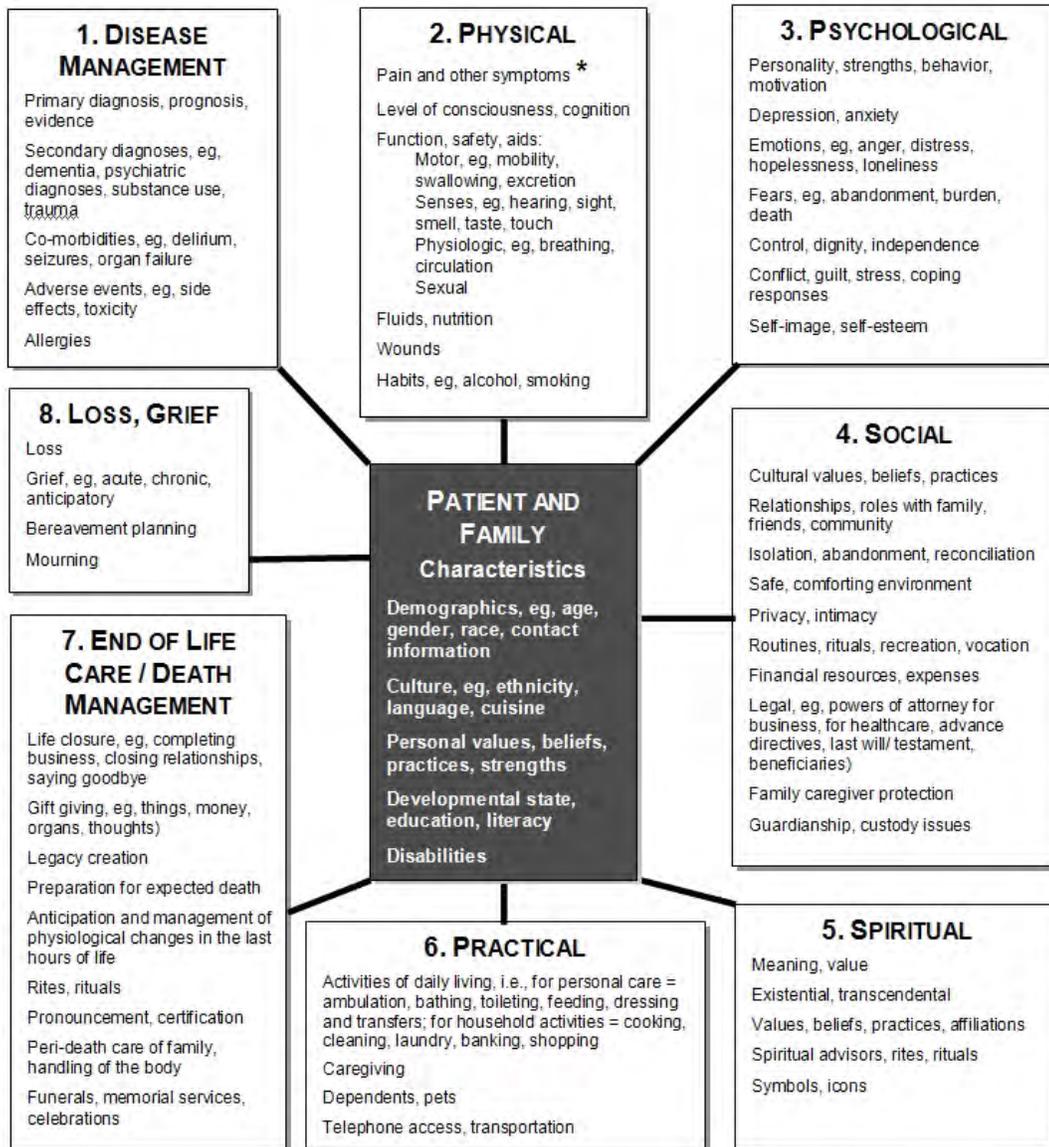
- Depression affects experience of pain
- Medication useless if can't get it
- Spiritual strength may enhance tolerance
- Feeling abandoned may be expressed as physical suffering
- Nonadherence to care plans, missing appointments, or becoming angry in interactions with health care personnel

As clinicians, it is important to have a comprehensive framework from which to work if we are to relieve suffering and enhance quality of life. We are often vulnerable to being very narrowly focused on a specific symptom or finding. For example, a narrow focus on physical pain might miss the Veteran who is depressed, who cannot afford pain medications, or is afraid that the pain means that she is going to become addicted or, even more frighteningly, to die. All of these aspects of the human experience will influence the experience of pain.

Similarly, a Veteran whose spiritual foundation is challenged may be more likely to complain about physical symptoms. Failure to address the spiritual dimension in a Veteran who is spiritually distressed may miss how such turmoil will impact or distort the physical dimension. As another example, a Veteran who feels abandoned by family, community, or medical professionals may express his or her suffering by emphasizing a physical complaint, or by giving up hope. Giving up hope may manifest in being nonadherence to care plans, missing appointments, or becoming angry in interactions with health care personnel. These behaviors can be responded to only at face value and their deeper meaning or portent may be lost and not fully addressed.

Assessment overview

Based on these concepts of suffering, it is helpful to have a framework that is rooted in the experience of the Veteran's and family's experience of illness. There are a number of conceptual frameworks that have been offered for whole patient care and assessment.^{6,7,8,9} One example is the expansion of Dame Saunder's total pain depiction referred to as "the square of care."¹⁰



* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

Slide 11

Assessment overview ...

- Summarize patient illness / treatment history
- Physical assessment
- Psychological assessment
decision-making capacity

Slide 12

... Assessment overview

- Communication assessment
- Social assessment
- Spiritual assessment
- Practical assessment

Comprehensive assessment starts with the taking of a good history. Begin with a summary of the Veteran’s illness and treatment. Continue with an assessment of physical symptoms, then psychological matters. This strategy provides a convenient transition into assessing decision-making capacity. From there, assess the Veteran’s preferences for information sharing and decision making. The social and cultural aspects of the illness experience can then be readily assessed. Assessment of the spiritual aspects follows. Finally, the practical aspects of support and care services are important to assess, as are the Veteran’s and the family’s anticipatory planning for increasing care needs and preferences around death.

This is one example of logical order of assessment. A key skill for clinicians is to be flexible about the order in which these domains are assessed. A Veteran, for example, may have intense pain during a visit which will preclude assessment in some of the other areas at that point. On the other hand, a Veteran may have minimal physical symptoms and may have a heightened need to talk about some of his or her spiritual needs at another point in the illness.

In the sections below, each of these assessment areas is described. The key lesson is that while comprehensive assessment might take place in one patient encounter, it may also take place over multiple encounters. Care needs to be taken in prioritizing each area of the comprehensive assessment and should generally be based on the acuity of the need. Care also needs to be taken in coordinating among team members: some team members will naturally feel more comfortable and have greater expertise with certain parts of the assessment. This is natural and should be welcomed and then carefully coordinated.

Illness/treatment summary

Slide 13



Illness/treatment summary

- Histories can be complex
- Make sure you are satisfied with previous treatment

The older Veteran in palliative care will likely have a long medical history with multiple interventions. The illness effects and the treatment's adverse effects often combine to create a complex history. In addition, there are often other concurrent illnesses and comorbidities.

Consider whether you are satisfied that the previous treatments were appropriate based on their known effectiveness and the preferences of the patient. For example, an assessment of a Veteran referred for hospice care may reveal that an appropriate curative treatment has not been thoroughly considered or discussed. Such a treatment should be presented to the Veteran or proxy prior to enrollment in the hospice program. It may be that efforts to control the underlying disease are appropriate even in advanced stages of illness.

Physical assessment

Slide 14



Physical assessment

- Common symptoms in advanced disease:
pain, weakness / fatigue, dyspnea, insomnia, weight loss, confusion, constipation, anxiety, nausea / vomiting, and depression
- Inquire about each severity
functionality

Physical assessment of a Veteran in palliative care is best organized by symptoms and functional activities rather than by organ system or anatomy. After symptoms and physical impairments are assessed, a physical examination can be conducted. A physical examination confirms findings from the history and provides baseline clinical information. It also establishes a relationship that includes therapeutic touch.

Occasionally, it may be helpful to conduct diagnostic tests. However, the results should be anticipated to clearly contribute to the therapeutic plan. Before ordering a test (whether relatively noninvasive, such as a hemoglobin or more invasive, such as a

biopsy), consider with the Veteran and his or her family how you will intervene or not intervene based on test results and how the test results help facilitate the goals of care. The consideration of ordering of a test of any sort gives clinicians an additional opportunity to discuss goals and preferences with the Veteran and family.

At times, the value of a test may be in the knowledge of disease progression (or stability) that it gives, even when no other therapeutic intervention is planned. Many times, the functional and cognitive changes that are occurring communicate the disease progression very clearly. Because there is a burden associated with some diagnostic tests and their results, keep these to a minimum if comfort is the primary goal.

Common symptoms

It is common for patients to experience multiple symptoms in advanced disease and during the last phase of life.¹¹ The most common symptoms are pain, weakness / fatigue, dyspnea, insomnia, weight loss, confusion, constipation, anxiety, nausea / vomiting, and depression. Many of these will not be reported spontaneously by Veterans and so it is important to inquire specifically about each one.

For every symptom, multiple potential causes should be considered. The symptom may be related to the primary illness, other illnesses, or the effects of medications. Further information about many common physical symptoms is in EPEC for Veterans Modules 6a-6c.

Pain as a model for symptom assessment

The assessment of pain is a model for other physical symptoms that Veterans may experience. In addition, it often serves as a natural point of entry into other aspects of whole patient assessment. Pain is highly prevalent and often undertreated.^{12,13} Once assessed, most physical pain can be controlled. The assessment of pain may be a gateway to the assessment of other physical symptoms as well as the psychological, social, and spiritual dimensions of illness. It may be easier to begin assessment by discussing physical symptoms which are often more accessible to a Veteran. In addition, in order to discuss some of the more social and spiritual dimensions of assessment, a Veteran needs to have pain relief first.

Because symptoms are inherently subjective, self-reporting is the gold standard for assessment. There is no reliable way to assess what the patient is experiencing other than by asking. Family members need to be asked as well but they may not always recognize all of the symptoms that Veterans experience. The cardinal aspects of symptom assessment are listed below with questions that are likely to elicit the desired information.

Location

- “Where does it hurt most? Does it go anywhere?”
- “How does your pain change over time?”

- “How long have you had this pain?”
- “Did it begin gradually or all of a sudden?”
- “Does it come and go, or do you have it all the time?”

Quality

- “What words might you use to describe the pain?”

Sometimes after asking this open-ended question, it can help to add examples such as throbbing, cramping, burning, and tingling.

Severity

- “How bad is it on average? At its worst? Is it getting worse or remaining stable?”

Modifying factors

- “Does it feel better when you’re in a certain position?”
- “Do you notice any change with [various activities]?”

Impact on function

- “To what extent does the pain interfere with your normal activities?”
- “What about your sleep?”
- “Your ability to walk?”
- “Your relationships with others?”

Effect of treatments

- “What have you been doing for the pain?”
- “Have you taken any medications?”
- “How much relief does that provide?”
- “Are there any non-medical things that you have been doing that help the pain?”

Patient perspectives and explanatory model

- “What do you think is causing the pain?”
- “What do you think the pain means?”

Two specific aspects of assessment, severity and function, deserve further discussion.

Severity

Despite pain's being subjective, Veterans often can accurately and reproducibly indicate the severity of their pain by using a scale. Scales for pain have been well validated as tools.^{14,15,16} They enhance the ability of the patient to communicate severity to health care professionals and enhance communication of severity between professionals. Numerical scales (0–10), visual analog scales, and faces scales (showing a sequence of faces in a row from happy to intermediate to sad; see Appendix) are all in use. The specific scale used is less important than using one in a consistent way over time. Some patients have trouble with the concept of rating pain on a numerical or visual analog scale. For those patients, asking whether pain or other symptoms are “mild, moderate or severe” can be helpful.

Function

It is important to assess functional impact of pain. Questions might include:

- “What does the pain prevent you from doing?”
- “What have you had to give up or change your way of doing because of pain?”
- “How are the physical aspects of relationships including sexual function?”

Observationally, the function can be assessed by considering the following:

- Can the Veteran move around with ease?
- Can the Veteran see or hear well enough?
- Is he or she safe from falls and other environmental risks?
- Can the Veteran complete activities of daily living? If so, at what level?

Psychological assessment

Slide 15

Psychological assessment

- Anxiety and depression are common and under diagnosed
- Let know emotional responses normal
- Discuss patient fears, unresolved issues, and goals of care
- Determine patient capacity

Ask screening questions about cognition—are there times of confusion, hallucination? Ask about mood—anxiety, sadness. These questions can be asked simply and straightforwardly:

- “How is your mood?”

- “Do you have periods of sadness?”

Depression and anxiety are among the most prevalent and underdiagnosed symptoms in patients facing the end of life (see EPEC for Veterans Module 5: Psychological Symptoms).

Among the most important psychological issues are the meaning of the illness, emotional state, and the existence of unresolved issues. The clinician will want to assess the individual and determine whether the Veteran is coping adequately or whether referral should be recommended. Always ask screening questions about suicidal ideation such as “have you ever thought of harming yourself? Or “have you ever thought about ending your life?” As a routine question among others, or indeed as an explicit and exploratory discussion, there is no evidence that it fosters thoughts of self-harm and is more likely to lessen the risk. Such conversations set the groundwork for later discussions if they are needed.

Emotional responses to illness

There is always an emotional response to serious illness; it challenges a person’s sense of themselves and their role in life. Ask about how the Veteran is responding to being ill. This can be done by asking simply: “What has it been like to live with this illness?” Consider naming some common responses, such as anger, grief, and tranquility. Some people move through stages of shock and struggle, and eventually reach resolution. Most people move between a range of emotions and typically not in a predictable order. Emotions come in surprising waves and/or can be persistent. It helps to give the Veteran a sense that this is normal. It frequently helps the Veteran if the clinician identifies the emotion, acknowledges it in an accepting way, and thereby normalizes it. Examples of questions that can be asked to explore the Veteran’s emotional response include:

- “In what ways has this illness affected you emotionally?”
- “Are you doing things that you enjoy?”
- “How has your mood been lately?”
- “How have you been coping with all of this?”
- “How have you handled stress in your life?”

Fears

Almost all patients have fears for the future as they face the end of life. Fears may be over the loss of control, increased dependency, loss of dignity, loss of relationships, and physical suffering. Fears for family members may be as important for patients as fears of physical symptoms. In tailoring a therapeutic relationship and a plan of care, it is critical to know what anticipatory anxieties the Veteran experiences.

“Are you concerned about being a burden to others? Do you feel in control of your life right now?”

Unresolved issues

Unresolved issues may be a prominent part of the experience of Veterans at the end of life. You may discover that what stands between the patient and a comfortable frame of mind is an unresolved issue or issues. Whether these issues have to do with settling old feuds, making or receiving last visits, or completing a lifetime project or piece of work, creating a plan of care that allows for and honors these tasks is important. Clearly, some tasks will physically be possible while others will be difficult to achieve.

These issues are rarely apparent to a clinician unless questions directed to this area are asked. Examples include:

- “Is there something that you would like to do before you get too sick?”
- “Many people have old differences they would like to settle before they die. Is there anyone you want to be able to communicate with before you die?”
- “Many people have places or people they would like to visit. Do you?”
- “Some have a piece of work they would like to finish. Do you?”

Decision-making capacity

Slide 16

Decision-making capacity ...

- Implies the ability to understand and make own decision
- Patient must
 - understand information
 - use the information rationally
 - appreciate the consequences
 - come to reasonable decision for him/her

Slide 17

... Decision-making capacity

- Any physician and some other clinicians can determine
- Capacity varies by decision
- Other cognitive abilities do not need to be intact

Decision-making capacity implies the ability to understand and make medical decisions for oneself. It can usually be determined by physician and selected other clinicians and does not routinely require a psychiatrist or a court ruling. For a Veteran to have decision-making capacity, he or she must be able to:^{17,18}

- understand the information;
- use it in rational ways to come to a decision;
- appreciate the consequences of the decision; and
- have that be a reasonable decision for him or her.

For example, consider a Veteran who refuses an amputation of a leg for treatment of osteosarcoma. A clinician needs to demonstrate that she understands the information about the condition and the options for care, that she could die if her leg is not amputated, and that this is a rational decision for her. The Veteran can meet criteria for decision-making capacity for a particular treatment, i.e., decision-specific capacity, and yet not be competent to handle her practical, financial, and legal affairs.

When a Veteran lacks capacity

Slide 18

When a Veteran lacks capacity

- Proxy decision maker
- Sources of information
 - written advance directives
 - Veteran's verbal statements
 - Veteran's general values and beliefs
 - how patient lived his / her life
 - best interest determinations

When Veterans lack the capacity to express their own values and preferences for medical care, treatment decisions must be determined by others. For Veterans who lack decision-making capacity, find a proxy decision maker to help clarify the Veteran's goals and consent to specific care plans.

Generally, the appropriate proxy is a person selected in advance for this role by the Veteran (see EPEC for Veterans Module 2: Advance Care Planning), or a person who has knowledge of the Veteran's values and preferences and is willing and able to serve in this capacity. When the patient has not preselected a proxy decision-maker, this usually falls to the next of kin. Legal criteria for proxy selection vary from state to state.

Guide the proxy/decision-maker to understand his or her role in determining what the Veteran would have wanted based on available information. Where information is lacking, it becomes necessary to try to determine what would be in the best interest of the

Veteran. This is often, but not always, the same conclusion and often errs more toward life prolongation.

To the extent that they are known, use the Veteran's values and preferences to determine the goals of care. Written advance directives, the Veteran's verbal statements, his or her general values and beliefs, and how the Veteran lived his or her life can all be useful. Together they allow an assessment of what the Veteran would have judged, i.e., a substituted judgment. Fundamentally, the process demonstrates respect for the Veteran, and builds trust that clinicians are acting in the interests of the Veteran. Further, by focusing on the wishes of the Veteran, there is reduced guilt or decision regret for the proxy, family members, physician, and health care team.

Here are some practical ways to elicit the Veterans' values and preferences in discussions with proxy decision makers:

- “Help me to understand what your husband was like before he got sick. What was most important to him?”
- “Has he ever said anything about how he would want to be treated if he could no longer make decisions for himself?”
- “What would he say in this situation?”
- “Do you have any other family members or friends who have experienced serious illness? Did he or she express how he or she would want to be treated in that situation?”
- “Based on everything you know about him, what do you think he would have wanted in this situation?”

Many of the approaches that work for an advance care planning discussion also work for establishing immediate goals of care, whether working with the Veteran or a proxy. In particular, it can help to go through a worksheet again, using predrafted scenarios, goals, and treatment options, prior to returning to the situation at hand. Often clarity and perspective return with this exercise, fostering a broad perspective and allowing a more comfortable settling into current goals.

Goals of care

Whether you are working directly with the patient or with the patient's proxy, assess thoroughly the goals of care. If a Veteran has made the transition away from hope of cure to a focus primarily on quality of life, it is important to relate goals of care to matters of personal meaning. Ask the Veteran what he or she thinks are the most important things to accomplish now. A range of possible goals should be explored, from aggressive comfort care to prolonging life until a certain meaningful event, e.g., a wedding or the birth of grandchild (see EPEC for Veterans Module 1: Goals of Care).

Since discussing “goals” can be abstract, consider more specific questions to ask:

- “What is most important to you now?”
- “Are there people you want to see or things you want to get done?”
- “Are there things you want to make sure to avoid?”

Communication assessment

Slide 19

Communication assessment

- There are many different communication styles
- Determine who is close to the Veteran
- Ask how much information the Veteran wants to know
- Ask who else should receive information and how much

Communication between Veterans and family members will occur in a variety of ways and clinicians need to respect different styles of communication. Whether a person is a “talker” or a “silent type,” meaningful communication can occur. Most people do better if there is someone with whom to share difficulties, concerns, and fears. It is useful to identify who this person is for the Veteran. It may be family, a professional, a close friend, a member of the clergy, or a member of the health care team. One of the most challenging aspects of caring for the seriously ill and at the end-of-life care is when the Veteran appears to be alone and socially isolated. In these situations, the members of the health care team become critical components of support.

There are different personal, cultural, and family styles of information sharing. Ask the Veteran how much information he or she wants to know and who else should be part of the information sharing. Ask how he or she wants to involve other family and friends in information about the illness.

Be particularly attuned for difficulties if the Veteran is keeping his or her diagnosis a secret, or if the family is attempting to do the same in reverse. In such cases, it can be helpful to ask the informed party if you can check with the uninformed party to see how much information he or she would like to have. Each side may be surprised at how much the other knows or wants to know. Sometimes it helps to organize a family meeting where the clinicians can help discuss the information and ensure that all hear the same information at the same time (see EPEC for Veterans Module 3: Communicating Difficult News).

Social assessment

Slide 20

Social assessment ...

- **Culture**
learned, repetitive, characteristic way of behaving, feeling, thinking and being a strong determinant in attitudes toward health, illness, dying
- **Veterans are acculturated to the military during their military service. This shared experience as a group will be expressed as part of the Veteran's culture.**

Slide 21

... Social assessment

- **Veterans will vary in their self-identification with military and Veteran culture.**
- **Look for care networks in a Veteran's community**
- **Explore financial concerns**
- **Allow Veteran to express the meaning of their illness**

Illness impacts the social aspects of life. Conversely, social circumstances impact illness. Although social assessment is traditionally the domain of social workers, clinicians of many backgrounds can begin it. The following areas of a person's social environment are relevant to the evaluation of suffering in the social dimension: caregivers for the patient, domestic needs of the patient, community support available to the patient, and financial resources available to the Veteran. The need for practical support, which may be an important element of the physical assessment, is also addressed here.

Examples of initial questions that can be asked include:

- “Who are important supports for you?”
- “How do you think we can most help them?”
- “When you've had difficult time in the past, who have you turned to?”

Community

A small percentage of patients with life-threatening illness get practical assistance from their community. However, services may be available and should be sought wherever possible. Social workers may know much more than other clinicians about a community's resources or about the resources of a specific VA facility. Many religious communities not only have a tradition of care, but also have service systems. There are disease-based advocacy groups that offer practical advice in some cases. Other local

resources such as library reading services may also be available. As an example, the Family Medical Leave Act (details available at <http://www.dol.gov/whd/fmla/>) can help support family caregivers of Veterans facing an increased need for care.

Cultural competence

Culture is a societal group's learned, repetitive, characteristic ways of behaving, feeling, thinking, and being. It is transmitted from one generation to another through language, role modeling, and group identification. For the Veteran, the additional consideration is the culture of the military service itself and the period of after active duty as a Veteran.^{19,20}

Culture is a strong determinant in attitudes toward health, illness, and dying.²¹ However, it is important to remember that people are individuals. The best way to understand another person's culture is to listen carefully to her or his values and beliefs. Do not assume that each individual's values, beliefs and practices track with cultural norms. Through respectful inquiry, clinicians quickly learn about each individual Veteran's background and specific cultural issues.

Since the way in which people perceive palliative care can be significantly influenced by their cultural values and beliefs, cultural competence among clinicians is essential.²²

Cultural competence has been viewed by many professional organizations as a continuum, and many have developed guidelines for cultural competency training and cross-cultural care.²³ One of the most widely used frameworks was first developed for mental health practice and has wide applicability. It focuses on an organization's overall cultural competence.²⁴

Cultural competence entails accepting and respecting cultural differences and assessing and seeking to expand knowledge base to ensure an inclusive relationship, in this case, centered on Veterans. Cultural proficiency entails promoting genuine cross-cultural initiatives in the relationship.

It is always best to use interpreters when language barriers exist; using family members is fraught with difficulty. If there is an interpreter, you can also learn from him or her if someone is available and knowledgeable in the relevant group's context for living. Although functional knowledge of English is required for military service Veterans may have acquired English as a second language and when faced with severe life-limiting illness they may be better able to express, discuss and understand medical information in their native language. It is quite likely that members of the Veteran's family and community will not be able to speak English or speak it fluently enough to navigate complex palliative and end-of-life issues as they relate to the concept of suffering. The Veteran's family should not be burdened with having to provide translation for their own care in emotionally charged situations.

Further cultural considerations are treated in various modules, including issues of information, truth telling and involvement of translators (see EPEC for Veterans Module

3: Delivering Difficult News), and maintaining reasonable hope (see EPEC for Veterans Module 1: Goals of Care).

Financial

In the general population, medical expenses are a frequent source of financial hardship. Veterans often receive medical bills that they do not understand and cannot pay. Some may be reimbursed slowly, but Veterans who have prided themselves in keeping up with the bills may feel shame. The desire to leave a financial legacy is strong. Savings for the grandchildren or for education may need to be spent on medical care, much to the misery of the family and the patient. Inquiry as to any financial hardship is important and, again, accessing social work support may be imperative.

Meaning of illness

Veterans facing a life-threatening illness are often thinking about questions that they do not articulate easily or freely. It often requires someone, such as the physician, to give permission. Questions such as:

- “What will happen to me?”
- “How will the illness proceed?” and
- “What will happen to my child?”

are nearly universally experienced. Veterans frequently will be thinking about death and dying, with questions such as:

- “How will I die?”
- “Where will I die (home, nursing home, ICU, hospice, etc.)?” and
- “What do I need to do (estate planning, life review, advance care planning, etc.)?”

The clinician may give permission for people to talk about these things by introducing the subject in a general way by saying:

“Many people in your situation think about dying. Is that something you are thinking about? What has that been like for you? What are some of your concerns?”

Another major issue tends to be loss of control. Plans are trumped by the illness. Independent people who have never considered being otherwise now face dependence. People face or fear loss of control in multiple spheres. Loss of body control, including the ability to feed, bathe, and toilet oneself, is a frequent concern. These losses of control are many times associated in many people’s mind with indignity and shame. This may be particularly true for a Veteran who has prided himself or herself with being self-sufficient.

Spiritual assessment

Slide 22

Spiritual assessment

- Learn aspects of Veteran's spirituality past and current spirituality, important religious rituals, who pastor is, etc. ask if there are spiritual activities a patient wants to practice
- Be aware of and discuss spiritual crises

Each person has a spiritual or transcendent dimension to his or her life which can manifest itself in many different ways. Clinicians often hesitate to inquire into this universal dimension of human experience, yet studies suggest patients welcome the inquiry.^{25,26} Spiritual life is understood by some in terms of religious feeling or practice, and by others in terms of personal meaning in a larger context. Seek and explore the interpretation most fitting to the patient.

Individuals who report a strong spiritual life sometimes report a greater sense of purpose and a greater sense of having come to terms with dying than others, as well as better communication and relationships. Clinicians should bear in mind the possibility that patients can experience significant spiritual growth and gain meaningful fulfillment during their last stage of life. The clinician should know how spiritual a patient has tended to be in the past, how inclined toward spiritual life he or she now is, whether or not he or she would like, or has, a pastor to visit, and whether there are religious rituals that are important. These can very often be supported in both hospital and home environments.

Spiritual activities

While it is helpful to know the religion and religious denomination or affiliation of a Veteran, the degree to which religion is important must be evaluated separately. Ask how often the Veteran has gone to religious services in the past and whether he or she would like to do so now. Ask if there are particular prayers or scriptural resources that are meaningful to the Veteran and are there any rituals or traditions that he or she would like help in practicing. Some Veterans engage in spiritual activities that are outside of organized religion. The level of activity in these pursuits is also relevant.

Occasionally, clinicians feel comfortable praying with a Veteran. Many Veterans would like their clinician to do so. This is not a necessary part of the patient-clinician relationship and the clinician must be thoughtful in offering this given their authoritative role. However, it can be helpful if the clinician is comfortable allowing the Veteran to express religious feeling. The clinician should be sure that the best available resources have been made accessible to the Veteran for his or her spiritual care.

Clinicians might ask about spiritual issues by using questions like the following:

- “Are you a spiritual person?”
- “What role does religion play in your life?”
- “Have you thought about what will happen after you die?”
- “What are the things that matter most to you?”
- “How have you tried to make sense of what’s happening to you?”
- “If you were to die suddenly, are you okay if important things for you would be left undone?”
- “As you look back on your life, what has given your life the most meaning?” and
- “What are some of the things that give you a sense of hope?”

A specific screening tool has been developed, entitled FICA, by Christine Puchalski and colleagues²⁷ and includes the following questions:

1. Do you consider yourself spiritual or religious?
2. How important are these beliefs to you, and do they influence how you care for yourself?
3. Do you belong to a spiritual community?
4. How might health care providers best address any needs in this area?

The answers to these questions can help direct more detailed exploration of spiritual beliefs.

Rituals

Ask if the Veteran wants special prayers, declarations, rituals, or last actions. The health care team should be sure that special prayers or actions and last prayers or declarations are carried out as the patient and family would like them to be.

More information about spirituality is also contained in EPEC for Veterans Module 16: Spirituality in Palliative Care.

Spiritual crises

Many aspects of advanced illness are not commonly appreciated to be fundamentally spiritual. Yet, the search for meaning and purpose in life is a spiritual quest. Likewise, the perceived loss of connection to a community or to a way of life may challenge the sense of meaning and purpose. Sometimes feelings of guilt or unworthiness may be manifestations of spiritual suffering. If they remain unrecognized, an appropriate plan for relief cannot be effectively instituted.

Other aspects may be more conventionally noted to be spiritual. Veterans may question their faith or express a desire for forgiveness and reconciliation. For those who believe in a higher power, they may feel a sense of abandonment or a sense of greater connection.

There are some general guidelines for spiritual assessment and it is important to remember this is a universal component of illness, affecting quality of life in profound ways. The clinician will frequently want assistance in managing spiritual suffering, but may play a critical role in identifying distress and initiating conversations.

Practical assessment

Slide 23

Practical assessment

- Ask about practical concerns and abilities, including functional status
- Learn about family or informal caregivers
- Make sure basic needs are being met

Practical assessment includes assessment of functional status, family and other informal caregivers' domestic needs.

Functional Status

Ask about who is available to help and how they are dividing work caring for the patient among each other. Ask about domestic needs, including how the patient manages with chores of day-to-day living: cooking, cleaning, shopping, banking, and paying the bills. Geriatric assessment has traditionally stressed the importance not only of activities of daily living (ADLs) such as bathing, dressing, toileting, transferring, continence, and feeding but of instrumental activities of daily living (IADLs) such as meal preparation, medication management, money management, telephone, transportation, and employment. Palliative care strives for a similar assessment.

Family and other informal caregivers

Virtually all patients have family, biological or chosen. The composition may vary tremendously. One convenient way to understand family is broadly to consider family to be anyone whom the patient considers family, whether related by blood or marriage or neither. That family may be composed of dependent children or elders. They may also be ill or limited by debility. When these people face death, the family has to be cared for in a different way and often by a different person. Ask about family and what arrangements have been made.

Most have or need someone to be a primary caregiver from their family and circle of friends. This is true even in a health care institution. This responsibility can be a full-time and demanding task when at home.

Studies show that most caregivers in the home are wives or daughters.²⁸ Consequently, widows and single people may be more isolated and may have to rely on paid or volunteer community help to meet their needs if they are to stay at home.

The relationship between the Veteran and the caregiver is important. Some Veterans and their caregivers find the relationship difficult and it can leave a lasting negative impact on caregivers. Others do not want to have their families caring for them, no matter how loving or willing. Likewise, some family members are unwilling or unstable to care for an ill relative. To intervene positively, both the Veteran and the caregivers must be assessed.

Many find that even with a willing family caregiver at home, there are unmet needs. Ask how well the Veteran feels his or her needs are being met. There may be needs for care on holidays or a need for supplementary help. There may be a need for respite care, in which a Veteran stays in a nursing home or other inpatient facility with the express purpose of allowing a break for his or her caregiver. This is a standard offering of Medicare-certified hospice programs. The process of hiring outside caregivers can be financially and emotionally difficult and complicated.

Domestic needs

As illness progresses, difficulty getting between the health care site and home is common. Ask about transportation needs. Difficulty obtaining food and/or with meal preparation is also common. It is reasonable to ask about such basic issues as food, heat, and light, and whether those needs are being met. In the event of a power outage, they will receive a priority response.

Anticipatory planning for death

Veterans and family members grieve over loss of function, and they grieve in anticipation of loss. Figuring out what grief is normal and what is complex or exaggerated and in need of intervention is an important part of assessment. Planning ahead can be a very helpful coping mechanism for present and future losses. Patients may readily relate their hopes for life closure, gift giving, leaving a legacy or they may be overwhelmed and need step by step support. Plans for how to accommodate these needs are important. Ask if the patient has, or would like to make, plans for rites, rituals, funerals, memorial services, and even celebrations (see EPEC for Veterans Module 2: Advance Care Planning, and EPEC for Veterans Module 11: Last Hours of Living).

Initial screening tools

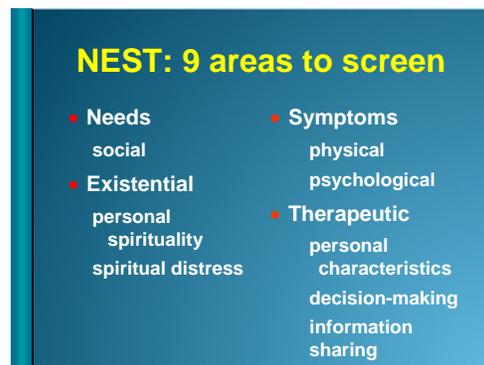
Slide 24



Each clinician will develop his or her approaches to assessment. One basic approach is to start by asking open-ended questions about the Veteran, his/her overall health and understanding of the situation during the initial screening. A number of examples were suggested in previous sections of this module. A complementary approach is to also consider asking a series of validated screening questions that efficiently assess each of the major dimensions of the issues that frequently cause suffering and the process of providing care. One such validated screening tool is ‘NEST’²⁹ described below.

Screening with NEST

Slide 25



‘NEST’ utilizes a series of questions selected for their sensitivity to detect needs that are of concern to the patients. These have been grouped into four dimensions to generate the mnemonic ‘NEST’: 1) **N**Needs in the social domain; 2) **E**xistential matters; 3) **S**ymptom management needs; and 4) **T**herapeutic relationship matters.

The order of the “NEST” questions may vary. If the Veteran is clearly experiencing a troubling symptom such as dyspnea it would probably be best to address this first. When first meeting with a Veteran, the most appropriate sequence may be to start with the *Therapeutic Relationship* questions from NEST as a way to build such a relationship. Start by orienting yourself to the Veteran’s cultural context. Leave inquiry into financial matters to the end. With practice they will flow smoothly in a conversational manner. It is important to touch on areas represented in the “NEST” questions to assure that many

facets of suffering are addressed so that the clinician does in fact perform a comprehensive assessment.

Table 1: NEST screening questions

NEST groupings (reversed)	Screening questions	Domains
To inquire about <u>T</u>herapeutic relationships:	1. How much do you feel your doctors and nurses understand how to relate to you with respect?	Veteran/family characteristics
	2. How clear is the information from the medical team about what to expect regarding your illness?	Information sharing
	3. How much do you feel that the medical care you are getting fits with your goals?	Decision-making
To inquire about <u>S</u>ymptoms:	4. How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, bowel or urination problems?	Physical
	5. In your mind, how often do you feel confused or anxious or depressed?	Psychological
To inquire about <u>E</u>xistential matters:	6. How much does religious belief or your spiritual life contribute to your sense of well-being?	Spiritual
	7. How much does this illness seem distressingly senseless and meaningless?	Spiritual
	8. How much do have you settled relationship with the people close to you?	Spiritual
	9. Since your illness, how much do you live life with a special sense of purpose?	Spiritual
To inquire about <u>S</u>ocial <u>N</u>eeds	10. How much trouble do you have getting access to the medical care you need?	Practical
	11. How much help do you need with caregiving – things like getting meals or getting to the doctor?	Practical
	12. How often is there someone to confide in or feel close to?	Social
	13. How much of a financial hardship is your illness for you or your family?	Social

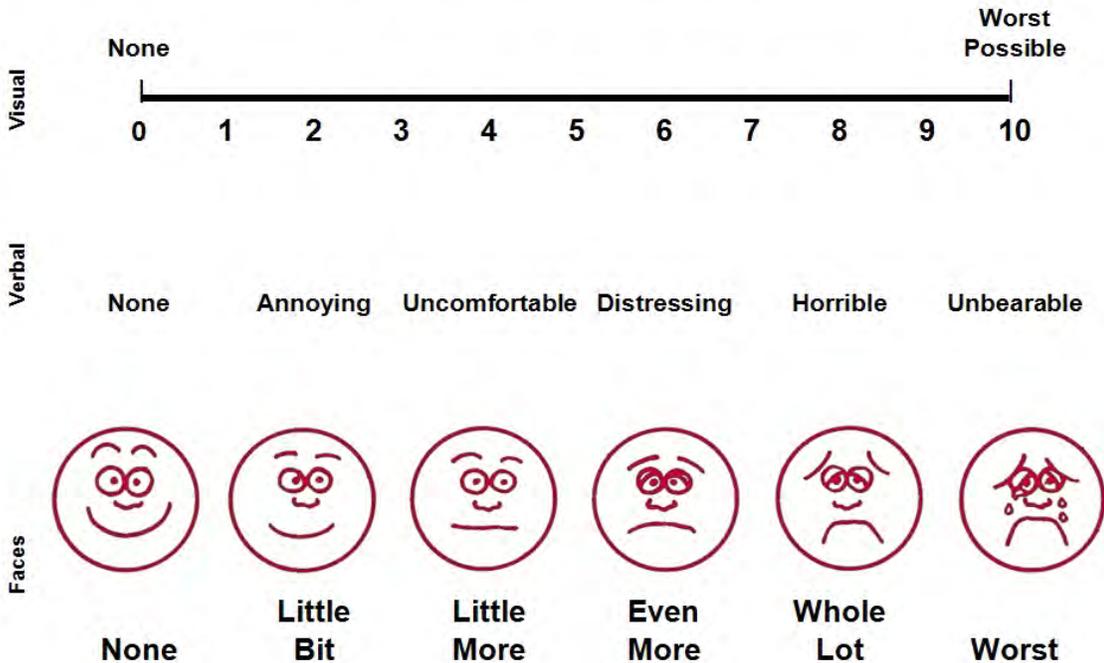
Detailed assessment

If the response to any of these questions suggests that there is a concern, then use more specific questions to explore the details. Depending on the extent of expressed needs, and

their severity, urgency, and priority, further evaluation may proceed directly or be postponed for another visit.

Detailed assessment strategies for many of the common issues facing Veterans and their families as well as the process of providing care are integrated throughout EPEC for Veterans in the respective modules. Whenever possible use one of the scales in **Figure 1** to quantify the severity of the symptom – whether physical, psychological, or existential.

Figure 1: Severity assessment scales



Note: The Faces scale is adapted from the Wong-Baker FACES Pain Rating Scale.²³

If there seems to be no issue within a given dimension, that area can be considered re-evaluated at future assessments.

As part of the detailed assessment, ask about past experiences with medications, particularly any adverse events, allergies or sensitivities.

Summary

Slide 26



The experience of an illness and the process of care have multiple dimensions for Veterans and their families. To effectively manage all of the issues that cause Veterans and families suffering, clinicians and other members of the care team must first be able to identify, assess, and understand them.

To conduct a comprehensive assessment efficiently, use a framework to guide functional inquiry (see Appendices 1-2). To ascertain whether frequently occurring dimensions of the end-of-life experience are concerns, start by asking 13 screen questions from NEST. Then, conduct a more comprehensive assessment for each of the issues where concerns or needs are identified. Detailed assessment strategies, including sample questions to ask, findings to look for on physical examination, and possible laboratory and radiological investigations are available in each of the EPEC for Veterans modules.

A whole-Veteran assessment sets the stage for the comprehensive palliative care team to address all of the Veteran's and family's sources of suffering. Use it periodically to screen for issues that require a detailed reassessment. Based on your findings and the Veteran's goals of care, revise the plan of care appropriately.

By comparing serial assessments, members of the palliative care team will be able to determine the outcomes of their therapeutic interventions.

Key take-home points

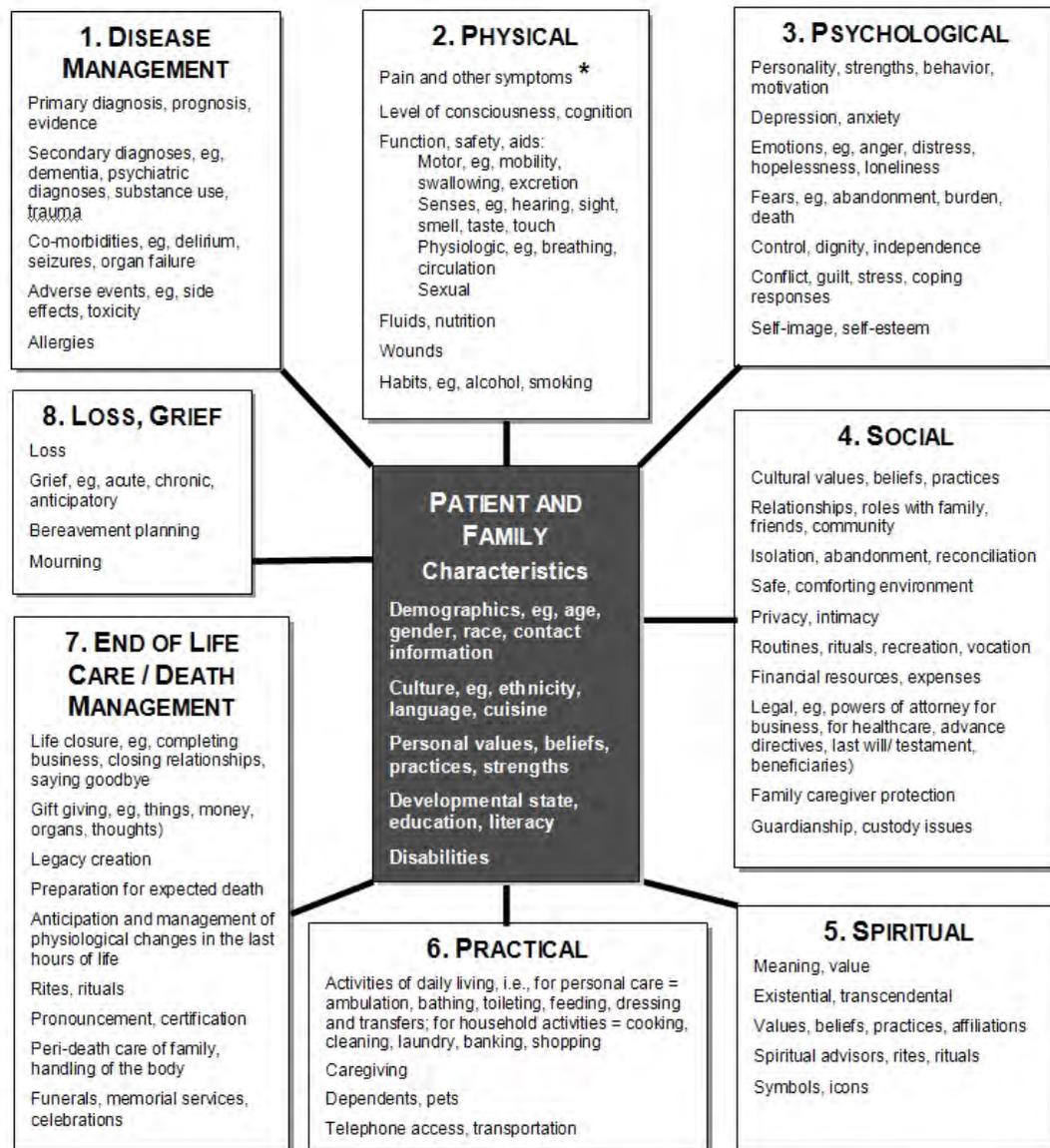
1. Veterans' suffering has a context; consider Veterans and families together.
2. Bodies do not suffer, only persons do. Personhood means having a past, present, and future. Facing a life-threatening illness challenges and often redefines usual sources of meaning. Loss of meaning is a form of suffering.
3. Conceptual frameworks, approaches for investigating and understanding suffering, and approaches for intervention to relieve suffering have been neglected in the training of physicians.
4. Whenever possible, quantify the severity of an issue.

5. Minimize the burden of laboratory and radiological investigations. Only order tests when the results will have a specific use or add to well-being.

Appendices

Appendix 1: Domains & issues of illness and bereavement

Veterans and families face multiple issues during illness and bereavement that cause suffering. These issues can be grouped into 8 domains. The most common issues are listed below.



* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

Appendix 2: Additional detailed assessment questions

In addition to the detailed assessments included in each of the modules of EPEC for Veterans, clinicians may find the following non-validated questions to be useful during a detailed assessment.

Physical issues

Assess both motor and sensory functions.

- What is the Veteran's performance status?
- Can the Veteran move around?
- Can the Veteran see or hear well enough?
- Is he or she safe?
- How are the physical aspects of relationships including sexual function?

Psychological issues

How is the Veteran responding to the fact of being ill?

Consider naming some common responses, such as anger, grief, instability, and tranquility.

Social issues

Ask about family and what arrangements have been made.

Spiritual issues

This assessment phase includes understanding the Veteran's:

Individual form of spirituality. How does the Veteran's spirituality offer a sense of well-being and coping resources to him or her?

“When you are looking for spiritual comfort, what do you do?”

If the Veteran seems hesitant, you can add:

“Some people listen to music, others pray or do something else; what helps you?”

To find out if there is a community component to the Veteran's spiritual life it can be simplest to ask:

“Do you have a community that you share your spiritual side with?” Or: “What role does religion play in your life?”

Existential distress. How much does the illness seem senseless and meaningless; how settled does the Veteran feel in regards to his or her diagnosis and prognosis and the

impact of that on personally important relationships? Be alert to the possibility of a spiritual crisis.

To gain insight into a Veteran's spiritual orientation, a preamble can be helpful: 'This illness seems to be especially distressing now.' Then go on to ask a direct question such as:

- "Do you sometimes feel abandoned or judged?"
- "How do you understand the meaning of your illness?"
- "How much distress is it causing?" and
- "Is it impacting any of your important relationships?"

Purpose. Does the Veteran have a sense of purpose in life that is fitting with the Veteran's prognosis and the illness' limitations?

- "How have you made sense of what's happening to you?" and
- "Do you feel that you have a sense of purpose in life that you can pursue, even though you are facing the end of life?"

A key question, whether for survivors or the terminally ill, may be:

- "Do you feel settled in regards to your diagnosis and prognosis?"

Unresolved issues

- "Is there something that you would like to do before you get too sick?" and
- "As you look back on your life, what has given your life the most meaning?"

For those with a poor prognosis who are aware of the fact, examples might be:

- "Many people have old differences they would like to settle before they die. Is there anyone you want to be able to communicate with before you die?"
- "Many people have places or people they would like to visit. Do you?"
- "Some have a piece of work they would like to finish. Do you?"
- "In what ways has this illness affected you emotionally?"
- "Are you doing things that you enjoy?"
- "How has your mood been lately?"
- "How have you been coping with all of this?"
- "How have you handled stress in your life?"
- "Are you concerned about being a burden to others? Do you feel in control of your life right now?" and

- “If you were to die suddenly, are there important things you feel would be left undone?”

What helps?

- “Do you have a community that can help?” and
- “Would it be helpful to bring in a team member with a suitable pastoral counseling background?”

Practical issues

Ask about the Veteran’s ability to complete her/his activities that support daily living.

- “Are you able to complete all your own ambulating bathing, toileting, feeding, dressing and transfers?”
- “Are you able to complete all your own cooking, cleaning, laundry, banking, and shopping?” and
- “Do you have any need for assistance with transportation?”

Loss, grief

- “How well do you feel you have adjusted to this [illness / loss / prospect]?”

Information sharing

- “How do you want to handle important health information?” and
- “What will allow for clear understanding and the best decisions?”

Decision making

- “What are the goals for your care that brought you here today?” and
- “What are the things you most want to accomplish?”

Appendix 3: Symptom assessment scales

Brief Pain Inventory (Short Form), reprinted by permission of the Pain Research Group. Copyright 1997. Available at <http://www.healthcare.uiowa.edu/igec/tools/pain/briefPain.pdf>. Accessed February 4, 2011.

Memorial Symptom Assessment Scale, reprinted by permission of the Memorial Sloan Kettering Cancer Center, New York, New York, USA. Available at <http://www.mywhatever.com/cifwriter/content/41/pe1262.html>. Accessed February 4, 2011.

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- ¹⁵ Memorial Symptom Assessment Scale, reprinted by permission of the Memorial Sloan Kettering Cancer Center, New York, New York, USA. Available at

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