

EPEEC for Veterans

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

Trainer's Guide

Plenary 1

Introduction to EPEEC for Veterans

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Contact EPEC by E-mail at info@epec.net, or

EPEC®

750 N. Lake Shore Drive, Suite 601

Chicago, IL 60611

USA

Phone: +1 (312) 503-EPEC (3732)

Fax: +1 (312) 503-4355

Plenary 1 trainer's notes

Principal message

The goal of palliative care and hospice is to relieve all types of suffering. Hospice and palliative care are becoming more widely available and more widely used, both in VA and in the United States overall.

Plenary overview

Plenary 1 is designed to introduce the EPEC for Veterans Curriculum and provide basic background in palliative care and hospice. It presents information on how people die in the US generally and VA, describes models of hospice and palliative care, discusses concepts of suffering as they relate to palliative care and outlines the EPEC for Veterans Curriculum.

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

The suggested timing for this plenary is:

Introduction	2-3 minutes
Trigger tape	10 minutes
Presentation	35 minutes
<u>Summary</u>	<u>2-3 minutes</u>
Total	49-51 minutes

3. Number of slides: 44

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 **Plenary 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 plenary. To establish the context for the session, make a few broad statements about the importance of palliative care. Tell participants the format you will use and the 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.

Then, proceed with the content of the plenary.

4. Show the trigger tape

After reviewing the objectives for the session, show the trigger tape. It has been designed to engage the audience and provide an appropriate clinical context for the session. This trigger tape describes palliative care at VA and includes testimonials from Dr. Tom Edes, Dr. Robert Petzel and multiple Veterans, their family members and their professional caregivers.

5. Present the material

Recommended style: Lecture

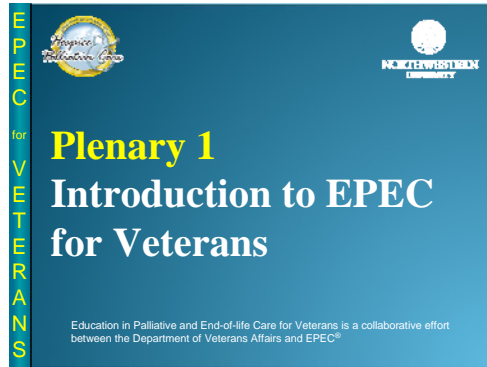
This plenary was designed to be presented as a lecture without much audience interaction. Use the slides to trigger the subject. Prepare ahead and practice so that it is smooth and interesting. The use of your voice, body language, and gestures can all add to your presentation and the clarity of the message you are delivering.

6. Evaluation

Ask the participants to evaluate the session.

Abstract

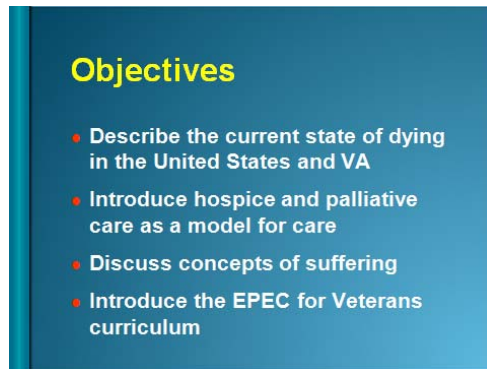
Slide 1



This plenary provides background for the EPEC for Veterans Curriculum. It presents a profile of how people currently die in the United States and contrasts this with data about the way they would like to die. Suffering can be conceptualized as a fragmentation of personhood, as a disturbed life story or as total pain. People don't suffer in isolation; Veterans and families must be considered together. Suffering is best relieved by using a team to approach the many elements involved in palliative and end-of-life care. The term *palliative care* defines a model for the relief of suffering and the improvement of quality of life across the spectrum of illness. Hospice is currently the most widely available program for the delivery of palliative care near the end of life.

Objectives

Slide 2



The objectives of this plenary are to:

- describe the current state of dying in the United States and at VA;
- introduce hospice and palliative care as a model for care;
- discuss concepts of suffering; and
- introduce the EPEC for Veterans Curriculum.

Introductory video

Slide 3



This module includes a trigger tape featuring Drs. Robert Petzel and Tom Edes, and the words of Veterans, their families, and their professional caregivers describing their care.

Introduction

Every year, more than two million Americans die of a variety of causes. Of these, approximately 600,000 are Veterans.¹ Of those Veterans who die each year, 20% are enrolled in the Veterans Affairs (VA) health system, and 5% die in VA facilities.² These numbers speak to the need to focus on providing the best possible care for Veterans at the end of life, particularly hospice and palliative care.

Hospice and palliative care is a philosophy of care. In 1982, Dr. Eric Cassell published his seminal article on the nature of suffering. Dr. Cassell pointed out that “bodies do not suffer, only persons do.”³ People are unique and do not experience a disease in the same way. People 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.

EPEC for Veterans focuses on the personhood of the Veteran. This plenary will highlight some of the barriers to providing high-quality end-of-life care that will be discussed throughout the curriculum.

How Americans died in the past

Slide 4

How Americans died in the past

- Early 1900s
 - average life expectancy 50 years
 - childhood mortality high
 - adults lived into their 60s
- Prior to antibiotics, people died quickly
- Medicine focused on caring, comfort
- Sick cared for at home (cultural variations)

In the early 1900s, average life expectancy in the United States was 50 years.⁴ Historically, until the development of antibiotics in the mid-20th century, people typically died quickly, often of infectious diseases or accidents. As only a few remedies were available to extend life, medicine focused on caring and comfort. While customs and traditions varied across cultures, most cared for their sick at home.

Medicine's shift in focus

Slide 5

Medicine's shift in focus ...

- Science, technology, communication
- Marked shift in values, focus of North American society
 - "death denying"
 - value productivity, youth, independence
 - devalue age, family, interdependent caring

Slide 6

... Medicine's shift in focus ...

- Potential of medical therapies
 - "fight aggressively" against illness, death
 - prolong life at all cost
- Improved sanitation, public health, antibiotics, other new therapies
 - increasing life expectancy
 - 1995 avg 76 y (F: 79 y; M: 73 y)
 - 2009 avg 78 y (F: 81 y; M: 76 y)

Slide 7

... Medicine's shift in focus

- Death “the enemy”
organizational promises
sense of failure if patient not saved

During the second half of the 20th and beginning of the 21st century, some have suggested that we have become a “death-denying” society valuing productivity, youth, and independence and devaluing age, family, and interdependent caring for one another. At the same time, new discoveries and technology have offered the potential of medical therapies previously unknown. Where once health care professionals could only provide comfort in the face of serious illness, the modern health care system can now “fight aggressively” against illness and death.

The development of public health strategies, a wide range of antibiotics and other medical interventions have increased life expectancy to an average of 77.8 years by 2005 (80.4 years for women compared with 75.2 years for men).⁵ New medications and therapies have changed the way we experience illness. These advances are to be welcomed but they run the risk of making palliative care a poor second choice to traditional care.

Place of death

Slide 8

Place of death

- 90% of respondents to the National Hospice Organization Gallup survey wanted to die at home
- Death in institutions
 - 1949 – 50% of deaths
 - 1958 – 61%
 - 1992 – 74%
 - 1998 – 63%
 - 57% hospitals, 17% nursing homes, 20% home, 6% other (1992)
 - 2000 – 75%
 - 60% in hospitals, 25% in nursing homes, 25% home

In contrast to the desire to die at home expressed by 90% of healthy respondents to a Gallup survey commissioned by the National Hospice Organization (NHO; now NHPKO) in 1996, death has generally moved out of the home and into institutions.⁶ Although the numbers of patients (as opposed to healthy individuals) who would want to die at home is lower than 90%, it is still a majority of people: a survey of patients in general practice showed that about 60% of them would prefer to die at home.⁷

Interestingly, as death approaches, at least one study found that the numbers of patients who wanted to be at home decreased.⁸ This likely has to do with high care needs that patients have as death approaches and implies an important role for palliative care units in VA and elsewhere.

By 1949, 50% of deaths in the United States occurred in institutions. As of 1958, this had increased to 61%. In 1992, 57% of Americans died in hospitals, 17% died in nursing homes, and only 20% died in their own homes. In 1998, 42% died in hospitals, 21% in institutions and 21% at home.⁹

As care for patients with life-threatening illnesses has shifted into institutions, a generalized lack of familiarity with the dying process and death has evolved. Most nonprofessionals have never seen a dead body except, perhaps, at a funeral. Fantasy about what death is really like is fueled by media dramatization, rarely reality.¹⁰

In one study for example, investigators found that the rate of successful resuscitation depicted on television approached 66%.¹⁰ This study is in contrast to data showing rates of survival to be less than 20%.¹¹

Place of death - in VA hospitals

Although we do not know the proportion of Veterans who die at home compared to in inpatient facilities, we do know about the distribution of inpatient deaths in VA. In fiscal year 2009 there were 20,793 inpatient deaths at VA Medical Centers. Of these, 5,198 were in the ICU, 7,070 in acute care, 1,663 in nursing home care units and 6,862 in hospice beds.¹² These numbers illustrate the importance of education for health care professionals regarding end-of-life care.

End of life trajectories

Slide 9

End of life trajectories

- > 90%
- predictable steady decline with a relatively short “terminal” phase
cancer
- slow decline punctuated by periodic crises
CHF, emphysema, Alzheimer’s-type dementia

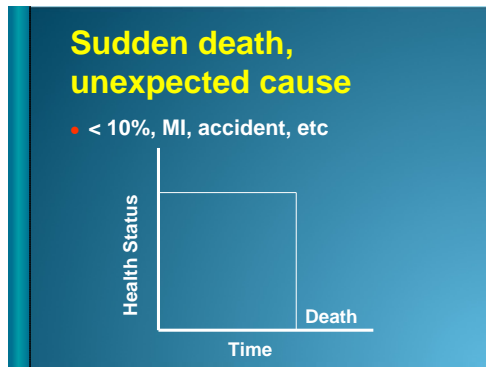
There are multiple trajectories of illness. A few of us (< 10%) will die suddenly of a myocardial infarction, accident, trauma or other unexpected event.

Most of us (> 90%) will experience chronic illnesses with either a relatively predictable, steady course and a relatively short “terminal” phase, e.g., cancer, or a slow decline punctuated by periodic crises, e.g., heart failure, COPD. More recently, a new theoretical

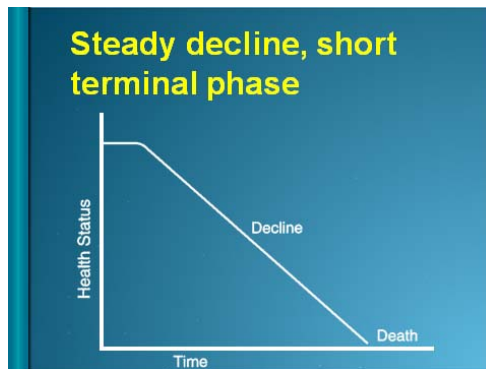
trajectory that better describes frailty, multimorbidity and dementia in which a low level of functional status may be present for years, associated with significant suffering and distress. The need for palliative care is often great for these patients but the prognosis is so difficult, that many are never referred to hospice.

For many years, these trajectories were theoretical; recent work by Lunney and colleagues, have given empirical basis to them.¹³ Each of these inflection points offers opportunities to intervene to both clarify goals of care and address symptoms.

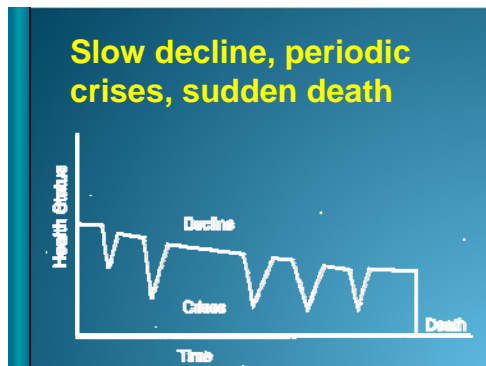
Slide 10



Slide 11



Slide 12



Barriers to end-of-life care

Slide 13

Barriers to end-of-life care ...

- Lack of acknowledgment of importance
- Fear of addiction, exaggerated risk of adverse effects
- Restrictive legislation concerning opioid prescribing

Slide 14

... Barriers to end-of-life care

- Discomfort communicating “bad” news and prognosis
- Lack of skill negotiating goals of care, treatment priorities
- Personal fears, worries, lack of confidence, competence

There are many reasons why end-of-life care in the United States is not what it could or should be. These include:

- Frequently, neither the public nor health care providers acknowledge that end-of-life care is important. It is often introduced too late to be effective, and funding is frequently inadequate to deliver quality palliative care.
- Fears of addiction, exaggerated risks of adverse effects, and restrictive legislation have resulted in inadequate control of symptoms.
- Discomfort with communicating bad news and prognosis, lack of skill to assist patients and families to negotiate clear goals of care and treatment priorities, and lack of understanding of patients’ rights to decline or withdraw treatment may lead to misunderstanding and excessive futile intervention.
- Personal fears, fantasies, worries, and lack of confidence have prompted many clinicians to avoid dealing with patients who are dying.

Models for care: Hospice and palliative care

Slide 15

Role of hospice, palliative care ...

- Hospice started in U.S. in late 1970s
- Percentage of total U.S. deaths in hospice
 - 11% in 1993
 - 17% in 1995
 - 25% in 2000
 - 39% in 2009

Slide 16

... Role of hospice, palliative care ...

- Median length of stay remains low
 - 36 days in 1995
 - 16% died < 7 days of admission
 - 20 days in 1998
 - 26 days in 2005
 - 30% died < 7 days of admission

Slide 17

... Role of hospice, palliative care

- Palliative care programs / consult services evolving
 - earlier symptom management / supportive care expertise
 - possible impact on life expectancy

Hospice

In the 19th century, *hospice* was a term to describe places where the dying could be cared for. They were generally run by religious orders. Cicely Saunders founded St. Christopher's Hospice in South London, England as a new kind of hospice. It is a place where a team of professionals in a single institution pursues the medical, emotional, social, and spiritual care of patients and families. It is also an academic hospice, where education and research are pursued simultaneously with patient care. What we now generally term *palliative care* has grown out of, and includes, hospice care.

In the 40 years since the founding of St. Christopher's, what has been called the hospice movement developed on the fringes of institutional medicine and is now very much a part of mainstream medicine.

Hospice began to appear across the United States during the late 1970s. While initially run by volunteers and supported by philanthropy, in 1982 the federal government began reimbursing hospice care for Medicare beneficiaries with a prognosis of less than 6 months.¹⁴

Subsequent decades have seen a marked growth in the number of hospices operating in the United States. However, even with this growth, hospices still care for only a minority of dying patients: 11% of all deaths in the United States in 1993, 17% in 1995, 25% in 2000, and 38.8% in 2007.^{15,16} Although the numbers of patients who die while being cared for by a hospice has been rising slowly, patients may not spend enough time in these programs to experience all of the potential benefits.

In 1995, while the median length of stay in hospice was 36 days, nearly one fifth of patients died within a week of admission. By 2005, median length of stay was 26 days. Potential reasons for late referral include reluctance to discuss care at the end of life on the part of clinicians, Veterans and families; difficulty with prognostication and issues related to integration of disease modifying treatment into a home hospice care plan.^{16,17}

It is now widely recognized that cognitive information such as that covered in this EPEC for Veterans Curriculum is necessary, but not sufficient, to deliver good end-of-life care to Veterans. Clinicians must often be creative in meeting the broad needs of their Veterans at end-of-life. Clinicians remain key advocates for Veterans and their families within the health care system, you may be an agent for change within the health care systems in which you work. Urge yourself and your colleagues to insist on these elements for your Veterans.

Slide 18



In the United States, *hospice* is used to describe four different concepts:

1. A site of care for the dying, such as a freestanding facility or a dedicated unit within a hospital or nursing home.
2. An organization that provides care in a variety of settings but usually focused on the patient's home.
3. An approach to care that is integrated into all manner of care sites and practices, including intensive care units if necessary. In this sense it is synonymous with palliative care.

4. A benefit available to Medicare beneficiaries.

Unfortunately, the use of a single term for all of these meanings has led to some confusion. For many Veterans, the term hospice still means a place to go to die. For many clinicians, the term *hospice* means a poorly understood community-based program into which a patient disappears after a physician signs a form certifying a prognosis of less than 6 months. These persist even though the majority of patients enrolled in hospice programs live in their own homes until they die because that is where they want to be.

It is incumbent upon all clinicians to understand the concepts, as well as the details, so that Veterans will get the best possible care. Just as clinicians work with their local hospitals, nursing homes, and other sites where health care is delivered, so clinicians need to understand and work with their local hospice agencies so that the best possible care is administered. The Hospice-Veterans Partnership (HVP) offers a toolkit to create collaborations between VA facilities and hospices.¹⁸ Through the HVP, 41 states have active partnerships with local hospices. In addition, 6,603 unique Veterans received VA hospice care in FY 2009.¹²

Hospice levels of care

Under the Medicare Hospice Benefit, there are four levels of hospice care that can be used to provide care to Veterans and their families, depending on their need and setting of care:¹⁹

1. **Routine care** is care provided in the patient's home on a day-to-day basis, i.e., a private residence; a residential, assisted living, or long-term care facility; a jail or prison; or wherever the patient lives.
2. **General inpatient care** is short-term care provided in an acute care or long-term care facility when 24-hour nursing is required to:
 - Manage pain, other symptoms, or other issues that cannot be controlled at home.
 - Provide care during the last hours of life when symptoms may change quickly.
 - Provide care when the patient's caregiver is too fatigued or stressed to provide proper care.
3. **Continuous care** is enhanced care provided for short periods in the patient's home when the patient needs 8 or more hours of care per day (of which > 50% needs to be skilled nursing care provided by a registered nurse (RN) or a licensed practical nurse (LPN)).
4. **Respite care** is care provided in an inpatient setting to give the patient's informal caregiver(s) (their family members and friends) a break from the day-to-day care they are providing at home. Respite care is typically preplanned for family events.

It is limited to 5 consecutive days at a time. Inpatient respite care requires that a nurse be available 24 hours per day.

Core services

All levels of hospice care must include the following core services:

- Interdisciplinary team care, including:
 - Chaplaincy, nursing care, physician services, social work and counseling, and volunteers
 - Occupational, physical and speech therapy
 - Home health aide and homemaker services
- Bereavement counseling
- Medical equipment and supplies
- Medications and therapies related to the terminal diagnosis

Palliative care

To move beyond the confusion, the stigmatization, and the restrictions that have evolved as unintended consequences of the Medicare hospice benefit, the concept of palliative care has evolved. Palliative care has developed as a defined medical, nursing and social work specialty with clear standards of practice.²⁰ Various groups have defined palliative care in diverse but related ways. Each of the proposed definitions has in common the focus on relieving suffering and improving quality of life. All of the definitions stress two important features: the multifaceted, multidimensional nature of the experience of living with an acknowledged time-limiting illness, and the priority of working as a team to achieve the relief of suffering and facilitate the enhancement of life. The importance of supporting the family and patient as a unit is clear.

Slide 19

Palliative care – definition one

“Palliative care seeks to prevent, relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure... Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs... It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them.”

- Institute of Medicine, 1998

The Institute of Medicine has defined palliative care as:

“Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure... Palliative care in this broad sense

is not restricted to those who are dying or those enrolled in hospice programs.... It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them.”²¹

Slide 20

Palliative care – definition two

“The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment.”

- WHO, 1990

The World Health Organization (WHO) has defined palliative care as:

“The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment.”²²

Slide 21

Palliative care – definition three

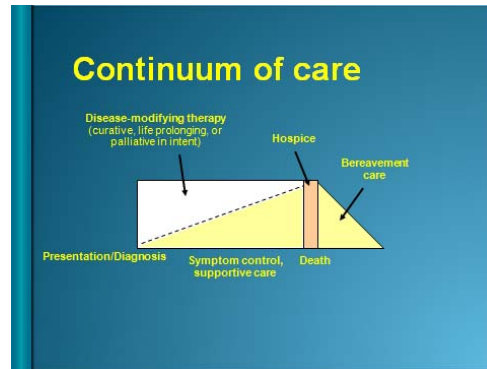
“A continuum of comfort-oriented and supportive services provided in the home, community and inpatient settings for persons with advanced disease. Programs emphasize the comprehensive management of the physical, psychosocial, social and spiritual needs of the patient and include bereavement care for the family .”

- Department of Veterans Affairs

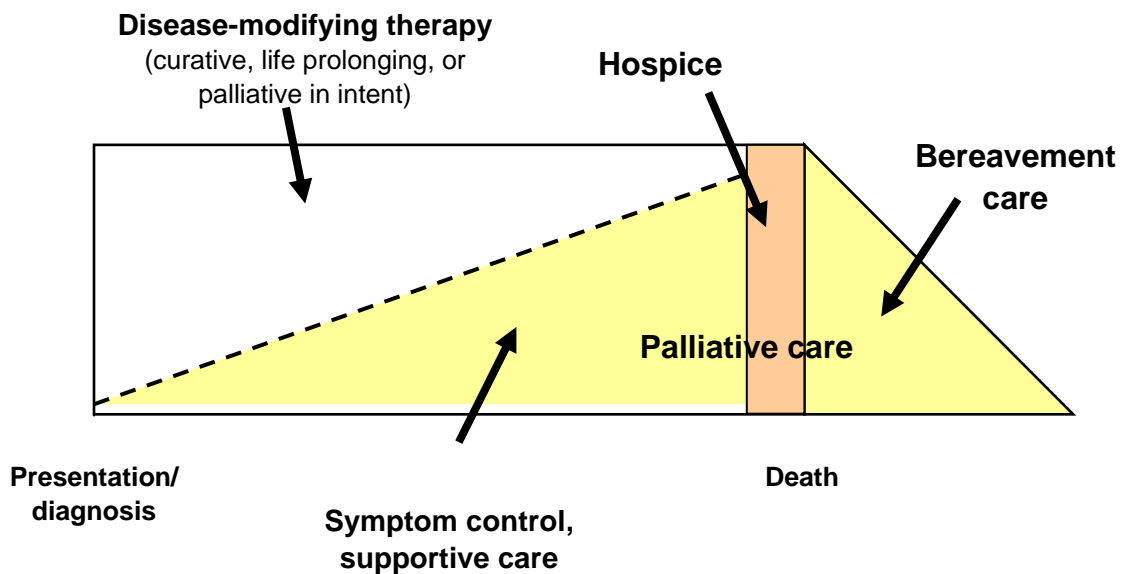
VA defines hospice and palliative care as:

“A continuum of comfort-oriented and supportive services provided in the home, community and inpatient settings for persons with advanced disease. Programs emphasize the comprehensive management of the physical, psychosocial, social and spiritual needs of the patient and include bereavement care for the family.”²³

Slide 22



Continuum of care



This continuum of care is illustrated above. This diagram shows how disease-modifying therapy or palliative therapies balance as an illness progresses. Comfort-oriented symptom control and supportive care increase over time, maximizing as dying culminates in death. Often people receive this care through a hospice program. Bereavement continues for some time after death. Palliative care provides for all 3 phases for the family as well as for the patient.

Delivering palliative care

Slide 23



Clinical palliative care can be made available at 3 distinct levels, primary, secondary, and tertiary care, in parallel with current concepts of all medical care.²⁴

Primary palliative care refers to the generalist skills and competencies required of all clinicians. Examples are skills in communication, pain and symptom management, team work, and health care system savvy.

Secondary palliative care refers to the specialist clinicians and organizations that provide consultation and specialty care. By analogy, while not all patients admitted to the hospital with pneumonia require an infectious disease specialist, some do. In palliative care, specially trained clinicians and care delivery models, such as palliative care consultation services, provide care in a variety of settings: the patient’s home, nursing homes, outpatient clinics, and hospitals.

Tertiary palliative care refers to the academic centers where specialist knowledge for the most complex cases is practiced, researched, and taught.

Consultation services

Consultation services help deliver specialist palliative care in a manner similar to other consultation services.^{25,26,27} Palliative care consultation services are a way to bring specialist knowledge and expertise about the relief of suffering and improving quality of life to bear *in combination with* other medical services in the hospital.²⁸

Inpatient units

Palliative care units have developed in hospitals for the same reasons that intensive care units developed - they are a response to increasing knowledge and the desire to provide care efficiently.

Veterans can be admitted to acute palliative care units in hospitals for a variety of reasons. They can be admitted directly from home when the ‘usual’ evaluation in the emergency department or oncology unit of the hospital does not seem appropriate. They can also be admitted from the emergency department, psychiatric units, the surgical recovery room, and the intensive care units.

Home care

Most Veterans experience the majority of their illness at home. Programs to extend palliative care services into the home are sometimes offered by oncologists or nurses making home visits themselves, or through organized services. Some home health agencies have developed special palliative care expertise. The most comprehensive programs for palliative care at home are hospice programs.

Long-term care

A variety of arrangements for the care of the frail and the elderly have been developed. A variety of names (group homes, residential care for the elderly, nursing homes, skilled nursing facilities) connote the range of services available. Palliative care services are becoming more frequently available in all of these settings. The most comprehensive programs for palliative care in long-term care settings are frequently hospice programs.

Outpatient care

The provision of palliative care can also be provided in the outpatient setting.²⁹ These are ideal settings for initial and follow-up visits with patients who are early in their illness and may be seeking disease modifying therapy with a curative intent.

Development as a specialty

The development of academic palliative care has been slow but steady.³⁰ The first modern academic hospice, St. Christopher's Hospice, was developed by Dr. Cicely Saunders and opened in 1967. Those who studied with Dr. Saunders and her colleagues developed similar academic programs at Oxford University, McGill University, and in conjunction with Yale University.

Curricula on palliative care have been developed and broadly disseminated.^{31,32} Certifying boards recognizing subspecialists in hospice and palliative medicine have been established both for physicians and for nurses.^{33,34,35} There are at least seven subspecialty peer-reviewed journals serving the field.³⁶ Chapters in general medical textbooks and subspecialty textbooks have been published. Fellowship programs are developing to train physicians who wish to subspecialize.^{37,38} VA Inter-Professional Palliative Care Fellowship program trains clinicians at six sites.

Palliative care in VA today

Slide 24

Comprehensive End of life Care Initiative (CELC)

Goals:

- Improve access to hospice and palliative care in all settings
- Build a sustainable hospice and palliative care infrastructure
- Implement quality measures and disseminate successful practices
- Increase expertise
- Evaluate and monitor effectiveness and sustainability of initiative

Slide 25

Reliable access

- Inpatient
 - Staffing of Palliative Care Teams
 - Staffing NEW HPC Units
 - Enhancing EXISTING HPC programs
- Home
 - Outreach to homeless and rural Veterans
 - Hospice-Veteran Partnerships
 - State level organization
 - Facility level relationships

Slide 26

Training and expertise in hospice and palliative care

- Veteran-centered curriculum for end-of-life care
 - Education in Palliative and End-of-life Care for Veterans (EPEC for Veterans)
 - PCNA Training Project
 - End-of-Life Nursing Education Consortium (ELNEC) for Veterans

Slide 27

Sustainable infrastructure

- Veteran-centered leadership training
 - VA Palliative Care Leadership Training in partnership with the Center to Advance Palliative Care (CAPC)

Slide 28

Quality

- Bereaved Family Member Quality Surveys
"The Voice for Veterans"
Foundation for future VA performance measure
- CELC Implementation Center
Driver for quality interventions, "sharing successes"
Leadership and mentoring

Palliative care at VA is coordinated by VA’s Hospice and Palliative Care Program and its Comprehensive End-of-Life Care (CELC) Initiative. In FY 2009, 41,085 palliative care consults occurred, with 59% of inpatient deaths preceded by a palliative care consult. During the same period 9,282 Veterans were cared for in inpatient hospice beds, accounting for 39% of all inpatient deaths. In addition to activity within VA facilities, the Hospice-Veteran Partnership (HVP) works in all 50 states to connect Veterans to community hospice resources. This has resulted in part, in an average daily census of 961 Veterans in VA-paid community hospice care. Finally, CELC working groups have launched a multipronged educational approach that has included leadership training in collaboration with the Center to Advance Palliative Care (CAPC), End of Life Nursing Education Consortium (ELNEC) for Veterans training, and Hospice and Palliative Nurses Association (HPNA) training for nursing assistants, in addition to EPEC for Veterans training.³⁹

Concepts of suffering

Slide 29

Concepts of suffering

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

What does it mean to suffer? All clinicians must have a conceptual framework within which to work, study, and teach if we are to have a hope of relieving suffering.

Eric Cassell outlined a conceptual framework for suffering.³ He pointed out that “bodies do not suffer, only persons do.” Individuals are unique and do not experience a disease in the same way. We suffer when our 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 built on the concept that personhood requires a past, present, and future by noting that human lives are, in a sense, stories.⁴⁰ Our story is our sense of self, and as we face dying, our story comes to closure. So often, when the patient comes to a physician or other health care professional, the emotional subtext of the patient'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 future looks different from before, and the present is consumed with new physical degeneration. The Veteran's private life is challenged by many new transitions, as is his or her usual role. The transcendent dimension may take on a new meaning.

Suffering is a challenge to meaning and loss of meaning may be a form of suffering. Facing the end of life may challenge our usual sources of meaning. Meaning usually must be found in new ways when death approaches. As you consider what you would list as the things that give you the most meaning and value in your life, think about how the prospect of disease might affect those. Ira Byock has described the nature of opportunity brought by suffering and facing the end of life.⁴¹

However, while every individual will have a unique experience of illness, there are common themes that could be identified. In listening to patients with advanced illness describe their needs and expectations for care, Cicely Saunders, founder of the modern hospice movement, conceptualized suffering as having four elements.⁴² She termed it "total pain" and identified the elements of physical, psychological (emotional), social (including practical), and spiritual pain. As you reflect on the things that you value most, and those that would be most important to you in the face of a life-threatening illness, most of them probably fit into these four categories.

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 face of suffering.⁴³

The broad perspective

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The broad perspective

- A narrow focus will miss the target

depression affects experience of pain
medication useless if not obtainable
spiritual strength may enhance tolerance
feeling abandoned may be expressed as physical suffering

All of these concepts of suffering take a broad perspective from which to view the experience of illness. As clinicians, it is important that we have a comprehensive framework from which to work if we are to relieve suffering and enhance quality of life.

For example, a narrow focus on physical pain can miss the Veteran who is depressed, or doesn't have the money for the pain medicines he is prescribed, or is afraid that the pain means that he or she is going to die. Yet, all of these aspects of human experience will influence the experience of pain.

Similarly, a Veteran whose spiritual foundation is challenged may be less likely to complain about physical symptoms, while failure to address the spiritual dimension in a Veteran who is spiritually distressed may 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. While each aspect of human existence is an integral part of who we are, undue focus on any one aspect may be detrimental (e.g., undue focus on a Veteran's social disconnection may distract a clinician from attending to physical needs).

Symptoms and suffering

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Symptoms, suffering ...

- **Physical symptoms**
inpatients with cancer averaged 13.5 symptoms, outpatients 9.7
greater prevalence with AIDS
related to
primary illness
adverse effects of medications, therapy
intercurrent illness

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... Symptoms, suffering ...

- **Physical symptoms**
many previously little examined
pain, nausea / vomiting, constipation, breathlessness
weight loss, weakness / fatigue, loss of function

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... Symptoms, suffering

- **Psychological distress**
anxiety, depression, worry, fear, sadness, hopelessness, etc

Multiple studies indicate that most patients and families who are living with a life-threatening illness can expect to experience multiple physical symptoms and psychological, social, spiritual, and practical issues. Most of these problems add to a patient's and family's sense of suffering and reduce their quality of life, particularly if they are present for a long time.

In one study of patients with cancer, inpatients averaged 13.5 symptoms while outpatients averaged 9.7 symptoms.⁴⁴ While some of these symptoms are related to the primary illness, some are adverse effects of medications or therapy, and others result from intercurrent illness.

In many studies of symptom prevalence, pain, nausea/vomiting, constipation, and breathlessness are significant.⁴⁵ As Veterans lose weight and become weak and fatigued, loss of function becomes increasingly present. For many people, the loss of their independence is devastating and a source of considerable suffering. For those who request hastened death, the loss of autonomy, control and independence is a primary reason (see EPEC for Veterans Module 13: Responding to Requests to Hasten Death).

In addition to physical symptoms, many patients and families also experience considerable psychological distress, including anxiety, depression, worry, fear, sadness, hopelessness, etc.

Social isolation

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Social isolation

- **Americans live alone, in couples**
working, frail or ill
- **Other family**
live far away
have lives of their own
- **Friends have other obligations, priorities**

Today, in contrast to our past, many Americans live alone, or with only one other adult. Often both need to work or, if they are older, at least one of them may be frail or ill. Other family members—brothers, sisters, children, and parents—may live far away. Friends have their own obligations and priorities. Some Veterans who use VA health care system are married, divorced, separated, or widowed. These Veterans, therefore, may have limited community caregiving resources do to estrangement and social isolation.

Caregiving

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Caregiving

- 90% of Americans believe it is a family responsibility
- Frequently falls to a small number of people
 - often women
 - ill equipped to provide care

While most of Americans believe it is a family’s responsibility to provide care for someone who is dying, this social isolation creates a very different situation from the one that existed in the past. Today, when a patient needs assistance, the burden of caregiving frequently falls to a very small number of people, often women, who may be unskilled and without the resources they need to provide that care.⁴⁶

Financial pressures

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Financial pressures

- 20% of family members quit work to provide care
- Financial devastation
 - 31% lost family savings
 - 40% of families became impoverished

In addition to the issue of who will provide care, financial issues associated with caregiving have a significant impact on the family. The 1997 Institute of Medicine Report, *Approaching Death*, documented that in the setting of end-of-life care, 20% of family members had to quit work or make another major life change in order to provide care for a loved one while 31% of families lost most of their savings caring for their loved one.²¹ In another study of cancer patients, 31% of families lost most of their savings.⁴⁷

Coping strategies

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Coping strategies

- Health adjustment and healthy bereavement is essential
- Vary from person to person
- May become destructive
 - suicidal ideation
 - premature death by PAS or euthanasia

Particularly in the face of prolonged suffering and unmanaged symptoms, strategies for coping with illness, disability and loss of control and independence are varied. In some Veterans distress may be so significant if suffering is not relieved that they may seek assistance for hastened death (see EPEC for Veterans Module 13: Responding to Requests to Hasten Death).⁴⁸

Goals of EPEC for Veterans

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Goals of EPEC for Veterans

- Practicing clinicians
- Core clinical skills
- Improve
 - competence, confidence
 - patient-physician relationships
 - patient / family satisfaction
 - clinician satisfaction
- Not intended to make every clinician a palliative care expert

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EPEC for Veterans Curriculum ...

- Comprehensive whole patient assessment
- Delivering difficult news
- Goals of care
- Advance care planning

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... EPEC for Veterans Curriculum ...

- Symptom management
 - pain
 - depression, anxiety, delirium
 - other physical symptoms
- Sudden illness

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... EPEC for Veterans Curriculum ...

- Responding to requests to hasten death
- Life-sustaining treatments
- Last hours of living
- Loss, grief, and bereavement
- Spirituality in palliative care
- Teamwork in palliative care

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... EPEC for Veterans Curriculum ...

- Psychosocial issues in Veterans
- Experiences of Veterans from different war eras
- Caring for Veterans in VA settings and beyond
- Legal issues

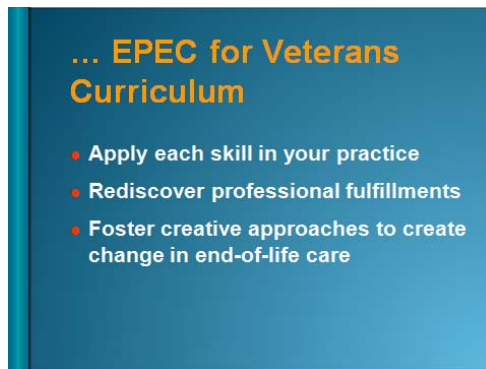
Through five plenary presentations and 17 modules, EPEC for Veterans covers the range of decision-making situations, approaches to manage the most frequently occurring symptoms, and the basic concepts of interdisciplinary supportive care that clinicians will face in end-of-life care. Some of these module(s) have been expanded from the original EPEC and EPEC - Oncology curricula. Others have been developed specifically for The EPEC for Veterans Curriculum. The EPEC for Veterans Curriculum is not an attempt to make every clinician an expert in palliative care, but rather to introduce basic concepts of palliative care to clinicians of all disciplines.

The topics include:

- Comprehensive whole patient assessment (Module 7)
- Delivering difficult news (Module 3)
- Approaches to:

- negotiating goals of care and treatment priorities (Module 1)
- advance care planning (Module 2)
- Guidelines for symptom management:
 - pain (Module 4)
 - depression, anxiety, delirium (Module 5)
 - other common symptoms (Module 6a-6c)
- Approaches to deal with:
 - sudden illness (Module 14)
 - requests to hasten death (Module 13)
 - requests to withhold or withdraw life-sustaining treatment (Module 10)
- The care required by the patient in the last hours of life (Module 11)
- Loss, grief, or bereavement (Module 12)
- Ethics and law in end-of-life care in VHA (Plenary 2)
- Spirituality in palliative care (Module 16)
- Teamwork in palliative care (Module 17)
- Psychosocial issues in Veterans (Module 8)
- Experiences of Veterans from different war eras (Module 9)
- Caring for Veterans in VA settings and beyond (Plenary 3)

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Once completed, in a manner analogous to the way that you learned during training, this knowledge needs to be applied in the environment in which you work to develop skill in its day-to-day application. In the end, we hope that EPEC for Veterans will push clinicians to rediscover some of the core values of our professions and foster creative approaches to advocate for, and create, change in the myriad of situations and places in which clinicians serve dying Veterans.

Summary

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The end of a person’s life can be one of the most important times in that life. While the way we die has changed considerably during the 20th century, neither our society nor modern medicine has valued end-of-life care. Concepts of suffering include fragmentation of personhood, stressed personal stories, opportunities for growth, and total pain. Interventions are not limited to professionals and health care delivery sites, but include those that can be mobilized by family, community, and others, and include social institutions. Definitions and models of palliative and hospice care were provided, together with suggestions for setting standards for end-of-life programs. Clinicians are not sufficiently trained to be competent or confident in it. The EPEC for Veterans Curriculum proposes to equip clinicians with knowledge, skills, and attitudes that can be tailored to their unique practice settings. The ultimate goal is to relieve suffering and improve the quality of the lives of all Veterans who are living with, or dying of, life-threatening illnesses.

History of hospice care

1950–60s In 1948, Cicely Saunders, a nurse-turned-social worker, encountered David Tasma, a Polish Jew dying of rectal cancer in a busy London teaching hospital. From her conversations with him, and her subsequent work as a volunteer at St. Luke's Home for the Dying Poor (founded in 1893 by Dr. Howard Barrett), Cicely Saunders decided to go to St. Thomas' Medical School in London, England.

1967 In 1967, after going to medical school to become a physician and many years of study and work at St. Joseph's Hospice, Cicely Saunders opened St. Christopher's Hospice in the south of London, England as the first academic hospice. It was a place where patients could go for relief of 'total pain' with its physical, psychological, social and spiritual dimensions. Through the education and research mission of St. Christopher's, Dame Cicely Saunders is credited with founding the modern hospice movement. Her contributions were recognized by the Queen of England by making her a Dame of the British Empire. She is now frequently referred to as Dame Cicely Saunders.

1974 Connecticut Hospice opened the first hospice in the United States.

In the United States, early hospice services were provided almost exclusively in patients' homes. The early United States hospice movement was created outside of the established health care system. In contrast with the United Kingdom, these teams were usually nurse and/or volunteer led.

1974 In 1974, Dr. Balfour Mount, a Canadian urologist, returned to McGill University in Montreal, Quebec, Canada after visiting St. Christopher's Hospice to open one of the first "hospice" units in Canada.

However, the word "hospice" in French had meant a place of last resort for the poor and the derelict for hundreds of years. To fill the need for an acceptable term to describe the place to care for the dying, Balfour Mount coined the term 'palliative care' (soins palliatifs en français) to be a synonym for "hospice" that would be acceptable to both English-speaking and French-speaking Canadians.

1975 Concurrently, a palliative care unit opens at the Royal Victoria Hospital, Montreal, Canada, and a terminal care unit opens at St. Boniface Hospital, Winnipeg, Manitoba, Canada. The latter later changes its name to "a palliative care unit."

1980 Twenty-six sites were selected to demonstrate the financial efficiency and humanitarian benefits of hospice care. The project was so successful; it led to early presentation to Congress.

1982-3 In the United States, the prevailing pattern of home-based care was systematized in the Medicare Hospice Benefit legislation passed in 1982 and implemented in 1983.

1990s It is important to know the history of the movement and terms in order to avoid misunderstandings. While the terms ‘hospice’ and ‘palliative care’ both have historical roots that vary regionally and nationally, there has been a convergent evolution in the development of clinical services to address the unmet expectations and needs of patients and families who were living with advanced life-threatening illnesses in many different countries and cultures.

Today, both ‘hospice’ and ‘palliative care’ have evolved to describe the same concept of care that aims to relieve suffering and improve quality of life. However, variations in funding and service delivery models still lead to considerable variability in the way that patients and families have access to this care.

2000s The hospice care industry in the United States has grown to become a significant provider of end-of-life care to Americans. As of July 2003, there were over 3,300 hospice programs scattered across the nation. They cared for some 885,000 patients in 2002 (\approx 30% of Americans who die). 41% of hospice programs were independent, freestanding organizations; 32% were hospital-based, 22% were home health agency based, and 5% were based in nursing homes or under other auspices.

Over 700 of the 7,000 acute care institutions and an unknown number of the 17,000 long-term care institutions provide some form of palliative care service to their clients today. However data that describes their services and their collective effectiveness is not yet available.

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