

# EPEEC-O

Education in Palliative and End-of-life Care - Oncology

## **Participant's Handbook**

Plenary 3:

## **Charting the Future**

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## Abstract

In this final plenary session, the curriculum themes are distilled with the aim of identifying goals for change and challenges to integrate palliative care as part of comprehensive cancer care. Needed change is categorized into institutional matters, those that only others can influence, and those that oncologists can influence. Participants should be able to leave this session with a tangible list of action items for improving palliative care in their community.

## Key words

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

## Objectives

After reviewing this module, oncologists and other members of the cancer care team will be able to:

- List the important themes from EPEC-O.
- Identify challenges to integrate good palliative care into comprehensive cancer care.
- Reflect on their own personal support needs.

## Clinical case on trigger tape

This video depicts a vision for the full integration of palliative care into comprehensive cancer care.

## Introduction

This plenary session builds upon all of the other sessions in the EPEC-O curriculum. There is an emerging consensus about the relationship of the relief of suffering with antineoplastic therapy as part of comprehensive cancer care.

## Themes of EPEC-O

The EPEC-O Curriculum was designed to provide oncologists with the core knowledge needed to provide excellent palliative care as part of comprehensive cancer 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 of palliative care, five overall themes emerge as important to the field, and these run throughout the 15 modules and 5 plenaries of the EPEC-O Curriculum:

1. Relief of suffering is a cornerstone goal of cancer care.
2. Palliative care represents progress in medical treatment.
3. Families and the community play an essential role in the care and well-being of cancer patients.
4. The interdisciplinary team is an integral part of providing whole-person care.
5. The oncologist 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 specialty of oncology, 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 early 21<sup>st</sup> century, we appreciate both the promise of understanding human biology as well as its limits. Cancer affects each of the dimensions of human experience: physical, psychological, social, and spiritual and frequently leads to death.

Patients expect that oncologists have a deep understanding of both the nature of suffering and how to relieve it. However, this expectation goes largely unmet in contemporary cancer care. Some of the dissatisfaction with modern cancer care may relate to this unmet need. It is one of the primary goals of the EPEC-O project to help oncologists meet this public expectation.

## Palliative care

The skills that oncologists use to relieve suffering and improve quality of life have been termed *palliative medicine*. Palliative medicine is part of the larger interdisciplinary field of palliative care. This is a rapidly growing medical endeavor. Throughout the EPEC-O modules, the curriculum has been structured to build an understanding of the concepts of palliative medicine, and to equip oncologists with the tools that could help them the most.

Most oncologists routinely incorporate some aspects of palliative care into their practice, many without thinking much about it, eg, palliative radiation therapy, palliative chemotherapy, symptom control, and supportive counseling.

Palliative care is a positive, humanistic, and technically powerful part of the general practice of medicine. 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-O has articulated a paradigm for cancer care that is centered on patients and on those who are closest to them in knowledge, care and affection, their families. It has tried to illustrate how critical it is to base priorities and interventions on the perspectives of patients and their families. When facing cancer, patients often need and want closer connections to their loved ones so they can consider their personal affairs and relationships. Personal aspects of culture and meaning can be particularly important for patients and families when they are confronting cancer, 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. Last but not least, oncologists 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 cancer. Relieving suffering in the physical, psychological, social, and spiritual domains requires a team effort that includes oncologists, 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 near 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 comprehensive cancer care from diagnosis to death.

## **Advocacy**

Oncologists, as a basic tenet of their profession, are advocates for patients and their health. However, much of what has been covered in EPEC-O is not widely practiced or available to patients. Besides acquiring the knowledge, attitudes, and skills necessary to administer good palliative care, as oncologists 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 palliative care for their patients. We should expect the best, both as physicians, and as human beings who may one day face cancer ourselves. Is the current system one in which we would like to be cared for? If not, then it is our duty as a profession to advocate for a system that provides good palliative care, both for our patients and for us when we need it.

## Challenges to integrate palliative care

There are 4 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

### Institutional culture, structures, and policies

Health care institutions may or may not facilitate good palliative 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 palliative care can be provided. Examples of institutional challenges are policies that prohibit families from freely visiting cancer patients, 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.

### Regulations

There are a host of regulations at the institutional, local, regional, state, and national levels that inhibit good palliative care. Triplicate prescription and other monitoring programs for opioids and other 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.

### Reimbursement

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 care relies heavily on the latter skills. Despite the well-documented gaps in contemporary palliative care, current utilization review guides are silent on the legitimate needs of patients and families with unrelieved suffering. 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.

## Individual attitudes

Finally, attitudes toward palliative care may represent one of the biggest challenges. There are still patients, families, and professionals who feel there is “nothing more to do” for a patient who has a life-threatening prognosis. Similarly, there are oncologists who view their role as only to treat the cancer rather than the patient who has the cancer. Society in general still tends to marginalize those with cancer and deny attention to the suffering. It is difficult to be around cancer, 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 challenges

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-O curriculum has been designed to help with the attitudes, knowledge, and skills that oncologists need in order to participate in good palliative and 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, 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 challenges to good palliative 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 challenge.

Issues	Root causes	Strategies to change (or fix)

## Oncologists' personal support needs

Unfortunately, patients, other professionals, and the public perceive that oncologists are among the individuals most likely to abandon care as the prognosis worsens. Perhaps it is because of our extra obligation as oncologists 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 cancer 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 unrelieved suffering, it may be necessary to be comfortable with the fact of our own vulnerability and 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; we are all susceptible to transference. 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 palliative care.

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

## Summary

EPEC-O is devoted to equipping oncologists with the attitudes, knowledge, and skills to provide the best possible palliative care for their patients. In this effort, oncologists 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 palliative 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 need it.

## Key take-home points

1. Palliative care is a positive, humanistic, and technically powerful part of the general practice of oncology. We must have the competence and the will as a profession to be certain that our patients do not suffer unnecessarily.
2. Oncologists 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 oncologists, 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 palliative care, both for our patients and for us when we need it.