

# **EPEEC for Veterans**

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

## **Trainer's Guide**

Plenary 5

## **Next Steps**

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

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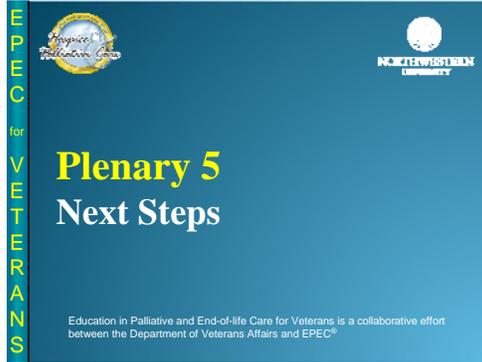
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## Abstract

Slide 1



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In this final plenary, the curriculum themes are distilled with the aim of identifying goals for change and barriers to the improvement of palliative care. Needed change is categorized into institutional matters, those that clinicians can influence, and those that only others can influence. This plenary will provide examples of action items for improving palliative care in local settings.

## Objectives

Slide 2



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The objectives of this plenary are to:

- list the important themes from the conference;
- identify barriers to good palliative care; and
- develop potential solutions.

## Introduction

This plenary builds upon the rest of the EPEC for Veterans Curriculum. It is designed to consider next steps and elicit contributions from participants. There is an emerging consensus about the nature of the barriers to quality palliative care. Some of these will be sketched out during the session as participants identify barriers and potential solutions to

them. There may be much in common from one group to another, but there may also be significant differences.

## Curriculum overview

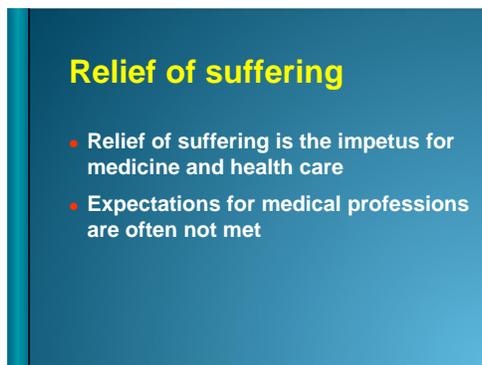
The EPEC for Veterans Curriculum is designed to provide clinicians with the core knowledge needed to provide excellent palliative and end-of-life care. The domains of this knowledge include symptom control, communication, and ethical issues in palliative care. To that end, the curriculum covers a wide range of topics from concrete steps to manage pain and other symptoms to broad approaches to help determine goals of care and treatment priorities.

From the cumulative experience and research in palliative care, four overall themes emerge as important to the field, and these run throughout the 17 modules and 5 plenary sessions of the EPEC for Veterans Curriculum:

1. Relief of suffering is a cornerstone of medical care.
2. Palliative care is an extensive and complex area of expertise in medicine that has much to contribute to patient comfort and quality of life.
3. Families and the community play essential roles in the care and well-being of patients facing death.
4. The interdisciplinary professional team is an integral part of providing whole-person palliative care.

## Relief of suffering

Slide 3



**Relief of suffering**

- Relief of suffering is the impetus for medicine and health care
- Expectations for medical professions are often not met

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One of the most basic motivations for the profession of medicine, and the impetus for all of health care, is the relief of human suffering.<sup>1,2</sup> It has only been in the past few decades that there has been a concerted effort to understand the nature of suffering and to develop the conceptual, technical, and practical frameworks to relieve it. In many ways, this has been made possible and necessary by the scientific advances in medicine. Now, in the 21<sup>st</sup> century, we appreciate both the promise of understanding human biology as well as its limits. Most of us will die after a long period of illness that will affect each of our dimensions of human experience: physical, psychological, social, and spiritual.

In the United States, patients expect that the medical profession including physicians, nurses, social workers, chaplains, pharmacists and others has a deep understanding of both the nature of suffering and how to relieve it.<sup>3</sup> However, as we reviewed in the opening plenary, this expectation may go unmet in contemporary America. Some of the dissatisfaction with modern medical care may relate to this unmet need. It is one of the goals of the EPEC for Veterans project to help the medical profession meet this expectation.

## Palliative care

Slide 4

**Palliative care**

- Recognized as a legitimate specialty in health care
- EPEC for Veterans Curriculum designed to equip clinicians with:
  - basic tools
  - understanding of concepts
  - understanding of benefits

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The skills that clinicians of all backgrounds use to relieve suffering and improve quality of life have been termed *palliative care* or *palliative medicine*. Palliative care is now recognized as a legitimate medical, nursing and social work specialty. The EPEC for Veterans Curriculum is not designed to provide specialty level knowledge but to equip clinicians of all specialties with basic tools. Throughout the EPEC for Veterans modules, the curriculum has been structured to build an understanding of the concepts of palliative care, and to equip the clinician with an understanding of the powerful benefits that it can bring.

Most clinicians routinely incorporate some aspects of palliative care into their practice, many without thinking much about it. We have tried to correct the misperception that palliative care is the absence, or withdrawal of medical care. We hope that the word “only” will fall out of the statement, “he only wants comfort care.”

Palliative care is a positive, humanistic, and technically powerful part of medicine. In fact, never before in the history of medicine have we had the power and understanding to relieve suffering to the degree that is possible today. It has a full complement of areas of special sophistication (e.g., pain and other symptom control), each with a growing literature, and it has its own demands for well-honed human skills.

# Families

Slide 5

**Families**

- Paradigm that is centered on Veterans and their families  
base priorities on their perspectives
- Families and decision making
- Clinicians need:  
skills and the framework to communicate and assess  
tools to intervene especially in managing symptoms

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The EPEC for Veterans Curriculum has articulated a paradigm that is centered on Veterans and those who are closest to them, their families. The term family includes all who are close to Veteran whether formally related or not. This curriculum has tried to illustrate how critical it is to base priorities and interventions on the perspectives of Veterans and their families (see EPEC for Veterans Module 2: Advance Care Planning; and EPEC for Veterans Module 1: Goals of Care). When facing death, Veterans often need and want closer connections to their loved ones so they can complete their personal affairs and relationships. Personal aspects of culture and meaning can be particularly important for Veterans and families when they are confronting death, and these significant aspects of life exist within the context of a network of people in a community. In addition, families can help with decision making, especially when the Veteran lacks decision-making capacity.

Clinicians need to have the skills and the framework to communicate and assess all of the areas of human experience that influence the suffering of patients and families (see EPEC for Veterans Module 3: Communicating Difficult News; EPEC for Veterans Module 7: Comprehensive Whole Patient Assessment; EPEC for Veterans Module 13: Responding to Requests to Hasten Death; and EPEC for Veterans Module 14: Managing Sudden Illness). Last but not least, clinicians need the tools to be able to intervene, particularly in the expert management of symptoms. If the Veteran is in pain, short of breath, hallucinating, or experiencing other symptoms, positive experiences are much less likely. All of the explorations of meaning and of social, spiritual and emotional support require basic physical comfort.

# Teamwork

Slide 6

**Teamwork**

- Support of the whole person requires interdisciplinary teamwork
- This approach should not be limited to hospice care
- Palliative care along with disease-modifying therapy is most powerful

positive outcome in mood, quality of life and survival

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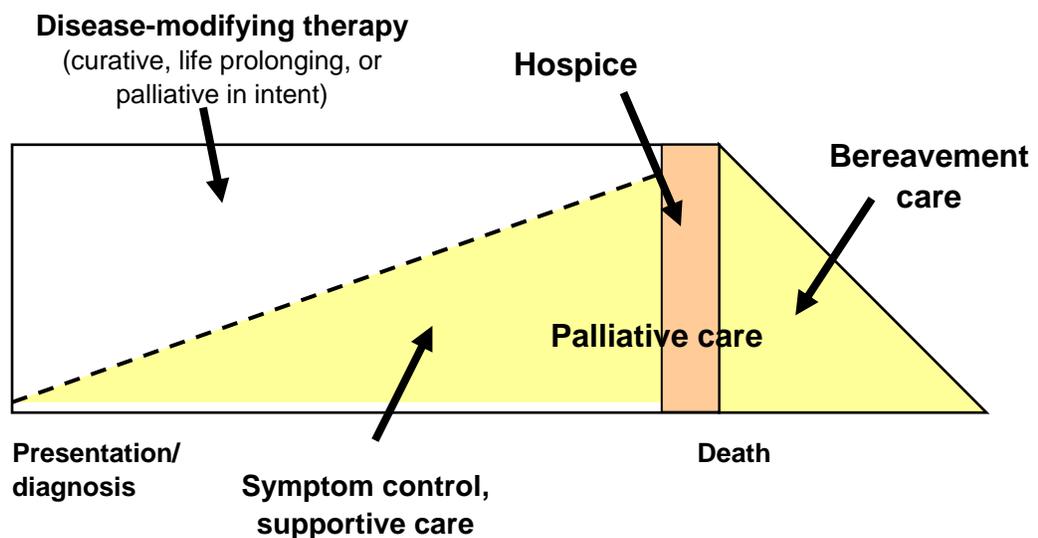
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Relief of suffering requires understanding and support of the whole person. It is the whole person who lives and dies, not just his or her physiology. Support of the whole person requires teamwork. No one person, no matter how skilled, can meet all of the needs of the Veteran and his or her family facing the end of life. Relieving suffering in the physical, psychological, social, and spiritual domains requires a team effort that includes physicians, nurses, social work, chaplains, and other disciplines working together. Hospice care is the most developed system of interdisciplinary palliative care for patients at the end of life. However, this interdisciplinary approach to care should not be limited to patients enrolled in a hospice program. Palliative care in various forms should be integrated into care at every stage of illness. As we discussed in Plenary 1, palliative care is perhaps most powerful when it occurs in conjunction with disease-modifying therapy. This approach has been shown to result in positive outcomes not only in terms of mood and quality of life but also in terms of survival.<sup>4</sup>

## Continuum of care



# Barriers

Slide 7

**Barriers**

- 4 areas where barriers reside:
  - institutional culture, structures and policies
  - regulations
  - reimbursement
  - individual attitudes

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There are four areas that we can highlight where barriers to good palliative care reside:

1. Institutional culture, structures, and policies
2. Regulations
3. Reimbursement
4. Individual attitudes

Health care institutions may or may not facilitate good palliative care. The cultures that develop within them are complex and not easily changed. Examples of institutional barriers are policies that prohibit families from freely visiting dying patients (such as limiting the number of visitors or visiting hours), policies that insist that a dead body be moved within 4 hours of death, the absence of pain and symptom management services and policies that promote adequate assessment and reporting. Change may be best accomplished by identifying and targeting small components of the institution for change. Are there specific aspects of your institutional culture that seem to impede high quality palliative care? Although this might not be a concern within VA, it may be for partners of projects which focus on institutional change including the Center to Advance Palliative Care (CAPC; [www.capc.org](http://www.capc.org)).

There may also be regulations at the institutional, local, regional, state, and national levels that inhibit good end-of-life care. Existing regulations for example have sometimes led to a fear of prosecution of physicians for prescribing medications aimed at the relief of pain and symptoms.<sup>5</sup> Institutional regulations may prohibit a patient from refusing a feeding tube or insisting on moving to another institution to die in order to avoid state scrutiny of their care.

Health care system administrators and physicians are influenced by the financial conditions attached to their activities. High-technology care that is procedurally based remains the most remunerative. Cognitive and counseling activities remain the least remunerative. Yet, palliative and hospice care relies heavily on the latter skills.

Finally, attitudes toward palliative care may represent one of the biggest barriers. There are still patients, families, and professionals who feel there is “nothing more to do” for a

patient who has a life-threatening illness for which there are no longer disease-modifying therapies. Society in general still tends to shun the dying and deny attention to their suffering. It is difficult to be around death, even for professionals, and many walk away in the face of unrelieved suffering. The first step to improving any problem is to acknowledge the problem exists. If it is deemed unimportant, then no progress can be expected.

## Confronting barriers

Slide 8



**Confronting barriers**

- Need to identify barriers
- Develop knowledge, skills, and attitudes
- Consider plans with colleagues to implement change

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If we are to advocate for the best possible care for Veterans, we need a clear idea of the barriers that must be overcome to get there. The EPEC for Veterans Curriculum has been designed to help with the knowledge, skills, and attitudes that teams and providers need in order to participate in good palliative care. Throughout the curriculum as well as in this session, you have likely identified many areas that might impede your ability to implement this information. Yet, experience has shown time and again that barriers can be confronted and resolved. In order to implement change, it helps to consider possible plans with colleagues.

## Clinicians' personal support needs

Many clinicians who practice palliative care find it important to provide for their own personal care, whether in the setting of professional counseling, religious or spiritual learning, or supportive personal or collegial relationships where experiences can be candidly discussed.

In order to be comfortable around the dying, it may be necessary to be comfortable with the fact of our own eventual mortality. There is not one clinician, indeed not one person, who does not have a reaction to the fact of mortality and to our own mortality as a part of that fact. The connection between the feelings of a patient and the feelings of a professional are known to be profound; the phenomenon of *transference* is an entire area of inquiry in psychology and psychiatry. Knowing our own emotional relationship to suffering and dying and maximizing the health of that relationship are essential. Finding the correct balance between engaging in the patient's experience and keeping a professional distance is a key to empathic and effective palliative care.

In assessing how to best support our own personal abilities to provide care to patients facing the end of life, consider how you would characterize your own responses to patients who were suffering and dying in your past personal and professional experiences. Most clinicians, even the best, will be able to identify negative emotions. Most will be able to identify positive emotions. Some clinicians who provide model care to patients near the end of life find the experience deeply gratifying. In considering yourself and your end-of-life care, ask yourself how you would characterize your own negative and positive responses to dying patients and their families.

## Summary

Slide 9



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EPEC for Veterans is devoted to equipping clinicians with the attitudes, knowledge, and skills to provide the best possible palliative care for the Veterans and families they care for. Together, clinicians can influence and overcome the barriers to good palliative care that persist. Our Veterans expect it. The skills we develop ourselves, and the institutions and systems we influence, will be the ones that we will experience when we reach the end of our lives. We need to engage this community of EPEC for Veterans trainers and go back to each of our practice settings to act now.

## Resources

Center to Advance Palliative Care. [www.capc.org](http://www.capc.org).

National Hospice and Palliative Care Organization. [www.nhpco.org](http://www.nhpco.org)

American Academy of Hospice and Palliative Medicine. [www.aahpm.org](http://www.aahpm.org)

Hospice and Palliative Nurses Association. [www.hpna.org](http://www.hpna.org)

Social Work Hospice and Palliative Network. [www.swhpn.org](http://www.swhpn.org)

## References

- <sup>1</sup> Cassell EJ. The nature of suffering and the goals of medicine. *N Engl J Med.* 1982; 306(11): 639-645.
- <sup>2</sup> Ferrell BR, Coyle N. The nature of suffering and the goals of nursing. *Oncol Nurs Forum.* 2008; 35(2): 241-247.
- <sup>3</sup> National Consensus Project for Quality Palliative Care. *Clinical Guidelines for Quality Palliative Care* 2009; 2nd edition: <http://www.nationalconsensusproject.org>. Accessed: February 10, 2011.
- <sup>4</sup> Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med.* 2010; 363(8): 733-742.
- <sup>5</sup> Reidenberg MM, Willis O. Prosecution of physicians for prescribing opioids to patients. *Clin Pharmacol Ther.* 2007; 81(6): 903-906.

