EPEC

Education for **P**hysicians on **E**nd-of-life **C**are

Participant's Handbook

Plenary 4

Next Steps

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Abstract

In this final plenary session, the curriculum themes are distilled with the aim of identifying goals for change and barriers to the improvement of end-of-life care in the US. Needed change is categorized into institutional matters, those that only others can influence, and those that physicians can influence. Participants should be able to leave this session with a tangible list of action items for improving end-of-life care in their community.

Key words

action plan, advocacy, barriers, families, palliative care, personal support needs, relief of suffering, teamwork

Objectives

The objectives of this session are to:

- list the important themes from the conference
- identify barriers to good end-of-life care
- develop potential solutions

Introduction

This plenary session builds upon all of the other sessions in EPEC; it is designed as a framework to solicit contributions from participants. There is an emerging consensus about the nature of the barriers to quality end-of-life 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 curriculum was designed to provide physicians with the core knowledge needed to provide excellent care at the end of life. 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 end-of-life care, 5 overall themes emerge as important to the field, and these run throughout the 12 modules and 4 plenaries of the EPEC curriculum:

1. Relief of suffering is a cornerstone goal of medical care.
2. Palliative care is an extensive and complex area of expertise in medicine that has much to contribute to patients comfort and quality of life.

3. Families and the community play an essential role in the care and well-being of patients as they face dying.
4. The interdisciplinary professional team is an integral part of providing whole-person end-of-life care.
5. The physician is a critical advocate not only for the individual patient but also for creating the conditions in which to provide the care that patients need.

Relief of suffering

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. 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 late 20th 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 US, patients expect that the medical profession has a deep understanding of both the nature of suffering and how to relieve it. However, as we reviewed in the opening plenary, this expectation goes largely unmet in contemporary America. Some of the dissatisfaction with modern medical care may relate to this unmet need. It is one of the primary goals of the EPEC project to help the medical profession meet this public expectation.

Palliative care

The skills that physicians use to relieve suffering and improve quality of life have been termed *palliative medicine*. This is a rapidly growing medical endeavor. Throughout the EPEC modules, the curriculum has been structured to build an understanding of the concepts of palliative medicine, and to equip the physician with an understanding of the powerful benefits that it can bring.

Most physicians 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 the general practice 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. To realize the full potential requires an understanding of advanced pathophysiology in every area of medical specialization. It has a full complement of areas of special sophistication (eg, pain and other symptom control), each with a growing literature. And it has its own

demands for well-honed human skills. We must have the competence and the will as a profession to be certain that our patients do not suffer unnecessarily.

Families

EPEC has articulated a paradigm that is centered on patients and on those who are closest to them, their families. It has tried to illustrate how critical it is to base priorities and interventions on the perspectives of patients and their families (see Module 1: Advance Care Planning; and Module 7: Goals of Care). When facing death, patients 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 patients 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 patient is no longer fully competent. Either way, it is more important than ever to allow the patient to be the center of care along with his or her family. Physicians 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 Module 2: Communicating Bad News; Module 3: Whole Patient Assessment; Module 5: Physician-Assisted Suicide; Module 8: Sudden Illness; and Module 9: Medical Futility.) Last but not least, physicians need the tools to be able to intervene, particularly in the expert management of symptoms. If the patient is in pain, short of breath, hallucinating, or experiencing other symptoms, positive experiences are much less likely to be possible.

Teamwork

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 patient and 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 the host of other medical 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 does not have to be limited to patients enrolled in a hospice program. It is a robust and positive way to relieve suffering and enhance quality of life that needs to be woven into the fabric of our mainstream health care systems.

Advocacy

Physicians, as a basic tenet of their profession, are advocates for patients and their health. However, much of what has been covered in EPEC is not widely practiced or available to patients in the United States. Besides acquiring the knowledge, attitudes, and skills necessary to administer good end-of-life care, as physicians we need to use our moral

persuasion to influence the system and advocate for high quality care for our patients. There are a host of reasons why needless suffering persists despite the power of palliative care in one of the most advanced health care systems in the world. Until recently, one of the greatest barriers has been the absence of physician advocacy demanding the best possible end-of-life care for their patients. We should expect the best, both as physicians, and as human beings who will one day face the end of life ourselves. Is the current system one in which we would like to be cared for when we reach the end of our lives? If not, then it is our duty as a profession to advocate for a system that provides good end-of-life care, both for our patients and for us when we need it.

Barriers

There are 4 areas that we can highlight where barriers to good end-of-life care reside:

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

Health care institutions may or may not facilitate good end-of-life care. The cultures that develop within them are complex and not easily changed. Although it is beyond the scope of this module to discuss these issues in detail, there are numerous projects and studies that aim to understand and change institutional practice so that good end-of-life care can be provided. Examples of institutional barriers are policies that prohibit families from freely visiting dying patients, policies that insist that a dead body be moved within 4 hours of death, and 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.

There are a host of regulations at the institutional, local, regional, state, and national levels that inhibit good end-of-life care. Triplicate prescription programs for Schedule II drugs have been demonstrated to limit the prescription of appropriate analgesics and to foster the prescription of inappropriate analgesics. Existing regulations have led to a pervasive fear of prosecution of physicians for prescribing medications aimed at the relief of pain and symptoms. Institutional policies and 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. Federal regulations are now restricting access of patients in advanced phases of illness to home care and hospice services at precisely the same time that there is increased focus on the need for these services.

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. Despite the well-

documented gaps in contemporary end-of-life care, current utilization review guides are silent on the legitimate needs of patients and families near the end of life. Some commercial insurers have gone so far as to insist that any patient with a do-not-resuscitate order must, by definition, not need to be in an acute care setting.

Finally, attitudes toward end-of-life 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 prognosis. Society in general still tends to shun the dying and deny attention to the 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.

Physicians' personal support needs

Unfortunately, physicians are among the individuals thought most likely to abandon care as the prognosis declines, or so patients, other professionals, and the public perceive. Perhaps it is because of our extra obligation as physicians to stay present and to continue care. Either way, we must address this widely acknowledged duty to do better.

Many physicians who engage in extensive end-of-life 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 physician, 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. The connection between the feelings of a patient and the feelings of a professional are known to be profound; 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 the key to empathic and effective end-of-life care.

In assessing how to best support each one of 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 physicians, even the best, will be able to identify negative emotions. Most will be able to identify positive emotions. Some of the physicians 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.

Confronting barriers

If we are to advocate for the best possible care for our patients, we need a clear idea of the barriers that must be overcome to get there. The EPEC curriculum has been designed to help with the knowledge, skills, and attitudes that physicians need in order to participate in good end-of-life 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.

Action plan

Consider for a minute what things in your practice setting need changing or present barriers to good end-of-life care for patients and their families. On the left side of a piece of paper, list the most important issues. On the right side of the page indicate the concrete or specific plan that would help overcome that barrier.

- "I" = Institutional "O" = Others "U" = Personal

Now that you have written down potential barriers, look at your list and identify which barriers are institutional, meaning they are barriers that are present as a result of the organization or system in which you work or by legal mandate. Put an "I" next to those barriers that are institutional and can only be addressed by your interaction at an institutional level.

Looking at the remaining barriers, identify those barriers that are a result of "others'" actions, beliefs, or concerns. "Others" may include partners in your practice, other members of the health care team, community members, and, of course, your patients and their families or significant others. Put an "O" next to those barriers that you believe are a result of "others." These are barriers that you might influence as a role model or be able to influence in an indirect way. They are not things that are directly in your power to change.

Finally, look at the remaining barriers. If the remaining barriers are not institutional and they cannot be linked to "others" as discussed a moment ago, then consider these to be your barriers that you can influence personally. Personal barriers can be based on personal values, expectations, plans, or beliefs. Examples might be attitudes toward death or poor end-of-life care. Place a "U" next to those barriers you believe are related to your own personal values.

As you can see, we have conveniently created an IOU list. This is your customized IOU list for discussion with colleagues and that we would ask you to address when you return to your practice so that you can provide optimum care for your patients at the end of life.

In the remaining time that we have, let's have some collective discussion about some of the barriers and possible solutions.

Now that we have a barrier, let's brainstorm possible solutions as a group.

We have had very little time to work with you on the barriers presented by your practice environment. Our point here can only be to begin the barrier identification and problem-solving process.

Summary

EPEC is devoted to equipping physicians with the attitudes, knowledge, and skills to provide the best possible end-of-life care for their patients. In this effort, physicians will want to work as a team with patients, families, nurses, social workers, chaplains, therapists, hospice programs, hospitals, home health care agencies, and long-term care facilities to achieve the promise of the current knowledge of palliative care. Together, physicians can influence and overcome the barriers to good end-of-life care that persist. Our patients 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 trainers and go back to each of our practice settings to act now.

Key take-home points

1. Palliative care is a positive, humanistic, and technically powerful part of the general practice of medicine. We must have the competence and the will as a profession to be certain that our patients do not suffer unnecessarily.
2. Physicians need to have the skills and the framework to assess all of the areas of human experience that influence the suffering of patients and families.
3. Relieving suffering in the physical, psychological, social, and spiritual domains requires a team effort that includes physicians, nurses, social work, chaplains, and the host of other medical disciplines working together.
4. It is our duty as a profession to advocate for a system that provides good end-of-life care, both for our patients and for us when we need it.
5. You have joined a growing number of physicians trained in/familiar with EPEC materials who will be implementing initiatives to provide quality end-of-life care.