The Practice of Palliative Care

A CLINICIAN’S GUIDE FOR SCREENING END GAME
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Page</th>
<th>Module</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>OVERVIEW</td>
</tr>
<tr>
<td>4</td>
<td>Learning Objectives</td>
</tr>
<tr>
<td>5</td>
<td>MODULE ONE</td>
</tr>
<tr>
<td></td>
<td>Clarifying Myths and Misconceptions About Palliative Care</td>
</tr>
<tr>
<td>8</td>
<td>MODULE TWO</td>
</tr>
<tr>
<td></td>
<td>The Goal Is Healing: Patient-Centered Care</td>
</tr>
<tr>
<td>10</td>
<td>MODULE THREE</td>
</tr>
<tr>
<td></td>
<td>Connected Communication: Best Practices for Communicating with Patients and Families</td>
</tr>
<tr>
<td>12</td>
<td>MODULE FOUR</td>
</tr>
<tr>
<td></td>
<td>Self-Care in a Palliative Care Setting</td>
</tr>
</tbody>
</table>
The documentary film *End Game* weaves together three stories of visionary medical providers who practice on the edge of life and death, helping to change the way we think about both. These medical providers are:

- The palliative care team at [UCSF Medical Center](#), the most sophisticated acute care hospital in Northern California
- [Zen Hospice Project](#), a unique mindful caregiving residential hospice
- [BJ Miller](#), MD, a palliative care specialist who has worked with both UCSF and Zen Hospice Project

The four professional development modules created for *End Game* invite clinicians and caregivers to use the full documentary, or segments of it, as a tool to increase understanding and reflect on their professional practices in palliative and end-of-life care. Topics include:

- Clarifying myths and misconceptions of palliative care for all clinicians
- Examining patient-centered care as a goal of palliative care and healing
- Discussing best practices for communicating with patients and families in palliative care
- Integrating self-care practices within a palliative care setting
LEARNING OBJECTIVES

• Define palliative care

• Clarify the medical care and support involved in palliative care and hospice care

• Understand communication best practices for end-of-life care as reflected in the work of UCSF and Zen Hospice Project

• Reflect on the importance of self-care practices

METHODOLOGY

Given the span of clinicians and training environments accessing the film and the modules, two training formats are offered:

• Option One: Screening a recommended scene from *End Game* followed by the four training modules. (Screening: 5 to 7 minutes; modules: 20 minutes each.)

• Option Two: Screening *End Game* from start to finish (run time 40 minutes), followed by training modules.

MATERIALS

• *End Game*: Film available on Netflix.

• Training modules: Each includes recommended film segments related to the topic of the learning module.

TARGET AUDIENCE

The modules were designed to be flexible and accessed individually, explored in small groups, or used in a larger discussion or course format. They are designed for all physician and nonphysician caregivers, including palliative care specialists. They are also designed for non-pain and non-palliative specialists of all backgrounds, including general internal medicine, emergency medicine, neurology, family medicine, physiatrists, psychiatrists, hospitalists, advanced practitioners, physician assistants, nurse practitioners, nurses, pharmacists, social workers, chaplains, and others.
INTRODUCTION
This module offers clinicians and caregivers an opportunity to be introduced to palliative care by screening a clip from End Game. The module also discusses several commonly held misconceptions about palliative care.

According to the Center to Advance Palliative Care, in the last fifteen years the field of palliative care has had stunning growth. Today there are 1,700 hospitals that offer more than fifty beds and staff a palliative care team. Palliative care is spreading beyond the hospital into community settings where people with serious illnesses live. Yet misconceptions about what palliative care includes and how it can benefit all patients with serious illness persist both within and outside of the health care system.

TOOLS
• Access to technology and equipment to screen video
• Technology for clinicians to complete an online questionnaire

MODULE ONE CLARIFYING MYTHS AND MISCONCEPTIONS ABOUT PALLIATIVE CARE

“I think it’s healthy people that think about how they want to die and sick people that think about how they want to live. It’s easy to fantasize about the beach and the mountains, and then you get sick and it’s like, ‘I just want to live.”

-STEVE PANTILAT, MD, USCF, END GAME

STEP ONE: SCREEN CLIP 1
EXPLAINING PALLIATIVE CARE

Start at the beginning of the film and end with the statement by Dr. BJ Miller (at 6:42), "That is what took me through medical school and into palliative care." In this clip, Dr. Steve Pantilat and Dr. Miller explain palliative care.

Post-screening Prompt: What details would you add to this explanation of palliative care?
STEP TWO: ADDRESSING MISCONCEPTIONS AND MYTHS

1. TRUE/FALSE: YOU DON'T HAVE TO CHOOSE BETWEEN LIVING WELL AND LIVING LONG. (TRUE)

Palliative care is for people approaching the end of life or at any stage of a serious illness. Palliative care practitioners focus on increasing patients’ ability to enjoy and live to the fullest, whether they are managing chronic pain that will last for years or mapping out the last six months of their life. Studies show that with palliative care you can live longer and better when facing a serious illness. You don’t have to choose. Palliative care can help make the end of life more comfortable and peaceful, and can be received alongside curative treatments. Its greatest benefit is in helping you understand your goals and determining what treatments can help you achieve them.

In 2010, The New England Journal of Medicine published a landmark study on palliative care. Led by Dr. Jennifer Temel at Massachusetts General Hospital, 151 newly diagnosed individuals with incurable lung cancer were divided into two groups. One group received palliative care alongside their chemotherapy, while the other got only chemotherapy. The study found that the patients who received palliative care with their curative treatments lived longer by almost three months. They had reduced pain and shortness of breath, relied less on antidepressants, led happier lives, and had a better quality of life. Families have also reported positive outcomes with palliative care during their bereavement.

2. TRUE/FALSE: PALLIATIVE CARE INCLUDES A TEAM OF CAREGIVERS AND IS NOT LIMITED TO PHYSICIANS. (TRUE)

Palliative care is provided by an interdisciplinary team of clergy, social workers, physicians, nurses, volunteers, and caseworkers who provide emotional, psychological, and spiritual support, as well as medical care for patients and their families.

3. TRUE/FALSE: PALLIATIVE CARE IS NOT JUST HOSPICE CARE. (TRUE)

All hospice care and end-of-life care are palliative care, but not all palliative care is hospice care or end-of-life care. Palliative care is available at any stage of a serious illness, while hospice is provided to people who have a prognosis of six months or fewer, as determined by at least two physicians. Hospice is the most widely available way to receive palliative care in the United States. Patients may receive hospice care at their place of residence (including their private residence, nursing home, or residential facility), a hospice inpatient facility, or an acute care hospital. The location of care may change depending on a patient’s disease progression and medical needs, as well as the plan of care established between the patient and the hospice. An interdisciplinary team of professionals is responsible for the care of each hospice patient, regardless of the patient’s setting. In 2014, 58.9% of hospice patients received care at their place of residence at the time of death.

4. TRUE/FALSE: 60% OF PATIENTS FACING END-OF-LIFE CARE SPEND MORE THAN 30 DAYS IN HOSPICE. (FALSE)

Analysis of data from the Centers for Medicare and Medicaid Services shows that 35% of end-of-life patients are enrolled in hospice fewer than seven days, and many more for fewer than thirty days (62%). Nearly nine in ten (82%) received fewer than 180 days of hospice care. Statistics from the National Hospice and Palliative Care Organization (NHPCO) from 2014 show that an estimated 1.6 to 1.7 million patients received hospice services.
STEP THREE: ANALYSIS OF CURRENT APPROACHES TO PALLIATIVE CARE ALONGSIDE TREATMENT FOR ILLNESS

Study this infographic and share the story you think it tells.

You may also want to investigate recommendations for strengthening, preserving, and protecting the Medicare hospice benefit.

- The Medicare Hospice Benefit—National Hospice and Palliative Care Organization
- Hospice Action Network
- Get Palliative Care
Addressing every part of the human is the goal of healing. People can be healed even if they aren’t cured.

-STEVE PANTILAT, UCSF. MAY 3, 2018, INTERVIEW

INTRODUCTION
This module focuses on patient-centered care in a palliative care setting. Whereas patient-centered care underpins most medical practices, it takes on particular meaning and complication in the case of serious illness and end-of-life care. In this case, a patient’s decisions are driven not just through education and information provided by a clinician, but also through in-depth connected communication about sensitive topics like the patient’s values and perceptions of quality of life, religious and spiritual beliefs, and his or her relationship to death.

TOOLS
- Access to technology and equipment to screen video
- List of discussion questions to project or pass out

STEP ONE: EXPLORING YOUR OWN BELIEFS AND PRACTICE

PARTNERSHIP DISCUSSION
Distribute the following questions and allow seven to ten minutes to complete. Let participants know that if they’re in a group setting, they will be invited to share their answers with a partner.

Questions:
1. What do you believe to be the goal of medical care?
2. What does the term “patient-centered care” mean to you?
3. Think back on an interaction or series of interactions you had with a patient who really stands out to you. What is it about that patient that stayed with you? What was it about the interaction?
4. What do you believe your patients would say is their favorite quality about you?

If you are in a group setting, gather in smaller groups of two or three to share and discuss answers with one another.

When conversation slows, come back together as a large group and ask participants to share part of their discussion.

**STEP TWO: DEFINING PATIENT-CENTERED CARE IN PALLIATIVE CARE SETTINGS**

In its seminal 2001 report, *Crossing the Quality Chasm*, the Institute of Medicine named patient-centered care as one of the six areas for improvement for transforming U.S. health care. They defined patient-centered care as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."8

In order for clinicians to respect and respond to patient preferences, we must be familiar with the patient’s needs and values. Think back to your group’s answers to the first two discussion questions, about the goal of medical care and the meaning of patient-centered care.

- Were you surprised by how different your answers were?
- What influences in our lives might make our answers different?
- What might make our answers similar?
- What might inform the answers for a patient who may have never considered these questions before?

In palliative care, conceptions of the purpose of medical intervention are particularly important. With rapidly advancing technology, clinicians have a wealth of knowledge and resources about pathways of disease management, symptom treatment, and other interventions meant to prolong life and cure disease. Often for people with severe illness where a cure is not likely or possible, choosing among these interventions is a balancing act, weighing potential benefits against side effects, quality of life, and length of life. This is challenging when much of medical training leads to reflexively valuing the tools that will prolong life. In the case of serious illness, where a cure is unavailable, what it means to “heal” takes on different meanings for different people.

Clinicians must explore and recognize their personal biases so they don’t interfere with understanding what is most valuable to patients. In palliative care, this skill is at the heart of offering patient-centered care—not only offering the options for intervention but doing so within the boundaries of a patient’s own understanding of how to achieve the outcome that is most important to them.

**STEP THREE: CLIPS OF CASE STUDIES FROM END GAME**

**CASE STUDY 1, MITRA: 8:20 TO 10:38**

In this clip, Dr. Pantilat is talking with Mitra’s mother, Vaji, and husband, Hamid, about the care options available to her.

Case study questions:
- How does Mitra’s husband feel about further treatment? What are his concerns?
- How does Mitra’s mother feel about further treatment? What are her concerns?
- What do you learn about the clinician’s point of view?
- What next steps would you lay out that would lead to a patient-centered care approach?

**CASE STUDY 2, PAT: 10:40 TO 11:59**

In this scene, clinicians and patient Pat discuss whether she wants to undertake another course of chemotherapy.

Case study questions:
- What is Pat’s preference with regard to further treatment for her cancer?
- What do you learn about the clinician’s preferences?
- Given this interaction, what are the next steps that would lead to a patient-centered approach?
"Surgery is one way to heal. Addressing emotion is another. It’s easy to forget this. When we have so many machines, we think this is what patients come in for, but we do that at our peril. Patients wish their doctor would just sit down and talk for five minutes. It is realistic to do; it doesn’t take long to make this connection. It can be hard and it can be sad, and it’s OK to let people emote."

- STEVE PANTILAT, UCSF. APRIL 27, 2018, INTERVIEW

**INTRODUCTION**
This module offers clinicians and caregivers the opportunity to discuss best practices for effective communication with patients and families. By viewing and discussing select scenes in *End Game* where palliative care clinicians are in conversation with patients, their families, and with colleagues, clinicians and caregivers can reflect on their own communication practices.

**TOOLS**
Access to technology and equipment to screen video

**STEP ONE: TAKING STOCK**
Before screening scenes from *End Game*, take a moment to reflect on one or all of these questions with a colleague or on your own.

1. How would you describe your approach to conversations about end-of-life care or dying with your patients?
2. What are the tools you find most effective in navigating difficult conversations as a clinician with your patients and their families?
3. What advice would you offer a new medical student about communicating with patients and families about end-of-life care and dying?
**STEP TWO: ANALYZING THE CHOICES AND CHALLENGES IN COMMUNICATION**

Watch each of these four short scenes selected from *End Game* to illustrate approaches to communication in a palliative care setting. Keep in mind that each excerpt is a moment taken out of the narrative arc of the film and out of the context of the patient’s larger history of medical care.

After each scene is screened, pause and take some time to reflect independently or discuss in pairs or small groups. Use these prompts:

- What was the scene about and what did you hear being discussed?
- What was done well?
- What was challenging, and what would you suggest as a different approach?

**CLIP 1: NEEDING SUPPORT (6:50 TO 8:20)**

In this clip we listen to Pat, a patient at Zen Hospice Center in San Francisco, speaking about her cancer diagnosis with volunteer Liz Bippart.

**CLIP 2: EXPLAINING TREATMENT (16:50 TO 18:34)**

In this clip we see a conversation between Pat and two nurses, Sueann Mark, RN, and Jolene Scarella, RN, about what to expect from chemotherapy.

**CLIP 3: DISCUSSING THE UNKNOWN (20:51 TO 23:50)**

In this clip we listen to a conversation between Dr. BJ Miller and Thekla Hammond during an appointment at the UCSF Symptom Management Service.

**CLIP 4: PROGNOSIS (25:04 TO 27:20)**

In this clip we see the palliative care team at UCSF discuss Mitra’s prognosis with her mother, Vaji, and husband, Hamid.

**STEP THREE: RESOURCES FOR COMMUNICATION BEST PRACTICES**

There are many organizations and ample resources to support families and patients in end-of-life conversations. Here is a sampling of resources that many professionals in *End Game* recommend.

- **California Health Care Foundation: Community-Based Palliative Care**
  www.chcf.org/resource-center/community-based-palliative-care
  Materials designed to assist organizations when planning, implementing, or enhancing their community-based palliative care services

- **Center to Advance Palliative Care (CAPC) and National Palliative Care Research Center (NPCRC)**
  A 2015 state-by-state report card on access to palliative care in our nation’s hospitals

- **The Conversation Project**
  www.theconversationproject.org
  Tools to support discussion of end-of-life care

- **End Well**
  www.endwellproject.org
  An interdisciplinary gathering of design, tech, health care, and activist communities working on human-centered innovations for the end-of-life experience

- **Get Palliative Care**
  www.getpalliativecare.org
  Articles, podcasts, videos, and webinars about palliative care

- **Hospice Action Network**
  www.hospiceactionnetwork.org
  An organization that advocates for policies that ensure the best care for patients and families facing the end of life

- **Vital Talk**
  www.vitaltalk.org
  A nonprofit organization that disseminates clinician and faculty development courses to improve communication between patients and clinicians

- **Zen Hospice Project Blog**
  www.zenhospice.org/blog
“Once you’re focused on care, you also need to be focused on self-care.”

- ROY REMER, DIRECTOR OF EDUCATION AND TRAINING, ZEN HOSPICE PROJECT. APRIL 9, 2018, INTERVIEW

**INTRODUCTION**

This module focuses on the importance of self-care for clinicians in a palliative care setting. Drawing from the training practices at Zen Hospice Project, the module offers time for reflection on how to practice different kinds of self-care.

**TOOLS**

Access to technology and equipment to screen video

**STEP ONE**

Providing care, end-of-life or otherwise, to seriously ill patients and their families requires emotional investment on the part of clinicians and caregivers. This may lead to burn-out, resentment, exhaustion, and other negative effects. Building self-care into your practice is an important part of providing consistent, high-quality care.

**CLIP 1: 1:24 TO 2:18**

This clip shows a UCSF team meeting with a social worker, physician, and chaplain to discuss Mitra’s care options.

“When we talk together about the patient, that team meeting is self-care, practicing as a team and supporting each other. Doctors are used to working with other doctors. You rarely get to work with people from other disciplines. [At UCSF] we work together at bedside and in rounds. That’s a type of self-care.”

- Steve Pantilat, MD, UCSF. May 3, 2018, interview
This clip includes Dr. BJ Miller describing the team’s ritual after a death at the Zen hospice.

**Discussion question:**
What practices are in place in your care setting to encourage self-care?

**STEP TWO: SELF-ASSESSMENT**

As part of their volunteer and staff member training, Zen Hospice Project asks caregivers to reflect on their own relationship with death and loss by writing a letter to a loved one they’ve lost. They then use what they write to learn about their own relationship to death and dying. Zen Hospice Project also teaches staff and volunteers to focus on self-care in five realms: physical, emotional, in relationship, spiritual, and attitudinal. Zen Hospice Project makes training materials and sessions available through their Mindful Caregiving Education series.

Ask learners to spend a few minutes writing a letter to a loved one they have lost. Depending on the group and the comfort level in the room, give learners the opportunity to read their letter to a partner. If it’s more comfortable, ask learners to re-read the letter to themselves, and identify and write down the emotions they see expressed in the letter. Ask them to reflect on and write about how those emotions relate to their feelings about death and loss in their work.

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**PHYSICAL**

What does it feel like in your body when you experience powerful emotions? What motions or activities provide relief?

**EMOTIONAL**

How do you express emotion? What person or people, type of art, or artistic expression or practice helps you to process your emotions?

**IN RELATIONSHIP**

With whom do you share the emotions you experience in your work? How do you support one another?

**SPIRITUAL**

How do you make sense of death? Do you have a spiritual practice?

**ATTITUDINAL**

How do you feel about your choice of work? Does this feeling change when your work evokes difficult emotions? In what way can you reconnect with your decision to do the kind of work you do?
1 For this section we have adapted portions of Steven Pantilat’s book, Life after the Diagnosis: Expert Advice on Living Well with Serious Illness for Patients and Caregivers. Boston: Da Capo Lifelong Books, 260–264.


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