



IV. End of Life Curriculum

GOAL: To evaluate and discuss pain and other symptoms at the end of life

Objectives: At the completion of this module, the resident will be able to:

1. Identify common symptoms associated with the final stages of dying and describe the importance of immediate treatment.
2. Describe the impact that symptoms have on the patient and the patient's family.
3. Discuss the ethical use of sedation to relieve patients of refractory symptoms at the end of life.



Module 2: Relieving Pain and Other Symptoms
Activity 7: Seminar

Pain and Other Symptoms at the End of Life

Facilitator's Guide

Developed by:

Laura Riegelhaupt, EdM
Marcia Levetown, MD

With special thanks to:

Sarah Kirk, PhD

Produced by:



The Initiative for Pediatric Palliative Care

Enhancing family-centered care for children living with life-threatening conditions through education, research, and quality improvement.

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DESCRIPTION

The goal of this seminar is to enhance the ability of practitioners from multiple disciplines to provide comfort to children and their families at the end of life by anticipating symptoms, preparing families, and assessing and treating symptoms immediately as they occur. The case also provides an opportunity to discuss the ethics of treating refractory symptoms with sedation. The session ends with a discussion of measures that can be taken to improve practice in one's own institution.

TIME ESTIMATE

60 minutes

LEARNING OBJECTIVES

Participants will be able to:

- Identify common symptoms associated with the final stages of dying and describe the importance of immediate treatment.
- Describe the impact that symptoms have on the patient and the patient's family.
- Discuss the ethical use of sedation to relieve patients of refractory symptoms at the end of life.

SEMINAR STRUCTURE

This seminar is a case-based discussion structured around a series of developing symptoms as a 3-year-old brain tumor patient approaches death.

CHOOSING A FACILITATOR

We recommend that the seminar be facilitated by one or more palliative care specialists. A team comprised of a physician or nurse and a psychologist or social worker who have experience working with patients and families at the end of life would be ideal.

CHOOSING A RECORDER

The group recorder should be an organized and attentive person who is willing to document ideas relative to quality improvement and institutional change that emerge from group discussion.



PREPARING TO LEAD

- Print:**
- This Facilitator's Guide in its entirety, including the participant handouts that appear at the end.
- Review:**
- The entire Facilitator Guide including:
 - "General Guidelines for Facilitating Seminars," which appear below.
 - Case study, discussion questions, and facilitator notes that comprise the remainder of this document.
 - Handouts for the seminar, which appear as attachments to this document.
- Arrange for:**
- A registration process to determine how many people will attend the seminar. We recommend no more than 20 participants for this seminar.
 - A room large enough for the number of registered participants.
- Obtain:**
- One copy for each participant of the handouts that appear at the end of this Facilitator's Guide.

GENERAL GUIDELINES FOR FACILITATING SEMINARS

Ahead of time:

- Strongly encourage participants to arrive on time and stay for the duration of the seminar. Late arrivals and disruptions will make it difficult for you to complete the lecture and exercise within the timeframe scheduled.
- Use your own words and your own presentation style to make the key points from the session notes in the Facilitator's Guide. The less you read aloud or refer to the notes, the more engaged the participants will be in your lecture.
- Consider who your participants are and feel free to give more time to some points than others.
- Add examples from your own experience to make the seminar more personal and relevant to your institution. This will also encourage participants to reflect on their own cases and practices.

At the outset of the seminar, it may be helpful to set a few ground rules for the discussion:

- Encourage participants from all disciplines to ask questions and share their relevant experiences.
- Keep your eye on the time. If you begin to fall behind, you may need to limit participant questions and discussion. Ask participants to hold their questions until the end, or ask the recorder to write down the questions for discussion later in the session as time permits.

- Remind participants that all opinions should be treated in a respectful manner, and effort should be made to include as many voices as possible. (If one or two individuals begin to dominate the discussion, make a comment about the value of hearing from as many people as possible and invite others to participate.)
- Explain that if individuals choose to share personal experiences, their comments should not be repeated in other settings.
- If you are addressing a group with little or no experience with the dying process, acknowledge that they may find the seminar disturbing and offer to stay and talk with them when the seminar is over.

LEADING THE SESSION

Introduce the seminar by conveying the following information. We recommend that you put the ideas into your own words.

During this 1-hour seminar, we are going to discuss a case study involving a 3-year-old girl in the final weeks of her life. We'll use this case as an opportunity to discuss a range of questions regarding pain and other symptoms at the end of life including:

- *What are some of the common symptoms a child experiences when approaching death?*
- *What are the treatment options?*
- *How do you ensure that a patient's suffering is relieved as quickly as possible?*
- *When is it appropriate to treat the causes vs. the symptoms themselves?*
- *What ethics questions may arise toward the end of life and how do you deal with them?*

If you have little or no experience with the care of a dying child, you may find it upsetting to discuss this case. Many caregivers find it painful to witness a child's suffering and death. This often results in avoidance. Use this seminar as an opportunity to think about what the patient and family are experiencing and the comfort you can bring them by being truly present and attentive to their needs.



CASE STUDY Three-year-old Sandra

TIME ESTIMATE: 1 hour

Distribute the case study, "Three-year-old Sandra." Ask participants to take a minute to read the first page of the case. Then facilitate a discussion using the questions and sample responses that appear below. Keep in mind that participants may come up with additional, valid responses.

The content points you'll find below each discussion question are not intended as a script. They are intended to help you facilitate the discussion.

CASE STUDY Three-year-old Sandra

Sandra's diagnosis

Three-year-old Sandra was diagnosed 8 months ago with a progressive brain tumor. She received intensive, cancer-directed therapy but the tumor continued to grow. Sandra's care team met with her parents to discuss the prognosis as well as her parents' fears and concerns about what Sandra would experience as her illness progressed. They also discussed Sandra's and their goals and hopes for the coming weeks or months. The care team reassured them that Sandra's symptoms would be controlled, at home for as long as possible and then, if necessary, in the hospital.

Despite profound grief, Sandra's parents decided to focus strictly on comfort care and quality of life. After several weeks at home, Sandra's parents brought her to the hospital because she was experiencing increasingly severe headaches.

Question 1:

What is the first thing that the care team should do?

This question is intended to raise the point that pain is a medical emergency and it should be treated immediately.

- The care team should determine the intensity of Sandra's pain and provide appropriate medication immediately. Then Sandra's pain should be monitored and medication increased until her pain is relieved.
- Caregivers must recognize that it is a huge disservice to let a child suffer for any period of time if relief is available.
- A more complete assessment, including a pain history and physical examination can wait until after Sandra begins to get some relief.

Question 2:

What factors should be considered when choosing a pain medication for Sandra?

- What medications has she been given in the past? Were they effective? Were the side effects tolerable?
- What is to be the route of administration? Can Sandra swallow pills? Is a liquid form available? Transdermal patch? Can an IV be avoided?
- What combination of long-acting and short-acting medications will she need?
- What other medications is Sandra taking?
- What can be done to treat the causes?

Distribute the “Opioid Formulations and Side Effects” handout, which appears on the next page, and briefly review (1) the opioid medications and the formulations in which they are available, and (2) common, opioid side effects and how they can be managed. Opioids and their potential side effects are addressed in greater details in other lectures and seminars in this module of the IPPC curriculum.

Continue with the case study on page 7.



OPIOID FORMULATIONS AND SIDE EFFECTS

Long-Acting Opioids	
Methadone	liquid tablets
MS Contin	tablets
Oxycontin	tablets
Fentanyl	patch
Short-Acting Opioids	
Morphine	elixir tablets IV SC
Oxycodone	tablets

Common Opioid Side Effects	Management of Side Effects*
Constipation	Sodium Docusate/Senna
Sedation	Sedation effect may wear off after a few days Methyphenidate/Dextroamphetamine
Nausea	Lorazepam, Ondansetron, Diphenhydramine, Metoclopramide
Urinary Retention	I/O catheter q 24 hours if no IV fluids I/O or indwelling catheter for IV fluids
Pruritis	Antihistamine
<i>*If side effects are intractable, consider changing to an alternate opioid.</i>	



SANDRA'S PAIN IS UNDER CONTROL. SHE GOES HOME.

Unlike most three-year-olds, Sandra is able to swallow tablets and she is given MS Contin along with oxycodone for breakthrough pain. Her pain is well controlled with these medications and Sandra is able to return home.

About a week later, Sandra's physician receives a call from Sandra's parents. They have noticed a gradual decrease in Sandra's energy. A week later Sandra stops eating and drinking. Her parents are very upset and after a day or so, they decide to bring Sandra back to the hospital.

Question 3:

What are some possible explanations for the fatigue that Sandra is experiencing?

When discussing this question, emphasize the importance of considering differential diagnoses. Some explanations for Sandra's fatigue include:

- Organ dysfunction
- Anemia
- Malnutrition
- Sleep disturbance
- Medication side effects
- Depression/anxiety

Question 4:

What would these causes suggest in terms of treating Sandra's lack of energy?

- Disease progression
- Malnutrition—small, frequent meals, or possibly mesterol acetate to stimulate her appetite.
- Sleep disturbances—consider a sedative for her to take at night. Tricyclic antidepressants can also aid sleep. *MELATONIN - BENZODIAZEPINES*
- Medication side effect—Try switching her to a different opioid medication, stimulant.
- Depression—Psychotherapy, spiritual support, medication (don't be averse to using medication.)
 - Selective Serotonin reuptake inhibitors
 - Psychostimulants (take effect quickly)
 - Tricyclic antidepressants

Question 5:

One of the most distressing symptoms to parents is when a child stops eating and drinking. How can the care team help to minimize some of the family's distress?

This question is somewhat open-ended in order to encourage participants to think about what the family is experiencing. Here are some points you may want to use to supplement whatever points the class makes.

Why an inability to eat or drink may be so upsetting:

- From the moment a child is born, providing nutrition is among a parent's primary responsibilities and pleasures.
- During the child's illness, attending to the child's nutritional needs is one of the concrete ways in which parents can contribute to the child's healing.
- When the child no longer eats, parents may feel helpless.
- Sandra's inability to eat or drink also may be the most visible indicator to date that she is dying.

What you can do to help minimize the family's distress:

- Avoid language like "starvation" and "dehydration."
- Focus on the goals of care. Make it clear that Sandra can be kept comfortable in other ways, without nutrition.
- Explain that supplemental fluids and nutrition can cause Sandra discomfort (e.g., increased swelling in the brain.)

Before moving on to the next step in Sandra's case, point out that depending on a child's expected life span, the following treatment options may be considered.

- Small, frequent meals
- Magesrol acetate
- Gastronomy tube
- Intravenous hydration
- Intravenous nutrition

SANDRA'S HEADACHES BEGIN TO INTENSIFY

A few days after being admitted to the hospital, Sandra begins to complain about headaches. Nevertheless, she continues to talk and play. A conflict arises when the staff delays providing additional pain medication. Because Sandra is talking, playing, and greeting them with the adorable smile they are used to seeing, the caregivers believe that her mother is exaggerating Sandra's pain. They also have some concern that by increasing Sandra's medication they would be treating the mother's suffering more than Sandra's.

Question 6:

The staff's concerns in this situation are not unusual. In this case, what factors should be considered? Is additional information needed? What action should be taken, if any?

Here are some sample points that you may want to raise:

- One of the greatest barriers to effective pain management is the fear professionals have of causing a patient's death. Opioid medications do carry some risk of respiratory depression. However, in Sandra's case, the risk is small.
 - The risk is greatest in opioid naive patients. Sandra is already receiving a 5 mg/hour continuous infusion of morphine plus an additional 3 mg/5 minutes for breakthrough pain.
 - Sandra is awake, sitting up in bed, and watching TV, showing no signs of sedation. She clearly is not being over-medicated.
- If they haven't already, the professionals should ask Sandra directly how her head feels. In this actual case, Sandra's response was, "My head hurts, my head hurts a lot." A pain measurement tool appropriate for a three-year-old child would provide a quantitative measure for comparison later.
- The professionals could look for physiological indicators of pain such as Sandra's respiratory rate. Sandra's respiration rate is 28, which is high for her age and an indication that she is distressed in some way.
- **If anyone—parent or child—reports pain, caregivers should *assume* that the child is in pain until proven otherwise.**