

EPEEC for Veterans

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

Trainer's Guide

Module 1

Goals of Care

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Principal message

Negotiating and determining the goals of care are essential issues for good end-of-life care. There are many possible goals of end-of-life care, from prevention, to cure, to prolongation of life, to being comfortable and active, to achieving a good death.

Module overview

There are many possible goals of health care, including preventing illness, curing disease, prolonging life, relieving suffering, improving quality of life, and experiencing a good death. No one goal is inherently more valid than another, and multiple goals may apply simultaneously. In general, attempts to treat illness can be pursued at the same time as efforts to relieve suffering and improve quality of life. The clinician must be able to identify what is reasonable for the Veteran to hope for, elicit values and preferences for care, and recommend treatments to help the Veteran reach his or her goals. The clinician must take into account the Veteran's culture and age-related communication challenges, and avoid approaches that often have unintended negative consequences.

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 collect participants' demographic data and complete the pre-test.

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Trigger tape & discussion	5-7 minutes
Presentation	35 minutes
<u>Summary</u>	<u>2-3 minutes</u>
Total	49-53 minutes

3. Number of slides: 38

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 1**

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 determining goals of care 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, consider presenting the trigger tape or the clinical case below. The case 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

Scene 1: A 50-year-old female Veteran had a lumpectomy, radiation, and chemotherapy 5 years ago for Stage II, ER, PR negative infiltrating ductal adenocarcinoma of the breast. She was premenopausal at the time of diagnosis, although she hasn't had any periods since then. Subsequent to this initial treatment, she was seen routinely, first every 6 months, then every year. Recently, she felt some pain in her ribs that won't go away. She had a bone scan before coming to the office today that showed likely metastases.

Scene 2 (3 years later): The Veteran is now 53. She had a brief response to chemotherapy, stable disease on second line chemotherapy, and progressive disease despite third line chemotherapy. She is more fatigued. Her pain is under good control with medications.

Trigger tape

The trigger tape consists of several VA clinicians as well as a family member discussing their experiences with goals of care conversations.

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. Use the trigger tape to illustrate the information. You may also use case examples of your own to provide clinical relevance to the information and make it more 'real' to the participants. You can also ask participants to comment and provide examples of their own. However, if you choose to do this, be careful not to get sidetracked and miss covering some of the material you want to include.

In many ways, this is one of the most important modules in the EPEC for Veterans materials. It covers the issue of hope and how to talk about this with patients and families. A key issue to stress in this module is that goal-oriented care is a fundamentally different way to approach medical decision making than the problem-oriented approach

that most clinicians have learned. Goals are fundamentally patient/family driven whereas problems are fundamentally driven by pathophysiology.

Alternative style: 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 determining goals of care.

Start the session by summarizing the overall approach to setting goals 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 life-threatening illness.

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 physicians, '2s' they are patients, and '3s' they are observers.

Ask the clinicians to take 10 to 15 minutes to conduct an interview to elucidate the patient's goals for care and treatment priorities. More time may be needed if participants are relatively unskilled in this technique.

After 10 to 15 minutes, stop the interview 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 physician 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 physicians, 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. Historically, medical decision making occurred in a dichotomous way; therapies with curative and/or life-prolonging intent were provided until no longer effective, and then the goal of care shifted abruptly to relief of suffering. The interrelated goals of care model emphasizes that relief of suffering can be integrated throughout the continuum of care and the Veteran's goals can be primarily curative, primarily palliative, or a combination of both.
2. The Veteran's and family's understanding of the medical condition should be confirmed prior to eliciting the Veteran's goals of care.
3. End-of-life issues are inseparable from the experience of grief and loss, and the clinicians should elicit concerns and express empathy to address the distress of

- Veterans and family members. Ask-Tell-Ask and the NURSE mnemonic are techniques that can be helpful in guiding clinicians through this process.
4. Goals of care should be negotiated between the Veteran or surrogate and the practitioner according to the Veteran's preferences and clinical circumstances. Clarification of goals helps the clinician determine which treatments to offer and helps the Veteran and family make decisions about which treatments to accept.
 5. The clinician should offer choices about treatments that are consistent with the Veteran's goals of care. The clinician should not offer treatments that are inconsistent with those goals or that have no chance of achieving those goals.
 6. Goals of care should be reassessed periodically, particularly after treatment milestones, changes in quality of life, and changes in prognostic indicators.
 7. There are approaches to *avoid* when discussing goals of care, including debating with the family about the medical reality of impending death; presenting difficult decisions in an impersonal or oversimplified manner; labeling the Veteran or family as "in denial" when they are actually experiencing normal grief and conflict; and using language with unintended consequences (e.g., "Do you want us to do everything possible?").
 8. Adjustments in communication strategies are required for older adults who possess characteristics that make communications more challenging. These include reducing the complexity and density of the communication, accommodating sensory deficits, and using "teach back" methods to assess understanding.

Clinicians should recognize the influence of personal cultural context on end-of-life decisions and attitudes.

7. Summarize the discussion

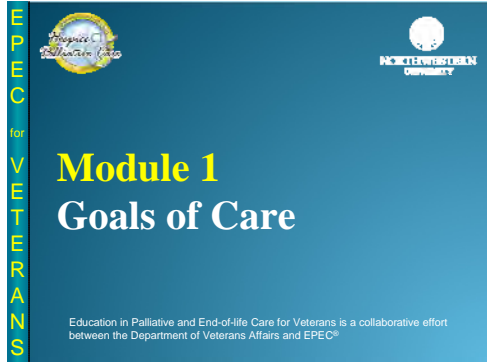
Briefly review each part of the presentation. Recap 2 or 3 of the most important points that were discussed.

8. Post-test/evaluation

Ask the participants to evaluate the session.

Abstract

Slide 1



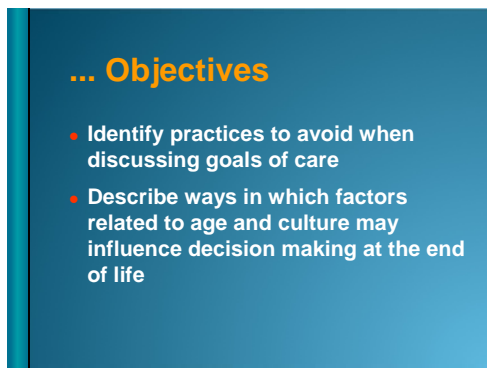
There are many possible goals of health care, including preventing illness, curing disease, prolonging life, relieving suffering, and improving quality of life. No one goal is inherently more valid than another, and multiple goals may apply simultaneously. In general, attempts to treat illness can be pursued at the same time as efforts to relieve suffering and improve quality of life. The clinician must be able to identify what is reasonable for the Veteran to expect, elicit values and preferences for care, and recommend treatments to help the Veteran reach his or her goals.

Objectives

Slide 2



Slide 3



After studying this module, clinicians will be able to:

- identify possible goals of care and how they interrelate and change;
- identify key practices for success in goals of care communications;
- demonstrate the ability to use the identified protocol to negotiate goals of care;
- identify practices to avoid when discussing goals of care; and
- describe ways in which factors related to age and culture may influence decision making at the end of life.

Clinical case

Slide 4



Scene 1: A 50-year-old female Veteran had a lumpectomy, radiation, and chemotherapy five years ago for Stage II, ER, PR negative infiltrating ductal adenocarcinoma of the breast. She was premenopausal at the time of diagnosis, although she hasn't had any periods since then. Subsequent to this initial treatment she was seen routinely, first every 6 months, then every year. Recently, she felt some pain in her ribs that won't go away. She had a bone scan before coming to the office today.

Scene 2: (3 years later): The Veteran is now 53. She had a brief response to chemotherapy, with stable disease on second line chemotherapy, and subsequently progressive disease despite third line chemotherapy. She is more fatigued. Her pain is under good control with medications.

The trigger tape for this module consists of clinicians and a family member discussing their experience with goals of care conversations.

Introduction

Slide 5

Introduction ...

- Departure from usual approach of asking patients about **treatments**
often jarring, fraught with misinformation and out of context
- Instead, asking patients to talk about **goals**, and the treatment team then makes recommendations based on those goals
greater respect for patient's priorities, fosters productive collaboration

Slide 6

... Introduction ...

- Each of us has a personal sense of
who we are
what we like to do
control we like to have
goals for our lives
what we hope for

Slide 7

... Introduction

- Expectations, hope and goals change with illness
- Military experience may influence Veterans' responses to life-limiting illness
- The clinician's role is to elicit the patient's goals and recommend treatments consistent with those goals

This module presents an approach that is an expansion of the usual focus of asking Veterans only about treatment preferences. Instead, the clinician asks each Veteran about his or her goals and then makes treatment recommendations based on those goals. The Veteran's goals are placed at the forefront, treatment recommendations are made in a context that makes sense, the collaboration is strengthened, and the odds of providing care inconsistent with the Veteran's goals are reduced.

Veterans and their families have very personal hopes and goals for their lives. As they confront life-threatening illness, they may start by hoping that nothing is wrong, that the diagnosis is not true. As they realize the full meaning of the illness, most will hope for a cure and long life. As each Veteran realizes that his or her illness will likely take his or her life, most will hope for the support to relieve suffering and improve both quality and

quantity of life. As their hopes change, so will their goals for care and their priorities for treatment. Each trajectory of changing goals is unique, and adjustment to each change may be accompanied by experiences of grief and loss.

Some Veterans have a strong survival response that drives them to fight for life no matter what comes their way. Some may have had experiences which inform them about the extent of physical and mental challenges they are capable of enduring. Their past experiences with escaping death in combat may contribute to a sense of invulnerability: “I survived the Tet Offensive. This is nothing compared to that.” For many combat Veterans, death was the enemy to be fought at all costs; letting go of treatment may feel like “surrender” – something “good soldiers” don’t do.

Other Veterans expected to die in combat, and have viewed any time since then as “extra” time they did not expect to have. Veterans with Posttraumatic Stress Disorder often experience a sense of a foreshortened future, with the belief that they will not have a normal lifespan. These Veterans may be unusually accepting of a poor prognosis because they have not expected to live as long as they already have. Regular review of these goals and priorities can help the Veteran, family, and health care team to strive for the same outcomes and avoid the use of unwanted treatments.

This module presents an approach for eliciting a Veteran’s goals of care and clarifying treatment priorities. While it focuses on Veterans who are nearing the end of their lives, the process can be used at any time during a person’s illness.

Goals of care models

Slide 8

Historical dichotomy

- Medical care was primarily provided to comfort those who were sick
- With scientific progress, the focus of medical care shifted to attempts to cure disease
- Little attention was paid to relief of suffering, care of dying
- Hospice / palliative care arose in response to a need

Slide 9

Dichotomous goals

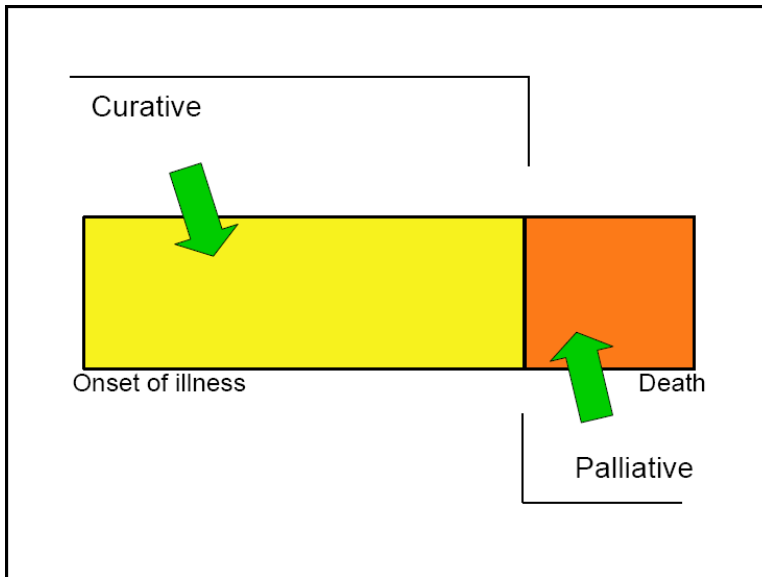
The diagram illustrates the transition from curative to palliative care. A horizontal bar represents the patient's illness trajectory. The left portion is yellow and labeled 'Curative', with a green arrow pointing to it. The right portion is orange and labeled 'Palliative', with a green arrow pointing to it. The bar starts at 'Onset of illness' and ends at 'Death'.

Dichotomous goals of care

Prior to the last century, the primary goal of medicine was to provide comfort. With significant developments in science and technology, the focus of modern medicine shifted to curing illness, prolonging life and fighting death. In the process, less attention was paid to the management of symptoms, the relief of suffering or the care of the dying. The hospice and palliative care movements were born in the 1960s and 1970s to fill a growing void. Hospice in the United States has primarily been restricted to the last six months of a person's life by the Medicare hospice benefit, and programs tend to provide care only to patients when cure is no longer possible.¹ Veterans, their families, and clinicians, however, may want to discuss therapies for some things and comfort-oriented care for other things.

Figure 1 shows a division between goals of care if medical decision-making occurs in a dichotomous way, where the initial goal is to provide therapies with curative and/or life-prolonging intent, and only shifts to relief of suffering when those treatments are no longer effective.

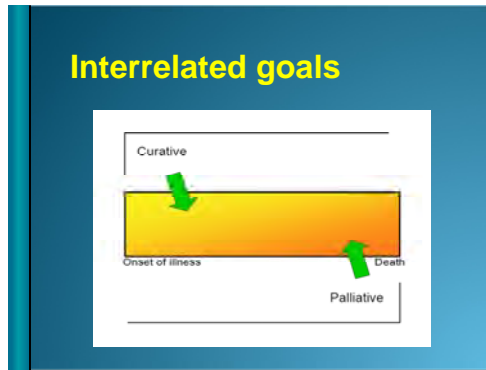
Figure 1: Dichotomous goals of care



This dichotomous approach does not adequately address many clinical situations. Some therapies aimed at life-prolongation may be appropriate until close to the time of death, and addressing suffering from the earliest stages of illness can be very important in improving well-being and diminishing fears. Many Veterans with life-threatening illnesses will have needs for psychological, social, spiritual, and practical support in multiple stages of their illness, not just in the period before death.

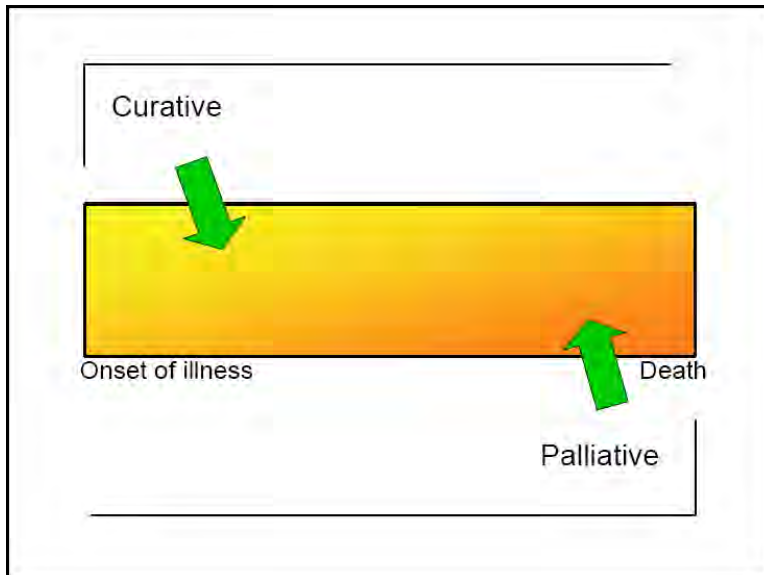
Interrelated goals of care

Slide 10



In contrast to the dichotomous model of care, **Figure 2** shows how the relief of suffering can be integrated throughout the continuum of care.

Figure 2: Interrelated goals of care



In this model, there may be more initial focus on therapies intended to cure the illness or prolong life. Later, relief of suffering may become increasingly important or even the total focus of care. Notice that therapies with a palliative intent are not an alternative to, or an abrupt change from, traditional care but rather part of the care plan from the beginning.² By accepting goals of care with both curative – or life-prolonging – and palliative intent, interdisciplinary care for symptom control and support can be available to all Veterans with any illness at any time those needs are present.

Programs that integrate palliative care and disease modifying therapy have been developed for a number of life-limiting illnesses, and the integration of palliative care into all disease management guidelines to reduce illness-related suffering is supported.³

Several observations are key for clinicians to consider in this framework:

Slide 11

Potential goals of care

- Cure disease
- Prolong life
- Maintain or improve function
- Maintain or improve quality of life
- Relieve burdens, support loved ones
- Relieve suffering
- Accomplish personal goals
 - attend important family events
 - go home
 - mend relationships
 - make peace with God
 - experience a good death

There are many potential goals of care.

These include curing disease, prolonging life, maintaining or improving function or quality of life, supporting families and loved ones, improving comfort and relieving suffering, and enabling the Veteran to accomplish personal goals. No one goal is inherently more valid than another; all are legitimate goals of care and each will be applied differently by each individual in his or her particular circumstances.

Multiple goals of care may apply simultaneously.

Although goals may seem to stretch along a continuum in a linear fashion, in fact the Veteran and clinician may want to seek disease control and other goals, e.g., staying out of the hospital, at the same time. They may not choose therapeutic options unless they allow for pursuit of multiple goals.

Slide 12

Multiple, changing goals

- Multiple goals often apply simultaneously
- Certain goals may be sacrificed to meet other goals with greater priority
- Goals change; this is expected, and ideally occurs gradually
- Explicitly include a goal of comfort from the very first encounter

Goals of care may be contradictory; some take priority over others.

A Veteran may want prolongation of life as the overriding goal but also insist that nothing be done that increases discomfort. The clinician knows, however, that treatments aimed at curing or controlling disease, such as a surgical operation or chemotherapy, may unintentionally cause temporary or permanent functional deterioration and suffering. It is the clinician’s role to help the Veteran and family understand the balance between the potential benefits and burdens of a particular treatment and to honestly address the impact on quantity of life and other goals of care.

Goals of care may change.

Over the course of an illness, goal of care may change in response to numerous factors. As a Veteran's prognosis and health status worsen, the goals of prevention, cure, and avoidance of death may become less important as they become less possible. At the same time, maintaining function, relieving suffering, and accomplishing specific life goals, e.g., attending a family wedding may become the primary goals of the Veteran's care.

The shift in goals is an expected part of the continuum of severe and life-limiting illnesses.

Changes occur throughout the Veteran's life and illness. In all situations, the nature and course of the illness and the Veteran's and family's goals for care are the factors which help the clinician determine the relative emphasis on cure and palliation in the mix of treatments and interventions offered.

Ideally, this shift in focus of care is gradual.

An abrupt transition in the focus of care from primarily curative care to primarily supportive care is difficult and jarring. Sometimes, there are truly emergent situations that drive a rapid shift. However, often there have been signs and symptoms that suggest disease progression and indicate the approach of a transition point. Although it can be difficult to discuss negative signs, clinicians are obligated to candidly inform Veterans and families of prognostic indicators to prepare them for upcoming transitions.

Explicitly include a goal of comfort from the beginning.

Trust is built and future transitions may be easier for the Veteran if, from the very first encounter, clinicians offer therapies to manage the experience of illness along with those to treat the disease (whether curative, life-prolonging, or palliative in their intent). This concurrent strategy permits some aspects of the plan of care to continue until death, rather than necessitating a change from one goal to another when curative goals are no longer appropriate, and helps avoid creating impressions of abandonment and 'giving up.'

Clinical case revisited

Scene 3: The 53-year-old Veteran has shown progression of her breast cancer after her most recent chemotherapy. On review of her goals of care she expresses that an important personal goal is to be able to travel to visit her daughter, who is due to deliver a grandchild in the next few weeks. In light of this a plan is developed to continue with monthly bisphosphonates injections to reduce the risk of bone fracture and pain, receive a transfusion to reduce anemia and fatigue, arrange contact with a palliative care provider at VAMC near her daughter's home, and insure an uninterrupted supply of medications, including opioids, for symptom control. In two weeks, it is anticipated that the Veteran

will return home where she will reexamine her goals of care and continue consultation about disease-modifying treatment.

Primary goals of care over time

Slide 13

Primary goals

- **Curative** – primary goal is to restore health by treating the underlying condition
- **Palliative** – primary goal is to promote comfort by relieving pain and suffering
- **Combination** – restoring health and promoting comfort are both important goals. When these two conflict, efforts may be directed more toward one goal or the other

Slide 14

Primary goals over time

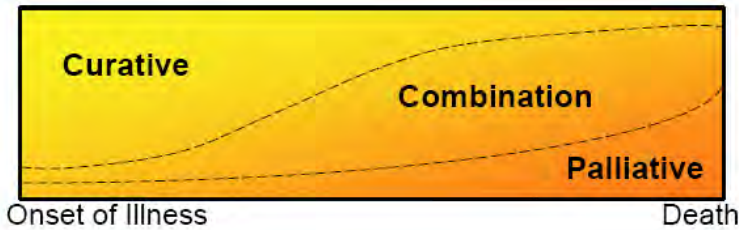


Goals are described by Veterans such that they fall into the following three general categories:

- **Curative** - the primary goal of care is to restore health by treating the Veteran's illness or underlying condition; efforts may also be made to promote comfort, provided they do not conflict with the goal of restoring health;
- **Palliative** - the primary goal of care is to promote comfort by relieving the Veteran's pain and suffering; efforts may also be made to restore health, provided they do not conflict with the goal of promoting comfort; and
- **Combination** - restoring health and promoting comfort are both important goals; when these two goals conflict, efforts may be directed more toward one goal or the other, depending on the specific circumstances.

Figure 3 illustrates theoretical changes in the distribution of Veterans adopting primarily curative, combination, or palliative goals of care over the course of life-limiting illness.

Figure 3: Primary goals over time



Upon diagnosis, many Veterans prioritize the goal of cure above all other goals. Over time, more adopt a combination of curative and palliative goals, prioritizing restoration of health or comfort depending on each individual’s assessment of the costs and benefits of each offered intervention. Closer to the end of life, when it is apparent that attempts at cure and disease control have not been successful, comfort is usually prioritized above all else. The selection of any of these approaches over the course illness is variable, depending upon aspects of the disease and factors related to each specific Veteran, e.g., overall health, response to treatment, psychological factors, and personal goals.

Table 1 provides information about usual treatment preferences for life-sustaining treatments and comfort care within each group. Veterans with curative goals will tolerate negative side effects and pursue interventions to restore health over all other goals. Symptom relief, while important, is secondary to attempts to treat the underlying disease. These Veterans will typically elect to accept all life-sustaining treatments despite the associated burdens, and are not appropriate for referral to hospice programs.

Veterans with a combination of curative and palliative goals may want to prolong life, but are unwilling to shoulder the burdens of some treatments. Interventions to restore health and prolong life will usually be selected by these Veterans unless the burdens of those treatments are considered too great. For example, a Veteran may elect to have artificial nutrition and fluids if not able to eat or drink, but not desire the use of a ventilator in the event of a respiratory arrest.

Veterans with palliative goals are usually unwilling to accept interventions which are likely to cause discomfort. They usually decline CPR and most other life-sustaining measures.

Slide 15

Usual treatment preferences for different goals of care			
Intervention	Curative	Combination	Palliative
CPR	Yes	Maybe	No
Artificial fluid/nutrition	Yes	Maybe	Usually no
Other life-sustaining treatments	Yes	Some but not others	Only for comfort
Hospitalization	Yes	Probably	Only for comfort
ICU admission	Yes	Maybe	Only for comfort
Hospice	No	Possibly	Usually

Table 1: Usual treatment preferences for those with curative, combination, and palliative goals related to life-limiting illness (for more information see EPEC for Veterans Module 10: Life-Sustaining Treatments)

Intervention	Curative	Combination	Palliative
CPR	Yes	Maybe	No
Artificial fluid/nutrition	Yes	Maybe	Usually no
Other life-sustaining treatments	Yes	Some but not others	Only for comfort
Hospitalization	Yes	Probably	Only for comfort
ICU admission	Yes	Maybe	Only for comfort
Hospice care	No	Possibly	Usually

It is important for clinicians to carefully assess the factors that are most important in achieving comfort for each Veteran – physical comfort may not always be the highest priority. For example, a Veteran who derives significant comfort from spending time interacting with family members may opt to forego treatments for shortness of breath, as side effects include reducing the Veteran’s level of alertness. In other cases a Veteran may accept some measures with negative physical side effects because he derives comfort from knowing that the interventions may keep him alive until family members arrive from distant locations.

Presenting the goals of care framework when talking with Veterans and their families will help communicate more clearly about the Veteran’s priorities and result in treatment plans that will help the Veteran meet his or her goals.

Key practices for success in goals of care discussions

Slide 16

Key practices for success in goals of care discussions ...

- **Assess readiness**
may need time to adjust to bad news
- **Create the right setting**
privacy, space, time
Veteran indicates who should attend and who should not

... Key practices for success in goals of care discussions

- Balance truth and hope
honest, straightforward
not too blunt
- Elicit concerns and sympathy
demonstrate empathy

Assess readiness

Before goals of care conversations can take place, Veterans and their families must have a clear understanding of the medical facts. Even if the health care team has provided information to the Veteran and/or family on numerous occasions, their current understanding of the Veteran's medical circumstances should be assessed. This may be done prior to the goals of care discussion in a separate conversation, or at the beginning of the same conversation in which goals of care are discussed.

Clinicians may need to give the Veteran and family time to adjust after receiving bad news. They may not be ready to discuss a shift in the goals of care immediately after hearing about progression of illness or treatment failure with negative implications for prognosis (see EPEC for Veterans Module 3: Communicating Difficult News). The clinician should allow time for the Veteran and family to process feelings of loss associated with bad news, as there is rarely an urgent need to immediately establish a new care plan. It is very important that discussion of relief of suffering *not* be linked with the implied expectation that the Veteran and/or family accept news of a limited lifespan. Even if not intended, the association may be made by families when a discussion of palliation takes place primarily in the same conversation as news about a negative prognosis. Language such as the following is suggested:

- "Our team values both quantity and quality of life."
- "Improving symptom control and reducing the burdens of suffering can often help you tolerate treatment, which can help your disease and improve your function and quality of life at the same time."

The desire to avoid accepting death may result in a desire to avoid accepting palliative goals if the two are perceived as linked. Treatment choices should always be framed as driven by caring rather than by a poor prognosis.

After the Veteran and family have been given time to adjust to bad news, some may not accept what they have been told about the prognosis. This should not stop the goals of care conversation. Instead, the provider can talk with the Veteran and family about treatment plans for alternative scenarios, including if things go as the Veteran and family

hope or if they do not. Most Veterans and their families can appreciate the wisdom of a strategy to “hope for the best and prepare for the worst.”

Create the right setting

The following are important elements in creating the right setting for the goals of care conversation: (See also EPEC for Veterans Module 3: Communicating Difficult News)

- reserve a room that allows for privacy and has enough chairs for all who will attend per the wishes of the Veteran; if the Veteran is unable to get out of bed and the conversation must happen at the bedside, ask any roommates or visitors to give you some time to meet privately with the Veteran and family if at all possible;
- schedule enough time and minimize interruptions; have someone else cover your pager during the meeting;
- respect the Veteran’s preferences with regard to who should be in attendance, who should not, who will make decisions and how consensus will be reached; and
- provide information to the Veteran/family ahead of time to make sure everyone understands that the purpose of the meeting is to establish, or update, goals of care so the Veteran receives treatments that are consistent with his/her wishes.

Balance truth and hope

Within the bounds of the topics and level of detail the Veteran and family are ready to discuss, tell the truth about the Veteran’s condition and the likelihood of benefits and burdens of interventions. Be honest and straightforward, but not too blunt. Clinicians, particularly physicians, have been shown to offer unrealistic prognoses that are almost always overly optimistic.⁴ The majority of patients say they want the truth.^{5,6} Withholding information about the possibility that the Veteran may die is not a helpful means of promoting hope; families need time to prepare emotionally and logistically for death, and withholding information can erode autonomy and trust.

A delay in the discussion could result in delayed decision making and prolonged use of life-sustaining treatments that may not have been selected had the Veteran/family had more time to emotionally adjust to the Veteran’s pending death, and sets the family up for complicated bereavement.

Hope is defined as the desire and search for a future good. Health care providers, patients and families have identified hope as very important. Most Veterans cope and sustain hope by making plans for the future, even if the future is not one they would have chosen for themselves. Most people have room to hope and plan for several possibilities simultaneously. Patients and families have a wide range of things they are hoping for, and although cure and prolonged life may be one of their hopes there are often many others and they are important to elicit and discuss.⁷

There are a number of outcomes for both Veterans and clinicians to hope for during care for severe and life-limiting illness, and these hopes will transform over time as some hoped-for outcomes become less likely. Veterans and their clinicians can hope that they will be cured, that they will live with their illness for a long time, that symptoms will be controlled, that important business can be accomplished before death, that death will be comfortable and safe, and that family will recover from their bereavement and proceed to live fruitful lives.

Veterans may have hope in a future that includes them even after their death by living on in the memory of or legacy that they have provided for their friends and family. This kind of hope is transcendent over death and illness. Regardless of whether or not desired goals, e.g., curing or controlling the disease, are possible, the clinician can talk about what can be done for symptom management, preservation of dignity, and the practical and emotional support of the Veteran and family. Legacy building and formation have been the focus of programs such as Dignity Preserving Therapy, as described by Chochinov and others.⁸ Such approaches may guide the interdisciplinary team in working with individual Veterans and their families to preserve hope and dignity near the end of life. At the same time, is important for clinicians to recognize that the process of grieving over lost hopes takes time and deserves respect. It is not helpful to try to rush the Veteran/family into focusing on new hopes when they are still intensely grieving over the loss of previous ones.

Elicit concerns and express empathy

Slide 18

Elicit concerns and express empathy

Ask – Tell – Ask
Bracket information you provide with questions to be sure you are giving the information that is most helpful to the patient

N – Name the emotion
U – Understand the emotion
R – Respect the patient
S – Support the patient
E – Explore the emotion

Back et al., 2005

It can be difficult for Veterans and family members to discuss goals, particularly when they have had to let go of hopes that are no longer realistic. When discussing goals of care, Veterans and families may express negative emotions including fear, sadness and anger. Veterans want their clinicians to show that they care and understand them as individuals rather than to focus solely on the physical aspects of their disease. Studies have indicated that physicians frequently do not adequately predict patient concerns.⁹ Be curious about their hopes and fears, and respond to both verbal and nonverbal cues. Ask Veterans and family members directly about their concerns, using open-ended questions and allowing plenty of time for responses. If the Veteran expresses a concern and asks for

information, consider the “Ask-Tell-Ask” approach to be sure that the information you provide is the most helpful to the Veteran.¹⁰

Veteran: “I’m worried about whether this treatment is going to do the job. What do you think?”

Clinician [**Ask**]: “To make sure I answer your question, can you tell me specifically what you’re wondering about?”

Veteran: “I’m worried I might not make it to my Marine Corps reunion in June.”

Clinician [**Tell**]: “I have confidence that with this treatment and the other things we can do to manage your symptoms, you should be able to attend the reunion.

[**Ask**] Do you need more information about what is expected from your treatment?”

Veteran: “No. The reunion was the biggest thing I was worried about.”

Demonstrating empathy during discussions of these issues is important to the well-being of the Veteran. Responding to cues of emotional distress does not increase the length of the encounter, and may shorten it if you respond right away to what is most salient to the Veteran.

The NURSE mnemonic is another example of a helpful framework in guiding expressions of empathy with Veterans and families.¹¹

N – Name the emotion

“You seem frustrated.”

U – Understand the emotion

“It must be so hard to have to depend on others when you’re feeling worn out.”

R – Respect the Veteran

“I’m so impressed that you have been able to stay so determined.”

S – Support the Veteran

“The team and I are here to help you stay as strong as possible.”

E – Explore the emotion

“Tell me more about how your fatigue is affecting you.”

Some Veterans may appear stoic, but this does not necessarily mean that strong emotions are absent. Normalize those experiences and give the Veteran an opportunity to acknowledge them.

- “Many Veterans going through the same thing have told me that sometimes they have strong feelings of sadness or anger. What feelings are you having right now?”

If the Veteran has a pre-existing diagnosis of an anxiety or depressive disorder, assess the impact of the illness on the Veteran's mental health.

- “How has the cancer affected your PTSD symptoms?”

When discussing goals of care with surrogates it is important not to underestimate the magnitude of the emotional toll taken on those who have the responsibility to make weighty decisions they have likely never before faced. It can be very difficult to cope with the stress associated with making complex decisions, often involving a great deal of confusing technical information, while also dealing with the emotional burdens of grief and loss. Expressing empathy does a great deal to strengthen trust and provide comfort to those who are in a very difficult situation. The following is an example of empathic support:

- “It is obvious that you love your father very much and are working very hard to figure out what is the best thing to do for him. It must be so hard for you to see him this sick. We want to do everything we can to support you through this process, and will give you all the information we can to make it easier to come up with the best plan we can in these circumstances.”

Understand your patient's values

Before you address the Veteran's goals of care, be sure you understand your patient as a person. If you do not know the Veteran well, ask questions to help you understand their values and priorities. This may include questions about how they have faced challenges in the past or the people who are most important to them. If the Veteran does not have capacity, ask the surrogate about the Veteran's characteristics and values.

Things to remember:

Value and appreciate what the Veteran or surrogate communicates

Acknowledge emotion with empathic statements

Listen carefully

Understand who the Veteran is

Elicit information about previously expressed values¹²

Find out whether the Veteran has any pre-existing documents in which values and treatment preferences have been expressed (see EPEC for Veterans Module 2: Advance Care Planning). These may include advance directives, state-authorized portable orders, or life-sustaining treatment plans recorded in the Veteran's medical record. The treatment preferences and surrogate noted in those documents should be confirmed, and if not, the Veteran should be offered assistance in completing new documents, as appropriate. If the Veteran lacks decision-making capacity, those documents can help guide the surrogate and provider in determining goals of care and life-sustaining treatment plans that are consistent with the Veteran's values.

Protocol for goals of care discussion

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Protocol for goals of care discussion ...

A standardized approach to elicit and clarify the Veteran's goals of care, establish a treatment plan consistent with those goals, and plan for reassessment

Slide 20

... Protocol for goals of care discussion

1. Confirm a shared understanding of the Veteran's medical condition
2. Elicit personal goals for health care
3. Clarify whether primary goals of care are curative, palliative, or both
4. Recommend treatments consistent with the Veteran's goals
5. Establish a plan and confirm it

The following protocol gives the clinician a standardized approach to discuss goals of care with Veterans and their families. It guides the clinician through the process of eliciting the Veteran's goals of care, clarifying whether those goals are primarily curative, palliative, or a combination of the two, establishing a treatment plan to help the Veteran reach those goals, and agreeing on a plan for reassessment.

The use of this or any other communication algorithm with Veterans presumes adequate decision-making capacity. In situations where a Veteran does not have decision-making capacity, the steps below will be undertaken with the Veteran's surrogate and family members. For a review of assessment of decision-making capacity, see EPEC for Veterans Module 7: Comprehensive Whole Patient Assessment.

Before you begin, confirm that everyone knows that the conversation is taking place to help make sure the treatment plan is in line with the Veteran's goals.

Step 1 of 5: Confirm understanding of the medical condition

Slide 21



1. Confirm shared understanding

- Start with, “What do you understand about what’s going on with your illness?”

Start by determining what the Veteran understands about his or her illness. Examples of open-ended questions include:

- “What do you understand about what’s going on with your father?” and
- “What have the doctors told you is going on?”

Use this opportunity to address misconceptions or provide information. Confirm that you share the same information before moving on to discuss goals.

Step 2 of 5: Explore the Veteran’s personal goals for health care

Slide 22



2. Elicit personal goals ...

- Transition by talking about the future...
“When you think about the future with this illness, are there any things you worry about?”
“Are there things that you hope you can achieve?”
“What things are most important to you?”

Slide 23



... 2. Elicit personal goals ...

- Ask about goals of care
“Different people want different things from their health care... (give examples)... What about you? What do you want from your health care so you can live well?”

Slide 24

... 2. Elicit personal goals

- When the Veteran lacks capacity to make decisions...
 - ask family members / surrogate what they know about what the Veteran would have wanted
 - if available, use the Veteran's advance directive to facilitate discussion

Tell the Veteran that you are aware that different people have different goals for their health care, and give examples. Then ask an open-ended question to explore the Veteran's personal goals of care. It may be particularly important to take a holistic approach and utilize the interdisciplinary team approach in working to define goals of care for Veterans that explicitly address issues such as limited social support, mental health, fractured or irregularly defined family relationships, substance use disorders and lack of trust in VA and/or health care system in general. If these issues are not assessed and addressed they will be serious barriers to communication and the expression of the Veteran's personal goals for health care.

When the Veteran does not have decision-making capacity, discuss with the surrogate and family what is known about what the Veteran would want in the present circumstances. Encourage family members to report any discussions they had with the Veteran about goals and care preferences, and, if available, use the Veteran's advance directive to facilitate the discussion.

Step 3 of 5: Negotiate goals of care

Slide 25

3. Clarify goals

- Clarify whether primary goals of care are curative, palliative, or both
 - "From what I understand, you have a combination of goals – you would like to try to keep the disease under control but also not spend a lot of time in the hospital."

Through a process of shared decision-making, establish goals for the Veteran's care that are both desirable to the Veteran and have some chance of success. Some goals may be relatively easy to reach, others may be "long shots," and others may be virtually impossible. The clinician is responsible for providing information to the Veteran about the likelihood of success of each goal discussed, and is not obligated to agree to pursue a goal that is clinically impossible to reach.

Determine whether a Veteran who states an unrealistic goal recognizes its unlikelihood. It is critical that this be done with recognition of the difficulty of coping with loss and the importance of hope.

- “I can tell how much you want to live a long time and how frustrating it has been as your health has gotten worse. How likely do you think it is that your heart failure can be reversed?”

Use “I wish” statements to identify with the Veteran’s desire for a goal that is no longer within reach.

- “I wish there were treatments available that could stop the cancer from growing. I know how much you want to get better, and if I could give you something that would make that happen, I would.”

The clinician should inquire about goals not mentioned by the Veteran or surrogate if those goals appear consistent with the Veteran’s values. The Veteran or surrogate may not be aware of the potential for some improvements, or may have forgotten to mention a goal that could be achieved through the current course of care.

Summarize the agreed-upon goals of care and ask for any clarifications or corrections. Remind the Veteran and family that the goals of care will be revisited over time and can be revised if the Veteran’s preferences change.

Step 4 of 5: Recommend treatments consistent with the goals

Slide 26

4. Recommend treatments ...

- Recommend treatments consistent with the patient’s goals
“Let’s look at a treatment plan that allows you to work toward your goals. I would recommend ...”
- Address preferences for future care (CPR, artificial fluid/nutrition, other life-sustaining treatments, hospitalization, ICU care, hospice)

Slide 27

... 4. Recommend treatments

- To make informed choices about life-sustaining treatments, Veterans and their surrogates need accurate information
 - what the treatments consist of
 - the benefits and their likelihood to patients in similar circumstances
 - the risks
 - the alternatives

Recommend treatments consistent with the negotiated goals of care and verify that they are acceptable.

- “Let’s look at a treatment plan that allows you to work toward your goals. I would recommend...”
- “What are your thoughts about this plan?”

Discuss preferences for life-sustaining treatments that are relevant to the Veteran’s care, which may include cardiopulmonary resuscitation (CPR), artificial fluid/nutrition, mechanical ventilation, dialysis, or other life-sustaining treatments. It may also be appropriate to discuss whether the Veteran wants to avoid hospitalizations or ICU care, or is ready to consider a hospice referral. Issues of culture competency and health literacy must be considered when beginning these discussions. Misperceptions regarding resuscitation, other life-sustaining therapies, and hospice must be addressed in order to evaluate whether these approaches are consistent with the Veteran's goals of care. For instance, hospice is often misunderstood as care provided only in the last days of life or in a specific setting or institution. In VA, home hospice care is often a broader support program for Veterans and their families that may be integrated with disease modifying therapy.

Most people are unable to list the primary elements of CPR and overestimate its rate of success. Television programs are an important source of information about CPR for many people, and television portrayals suggest that the rate of survival among those receiving CPR is higher than the most optimistic rates reported in the literature.¹³ It is important that Veterans and their families understand the likely outcome and potential benefits and burdens of, and available alternatives to life-sustaining treatments. Among hospitalized patients who receive CPR, approximately one in six survive to discharge; the chances of survival are significantly lower for patients with metastatic cancer, dementia, or other severe life-limiting conditions.¹⁴

Check to see if the Veteran is ready to discuss these topics.

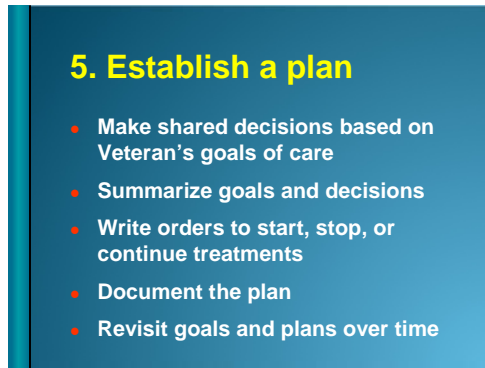
- “It would be helpful for me to know what kinds of treatments you would want if things get worse and you aren’t able to tell me what you want. Would it be ok to talk about those now?”

Some Veterans will be ready to talk about these choices and others will not. It is important not to push for decisions when the Veteran or family is not ready to make them.

Recommendations for or against specific treatments, with recognition of the difficult nature of the decision, are often very helpful for the Veteran and family, especially for decisions involving treatments with significant burdens to the Veteran. For complete information about discussing life-sustaining treatments with Veterans and their families, see EPEC for Veterans Module 10: Life-Sustaining Treatments.

Step 5 of 5: Establish a plan with the Veteran

Slide 28



5. Establish a plan

- Make shared decisions based on Veteran's goals of care
- Summarize goals and decisions
- Write orders to start, stop, or continue treatments
- Document the plan
- Revisit goals and plans over time

The final step is to establish a plan and confirm it with the Veteran. The clinician should facilitate shared decision making about treatments, and then provide a summary of the decisions that have been made to confirm shared understanding and agreement. The clinician is responsible for documenting the discussion, including goals of care and treatment plans, and writing associated orders in the Veteran's medical record. Reassessment of goals of care should take place periodically, particularly after treatment milestones, changes in quality of life, and changes in prognostic indicators.

Be sure to give the Veteran and family the opportunity to express any remaining concerns or questions before concluding the meeting, and encourage the Veteran to contact you if goals change prior to your next planned encounter.

Approaches to avoid

Many well-intentioned clinicians may, during goals of care discussions, inadvertently damage the joint decision-making process and their relationships with Veterans and their families. There are some approaches that are likely to lead to unwanted consequences, including increased defensiveness on the part of the Veteran and/or family, damage to the therapeutic relationship, and the selection of treatments to attempt to prolong life when they are very unlikely to provide benefit.

Avoid debate about the medical reality of impending death

Slide 29



Approaches to avoid ...

- Avoid debate with the Veteran or family about the medical reality of death
 - don't keep bringing up the DNR order if they are not ready to consider it
 - look for opportunities to align
 - use "I wish" statements
 - ask for permission to talk about what can be done if things don't go as hoped

If the Veteran or family members are not ready to accept a negative prognosis, do not try to convince them that the Veteran is going to die. Repeatedly approaching the Veteran or family members about a DNR order is more likely to increase defenses than to help them adjust to the impending loss. Instead, align with the Veteran and family as much as possible and openly express empathy. Use “I wish” statements and express your intention to do everything you can to help the Veteran.

- “I wish I could tell you there are treatments that could make him healthy again. I know this must be so hard for you, and you have my word that we will do everything we can to take excellent care of your dad.”

Families are often willing to accept a trial of treatment followed by reassessment.

- “Let’s see if he responds to this treatment over the next two days. Would it be ok to look ahead and talk about what options we will have to take care of him if things don’t turn around?”

If the Veteran or family members are not ready to talk about those issues, validate their feelings (“I can understand why you would not want to talk about this”) and give them more time. Pushing toward acceptance of palliative goals when someone is not ready will not help. It will only cause a greater sense that they are misunderstood or that their loved one’s life is less important to you than it is to them, and will cause them to trust you less rather than more.

Avoid oversimplifying the decisions to be made

Slide 30

... Approaches to avoid ...

- Avoid present difficult, value-laden decisions in an impersonal or an overly simplified manner

leads to uncertainty
acknowledge lack of clarity
discuss how the team will support Veteran/family

End-of-life decisions are complex, emotionally difficult, and influenced by individual values. It is critical for providers to acknowledge these factors and recognize the amount of stress that is experienced by decision makers. By presenting the decisions impersonally or as if there are “right” or “wrong” answers, the clinician only increases the sense of confusion and ambiguity, and under those conditions most people choose options that attempt to prolong life. These decisions can lead to later regret if the decision maker looks back and perceives that they only increased their loved one’s suffering and prolonged their death. Veterans and their families will benefit if providers acknowledge the lack of clarity about “the right thing to do,” and offer to support the decision-making

process by providing information, answering questions, and providing recommendations that are informed by the Veteran's and family's stated values.

Avoid labeling the Veteran or family as “in denial”

Slide 31

... Approaches to avoid ...

- **Avoid labeling the Veteran / family as “in denial” when they are actually experiencing normal grief and conflict**
may be a sign that they need more time to grieve and adjust
don't label the family as pathological if they do not agree to a DNR order on your timetable

Most people instinctively fight death and want to live. When provided with information that their efforts to avoid a premature death will not be successful, it is common to experience difficulties coping with the associated grief and emotional distress. If a Veteran or family member is not ready to talk about goals of care, DNR orders or treatment plans after receiving bad news, it is most often an indication that the person has not had enough time to emotionally process very upsetting information. When clinicians label Veterans or family members as “in denial,” they do not adequately appreciate the grief being experienced and therefore do not provide the proper care in response. Although denial can occur, resistance to moving toward decisions or actions that acknowledge a poor prognosis is usually a sign that an individual needs more time and support to meet the huge emotional challenges of the circumstances.

In order to protect themselves from the grief and distress of Veterans and families, clinicians can, without realizing it, separate themselves emotionally by perceiving expressions of grief and conflict as signs of denial. Clinicians can benefit from regular self-assessment of the impact of such emotionally difficult work and the coping strategies they are using to manage their own emotions.

Avoid using language with unintended consequences

Slide 32

... Approaches to avoid

- **Avoid using language with unintended consequences.**
“Do you want us to do everything possible?”
“Do you want us to be aggressive or not?”
“Will you agree to discontinue care?”
“It's time we talked about pulling back.”
“I think we should stop active therapy.”

Some questions and statements have unintended consequences. Examples include:

- “Do you want us to do everything possible?”
- “Do you want us to be aggressive or not?”
- “Will you agree to discontinue care?”
- “It’s time we talked about pulling back.”
- “I think we should stop active therapy.”

Most of these questions imply a dichotomous choice: do everything or do nothing; provide good care or substandard care; treat or abandon. If goals of care conversations focus on what *can* be done, and improving the Veteran’s well-being is always at the top of priority list regardless of the primary goal of care, Veterans and family members will be reassured that they will not be abandoned. Always stress what can and will be done to help the Veteran and family; always give options and care when Veterans/family are having to release some goals of care. The following is an example of such language:

- "By moving your dad to the Palliative Care Unit from the MICU you can spend much more time with him while we focus on comfort, symptom control, and possibly home care."

Special concerns

Slide 33

Older adults ...

- **Factors that can influence goals of care discussions**
 - tend to be less assertive with physicians
 - more likely to be influenced by companions
 - may experience sensory deficits, cognitive loss
 - higher rates of poor health literacy

Slide 34

... Older adults

- **To meet the challenges:**
 - reduce complexity of communications – use simple language, avoid jargon
 - reduce the density of communications – no more than 3 key concepts per encounter
 - assess & accommodate for sensory deficits
 - use “teach back” method with both patient and caregiver

Older adults

Older adults make up a significant proportion of Veterans who need end-of-life care, and the proportion of older adults in the population is projected to increase. Some characteristics that commonly occur in older adults may make communication about health care goals more challenging. Older adults tend to be less assertive with clinicians and may not express their opinions when they disagree with recommendations.¹⁵ Older cancer patients are more likely than younger patients to prefer a passive role in treatment decision-making processes.¹⁶ Older adults are often accompanied by family members or other companions, and those individuals can engage in behaviors that either promote or detract from patient autonomy.¹⁷

Many older adults experience sensory deficits and/or cognitive loss which may affect their ability to perceive or comprehend information that is presented visually or auditorily.^{18,19} Especially when the deficits are mild to moderate, the clinician may not be aware that the Veteran has sensory or cognitive losses significant enough to interfere with the Veteran's ability to profit from standard communications about goals of care.

Low health literacy has been shown to be a significant challenge for older adults. Health literacy is defined by the AMA as "a constellation of skills, including the ability to perform basic reading and numerical tasks, required to function in the health care environment."²⁰ Older patients have among the lowest health literacy rates, placing them at risk of poor quality medical decision making and poor health outcomes.²¹ Although less is known about health literacy specifically among Veterans, some recent data suggest that up to 20% of Veterans may have low health literacy.²²

Adjustments in communication strategies are required when discussing goals of care with older adults with characteristics that make communication more challenging. It is recommended that the clinician ask older Veterans if they have any problems with their hearing, vision, memory or concentration; although they may deny problems that are actually present, simply asking the question can elicit useful information, cuing the clinician to speak louder or to avoid the use of visual prompts. When working with older Veterans with communication barriers, the complexity of communications should be reduced, the use of jargon and technical terms should be avoided, and the density of communications should be reduced to no more than three key concepts per conversation.²³ For more information, please see the EPEC for Veterans Module 3: Communicating Difficult News.

Cultural competence

Slide 35

Cultural competence ...

- End-of-life attitudes, decisions influenced by personal cultural context
- Can influence role expectations for Veteran, family, providers and community communication patterns dynamics of decision-making

Slide 36

... Cultural competence ...

- Ethnicity may be associated with shared beliefs and values that influence decision-making at the end of life
- Health literacy – key variable
- Some cultures emphasize family over individual decision making

Slide 37

... Cultural competence

- Differences within groups are commonly greater than differences between groups
- Be aware of potential differences but do not assume they exist
- Ask about communication preferences, decision-making strategies, disclosure

Cultural background and context can include religion, ethnicity, educational background, spiritual or religious beliefs, or any identification with a particular community. Each individual’s personal cultural context inevitably influences attitudes toward end-of-life decision making and care. Cultural background and context can shape Veterans’ and family members’ expectations regarding the role to be played by the Veteran, the family, health care providers, and members of the community in end-of-life decision making and care. Cultural background also shapes communication patterns of health care providers, Veterans, families, the approach to treatment decisions, and the way health care providers, Veterans, and families respond to and cope during the dying process.

Culture may have an effect on Veteran values and how they influence decisions about goals of care. For example, in the context of end-of-life care, African-Americans have been noted to use hospice at a lower rate than Caucasians,²⁴ particularly for noncancer

diagnoses,²⁵ and to leave hospice to seek life-prolonging treatments more frequently than other groups.²⁶ One recent study indicated that older African Americans from the southeastern U.S. were more likely than older whites from the same region to have discomfort when discussing death, want aggressive care at the end of life, have spiritual beliefs that conflict with palliative goals of care, and distrust the health care system. These factors together, but not alone, were found to influence end-of-life decisions.²⁷

Although traditional medical and bioethical norms in the United States are supportive of autonomy and truth-telling with respect to medical care, in some subcultures the risks of truth-telling are considered to outweigh the benefits. For example, traditional Navajo beliefs hold that talking about potential negative outcomes causes them to happen.²⁸ Preferences for withholding information from the patient and allowing the family or the clinician to make decisions are also common in other cultures outside the United States.²⁹ Clinicians should be aware of the prevalence of different communication styles among individuals from particular populations and seek to determine the Veteran's preferences and values.

Health care providers and palliative care clinicians should also be aware that bias or insensitivity in society in general or among health care providers can contribute to Veterans with disability having negative interactions with the health care system. Disabled Veterans may be particularly disconcerted and wary of discussion of quality of life since they may have experienced biases that their quality of life is diminished by their disability, when in actuality their quality of life is high. It is critical that hospice and palliative care services be integrated with care for the disabled community.

Each Veteran should be given the opportunity to define communication preferences, including what and to whom information should be disclosed and the strategies that will be used by the Veteran and family to make decisions. The culturally competent clinician respects individual values and cultural backgrounds, and works to understand and integrate these aspects of the individual into patient-centered care.

Summary

Slide 38



Determining goals of care with Veterans and families as early as possible in the course of serious and life-limiting illness ensures that the Veteran will receive treatments consistent

with their goals. Veterans' goals of care when experiencing life-threatening illness are generally curative, palliative, or a combination of the two. From the initial encounter, palliative care goals can be integrated with other goals which may appropriately change over time. Treatment decisions will be informed by disease characteristics, goals of care, and individual factors. A protocol for discussing goals of care has been offered, along with key practices for success, approaches to avoid, and information about factors that may influence end-of-life decision making among special populations.

Key take-home points

1. Historically, medical decision making occurred in a dichotomous way; therapies with curative and/or life-prolonging intent were provided until no longer effective, and then the goal of care shifted abruptly to relief of suffering. The interrelated goals of care model emphasizes that relief of suffering can be integrated throughout the continuum of care and the Veteran's goals can be primarily curative, primarily palliative, or a combination of both.
2. The Veteran's and family's understanding of the medical condition should be confirmed prior to eliciting the Veteran's goals of care.
3. End-of-life issues are inseparable from the experience of grief and loss, and the clinicians should elicit concerns and express empathy to address the distress of Veterans and family members. Ask-Tell-Ask and the NURSE mnemonic are techniques that can be helpful in guiding clinicians through this process.
4. Goals of care should be negotiated between the Veteran or surrogate and the practitioner according to the Veteran's preferences and clinical circumstances. Clarification of goals helps the clinician determine which treatments to offer and helps the Veteran and family make decisions about which treatments to accept.
5. The clinician should offer choices about treatments that are consistent with the Veteran's goals of care. The clinician should not offer treatments that are inconsistent with those goals or that have no chance of achieving those goals.
6. Goals of care should be reassessed periodically, particularly after treatment milestones, changes in quality of life, and changes in prognostic indicators.
7. There are approaches to *avoid* when discussing goals of care, including debating with the family about the medical reality of impending death; presenting difficult decisions in an impersonal or oversimplified manner; labeling the Veteran or family as "in denial" when they are actually experiencing normal grief and conflict; and using language with unintended consequences (e.g., "Do you want us to do everything possible?").
8. Adjustments in communication strategies are required for older adults who possess characteristics that make communications more challenging. These include reducing

the complexity and density of the communication, accommodating sensory deficits, and using “teach back” methods to assess understanding.

9. Clinicians should recognize the influence of personal cultural context on end-of-life decisions and attitudes.

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