# PEDIATRIC END-OF-LIFE CASE STUDIES

INTRODUCTION & OVERVIEW

PURPOSE: This educational presentation and accompanying curriculum will address select issues around pediatric end-of-life care.

Users should emerge with increased understanding, compassion, and resources for working with families facing pediatric end-of-life, especially when associated with cancer.

Please pause clips as desired to read at self-directed pace.

MODULE USE: This module can be adapted for use with small groups, large classrooms, or self-directed learning, coupled with a discussion group.

The video stories can be presented together or each story can stand alone. Reading the reference materials can enhance the learning experience.

An extended session of interaction or multiple sessions may be required to adequately review and discuss the material—<u>This Module</u> is intended to be a <u>Flexible Learning Tool</u>!

TARGET AUDIENCE: This activity has been developed to meet the educational needs of physicians, nurses, social workers, chaplains, case managers, volunteers and students who care for children and their families facing chronic and potentially life-limiting illness.

FORMAT: This module includes an introduction, competencies, learning objectives, video case studies, discussion questions, take-home points, and abridged resources.

Online offerings include this PowerPoint presentation and expanded curriculum and resources, and credits in downloadable PDF format at:

aquariusproductions.com/lion

# Support

This activity is supported by Cooperative Agreement U58/CCU24311 from the Centers for Disease Control and Prevention, Program Officer: Laura Zauderer.

Produced by Community Media Productions, an independent not-for-profit organization.

# **Advisors**

Lori Butterworth, BA
Devon Dabbs, BS
David Dickens, MD
Deborah L. Dokken, MPA
Larrie W. Greenberg, MD
Hollye Harrington Jacobs, RN, MS, MSW
Marcia Levetown, MD
Pam Malloy, RN, MN, OCN
Cindy Stutzer, RN, MS

# **Disclosure Statement**

All advisors involved in content development have disclosed no significant relationship with any commercial company whose products and services are discussed in this educational material.

In 1960, childhood cancer was rarely curable. Now the cure rate approaches 80%.

Yet from 1990 - 2004, a total of 34,500 childhood cancer deaths were reported in the US, with 2,223 children dying in 2004.

"The loss of a child is an extraordinarily difficult event."

(Korones, 2007; MMWR, Dec. 7, 2007)

Children facing end-of-life often spend years going in & out of the terminal phases of their disease.

Chronically and terminally ill children and their families may experience varying degrees of suffering as they strive for good quality of life.

(Docherty, et al, 2007)

Chronically and terminally ill children and their families may benefit from comfort care and specialized support to address quality of life and suffering, whether:

Physical Social

**Emotional** Spiritual

In this module, we will explore one intimate case study on end-of-life, looking at:

- O How the end-of-life (EOL) of a child unfolds
- The impact of that loss on the family and health care team (HCT)
- The need for specialized support from health care professionals (HCPs)

We will explore communication & decisionmaking challenges and strategies regarding:

- O Honest disclosure of prognosis, treatment options and care goals, while valuing hope
- The use of palliative care along w/curative treatment early in the course of the illness
- O Supportive care/limits of care at end-of-life

This case study portrays real-life, unscripted, complex situations that occur in a Midwestern city and hospital, and is not intended to be a best practice example.

The case study serves as a trigger and conversation starter. An Overview of select pediatric end-of-life issues follows, with references for further study and reflection.

# **Suggested Use**

STOP. View <u>movie clips</u> now. Discuss, think about or write reflections on:

- 1. Learning objectives & discussion questions found at the beginning, middle and end of this module.
- 2. The Overview of Pediatric End-of-Life Care in a downloadable PDF format.

# **OVERVIEW** Pediatric End-of-Life Care

### **SECTION ONE**

Children Who Suffer
And Pediatric Palliative Care

#### Needs of children who suffer

In the US, more than 500,000 children suffer from life-limiting/life-threatening conditions.

Many survivors of cancer and other serious childhood diseases cope with:

• Effects of ongoing and past treatments

• Symptoms of advancing disease

(Himelstein, 2004; Wolfe, 2000)

#### Needs of children who suffer

Invasive and life-sustaining measures continue to be part of care for many, including:

- Repeated intensive chemo, radiation, and other medical therapies with side effects
- Scary or painful medical procedures
- Social isolation (Mack and Wolfe, 2006)

#### Needs of children who suffer

Researchers estimated that on any given day in 2001, about 8,600 children could have benefited from pediatric palliative care services.

(Feudtner, 2001)

# What is pediatric palliative care?

**Medical treatment** that provides for the RELIEF OF:

physical,

social,

emotional,

& spiritual SUFFERING

of children and their families, TO IMPROVE QUALITY OF LIFE.

(IOM, 2003)

# What is pediatric palliative care?

#### Supportive or wraparound services, such as:

- Coordination of care to prevent fragmentation of services
- O Assistance in making transitions between care settings
- Care of psychological and spiritual needs (CAPC, 2011; The Catalyst Center, 2011)

# palliative care is

- Evidence-based medical treatment
- ✓ Vigorous care of pain and symptoms
- ✓ Care at the same time as efforts to cure or prolong life

# palliative care is not

- "Giving up" on a patient
- X Replacing curative or life-prolonging care
- × Hospice



# Benefits of pediatric palliative care

Early initiation of palliative care can decrease:

- **⊙Pain**
- **⊙Nausea**
- **⊙Vomiting**
- **⊙Sleeplessness**
- **⊙**Constipation

And, increase overall quality of life and well-being. (Mack and Wolfe, 2006)

# Benefits of pediatric palliative care

#### Studies show that palliative care programs can:

- Reduce hospital and intensive care unit length of stay
- Smooth coordination of care between settings
- Double or triple hospice referral rates for patients in the last few weeks of life (CAPC, 2011)

# The number of children receiving palliative care is on the rise

In the 1998 American Society of Clinical Oncology survey:

• 36% of pediatric oncology centers reported access to a palliative care team

In the 2005 Children's Oncology Group survey:

• 58% of responding Children's Oncology Group institutions had a palliative care team

(Friebert, 2009)

Children with life-limiting conditions and their families often face barriers to accessing palliative care services, including:

- The gaps and limitations in coverage
- Financing of pediatric palliative care programs

(The Catalyst Center, 2011)

State-mandated public benefit laws such as Medicaid tend to center on hospice services in the last six months of life—not on palliative care from the point of diagnosis until end-of-life care is needed.

This excludes children who can benefit from palliative care services long before they either need of become eligible for end-of-life care.

(The Catalyst Center, 2011)

Now under the Affordable Care Act of 2010, children enrolled in both Medicaid and CHIP can receive both pediatric palliative and hospice care services through waiver programs:

- o If—the children have a life expectancy of six months or less
- O But—the services vary by state and can be limited in scope. (PPACA, 2010)

Insured children who do not qualify for public benefit programs face obstacles:

⊙Private insurers continue to use the option of excluding many palliative care services from their benefits packages.

⊙Self-funded plans (about half of private insurance plans nationally) are not required to adhere to state-mandated benefit laws.

(The Catalyst Center, 2011)

Children without insurance face obstacles to accessing palliative care—they are dependent on:

- Out-of-Pocket payment by families
- Philanthropic support received by nonprofit organizations, including hospitals

(The Catalyst Center, 2011)

# Model pediatric palliative care

Begins at diagnosis;

Is integrated with curative care;

Continues throughout illness, until cure or death.

(American Academy of Pediatrics, 2000/2007)

# **SECTION TWO**

Children Who Die And Hospice Care

# Children are not supposed to get sick and die, but some do

53,000 U.S. infants & children (aged 0 - 19) die each year.

Cancer is the #1 disease killer of children (ages 1 – 19).

(ChIPPS, 2001; IOM Report, 2003a, MMWR, 2007; NHPCO, 2009)

#### Needs of children who die

#### **Children who die of cancer:**

- May have long periods of stability with sporadic episodes of serious illness, one of which eventually leads to death.
- Early episodes may be responsive to intensive treatment—and which episode will eventually cause death is difficult to predict.

  (Mack & Wolfe, 2006)

#### Needs of children who die

#### Children who die of cancer often:

- Receive particularly aggressive treatment even for the final serious episode, because the recovery may still seem possible
- Experience a poorer quality of life
- O Die with unmet pain/comfort care needs (Wolfe, 2000)

#### Needs of children who die

The outcome may be poor preparation for death on the part of the child and family, and a death that differs from the child and family's goals for the end-of-life period.

(Mack & Wolfe, 2006)

#### Needs of children who die

Researchers estimated that on any given day in 2001, about 5,000 children could have benefited from hospice care.

(Feudtner, 2001)

Supportive, comfort care that addresses the needs of the child & family, pain and symptom relief, and quality of life at child end-of-life.

(Morrow, 2009)

A Medicaid benefit provided when—

• The child has six months or less to live.

• The child and family AGREE TO STOP all curative & life-prolonging treatment.

(Morrow, 2009)

#### A Medicaid benefit for:

- Doctor services, nursing & respite care
- Medical equipment & supplies
- Home health aide/homemaker services
- ⊙Drugs for symptom control/pain relief (Morrow, 2009)

#### A Medicaid Benefit for:

- Physical, occupational, speech therapy
- Laboratory & other diagnostic studies related to the terminal illness
- ⊙Social work, dietary, spiritual and other counseling; and, bereavement support for family (Morrow, 2009)

# The number of children receiving hospice care is on the rise

In 1983, of the 1,400 hospices in the United States, only four accepted children.

By 2009, of the 3,600 hospices in the U.S., many accept children. Over 450 sites have child-specific programming.

(Walker, USINFO, 2007; National Hospice and Palliative Care Organization, 2010)

# Challenges to "traditional" hospice or end-of-life care

Predicting decline in children undergoing life-sustaining treatments has been found to be a difficult science.

Terminally ill children often go in and out of the terminal phases of their diseases for many years. (Docherty, 2007)

# Challenges to "traditional" hospice or end-of-life care

It is difficult for staff & families to:

- Find the 6-month dying point
- Transition from curative to comfort care
- Turn care over to a hospice team

(Docherty, 2007)

# Challenges to "traditional" hospice or end-of-life care

Justin and his family did not choose to utilize hospice care, even though the services were offered by the medical team.

They did not want to "give up" or stop curative care.

# **Legislative Update**

The Patient Protection and Affordable Care Act was signed into law on March 23, 2010.

It requires state Medicaid programs to pay for curative with life prolonging treatment AND hospice services for children under 21 who qualify.

(NHPCO, 2011)

### Per The American Academy of Pediatrics

Broaden <u>Hospice Care</u> eligibility criteria:

 Beyond the current life expectancy of 6 months or less Allow access to Palliative Care along with Curative Care:

 Throughout the course of illness, regardless of the outcome

(AAP, 2000/2007)

# **SECTION THREE**

Communication

Along the Continuum of Care

#### **Communication**

A Vital Part Of Palliative Care is learning how to communicate about painful & emotional issues with hope, even at end-of-life:

- Telling children and families bad news
- Evaluating treatment options & care goals
- O Discussing limits of care

(Korones, 2007)

In a study about their children's end-oflife care, many family members reported:

• Poor and inconsistent communication

O Poor delivery of bad news

O Insensitive remarks by HCPs

(Contro, 2002)

#### In another study:

- 40% to 70% of hospital staff felt inexperienced talking to dying patients and their families about end-of-life care
- 30% to 60% of attending physicians, residents, and nurses felt inexperienced in managing the pain and other symptoms of dying children (Contro, 2004)

Children who are not informed of the gravity of their illness:

- Often know they are very sick or dying
- Often feel isolated and alone

(Korones, 2007)

Siblings with a terminally ill brother or sister need:

• Encouragement, support and love

• The freedom to ask questions

• Age appropriate information

• School support (lan Anderson EOL, Module 12)

Joining with a family in their hope is an essential initial step, and a natural extension of the palliative care approach.

(Horgan, 2009)

Physicians rightfully struggle to promote hope in the patient with advanced disease and to support a positive outlook.

Yet, this approach is often accompanied by an unjustified fear that discussing death may {unduly} distress patients.

Initial guidance and support need not focus on end-of-life details in most cases (patient does not appear to be actively dying).

When end-of-life details are addressed without careful assessment of where the family resides on the continuum of hope, new and fragile relationships can be broken. (Horgan, 2009)

Physicians sometimes limit or carefully tailor prognostic information to preserve hope, such as:

- Avoid discussing prognosis when asked directly
- Give overly optimistic information
- Focus on treatment options
- Give no prognostic information

(Mack, 2007)

Parents tended to derive more hope from physician communication when it included detailed, full prognostic information, even when the prognosis was poor.

(Mack, 2007)

The clinical "trick" that families desire medical practitioners to perform is being present with compassion while disclosing prognosis and all treatment options.

(Horgan, 2009)

Physicians should feel relieved to know that it is not their job to "correct" the patient's hope...

The key question is whether this hope is interfering with appropriate planning and behavior.

### Communication & information processing

Conversations about end-of-life treatment issues are emotionally charged, and it is hard for patients and families to make decisions without first processing some of the accompanying emotions.

### Communication & information processing

Communication techniques that are openended and focus on patients' and family member's emotional states are more likely to:

- O Align the physician with the patient
- O Help patients marshal and draw strength from their existing resources

### Communication & information processing

Researchers highlight the need to <u>pace</u>
<u>discussions</u> according to the family's state of readiness—carefully assess the child's/family's:

- Understanding and desire for information
- O Absorption and retention of information

(Mack and Wolfe, 2006)

# Communication & information processing Meet the child and adolescent at their level of development, which evolves over time:

- O Look for clues to their understanding via play, drawings, dreams, writings, and behavior
- Have appropriate HCT members do routine assessments & provide psychosocial support (Korones, 2007)

#### Communication & culture

Develop the treatment plan in the context of the patient's and family's:

Beliefs

**Values** 

**Cultural history** 

(lan Anderson EOL, Module 5)

#### Communication & culture

Explore and acknowledge the cultural, spiritual and ethnic beliefs/values of the child/family.

Realize ethnic/religious groups have a shared sense of meaning & traditions regarding illness & death.

(lan Anderson EOL, Module 12)

#### Communication & culture:

HCP cultural awareness checklist

- Do I understand how the patient/family perceives the cause and nature of this illness?
- Do I understand how the patient/family perceives the nature and meaning of death?
- Are there any death related rituals or observances they wish to honor or perform?

(lan Anderson EOL, Module 8)

#### Communication & culture:

HCP cultural awareness checklist

- What is my cultural background, including ethnic, religious, educational, regional, and economic?
- How does my cultural background impact my approach to end-of-life?
- How do my fears, beliefs, and past experiences affect me as a health care provider? (lan Anderson EOL Care, Module 8)

### Communication & decision-making

Advance care planning is a useful tool for approaching conversations with patients.

Advance care planning is the process by which patients, together with their families and health care practitioners, consider their values and goals and articulate preferences for future care.

### Communication & decision-making

Advance care planning should occur within a framework that emphasizes:

Responding to patient and family emotions

 Eliciting and establishing goals throughout the course of palliative care treatment

(Tulsky, 2005; Horgan, 2009)

# Communication & decision-making

Help families focus on goals & make decisions that respect patient's wishes, values and goals.

Ask families the reasoning behind their decisions & who knows patient best.

Remember the role of other team members in educating families and dealing with conflict.

(Ian Anderson EOL, Module 4)

# Communication & decision-making Am I including interdisciplinary team members?

Palliative or Comfort Care Consultants

Biopsychosocial support

Financial, legal & practical support

Spiritual, religious, bereavement support

Psychosocial support via play/art activity

School and community liaison

## **Talk About Treatment Options:**

- How realistic is it that this will cure the disease?
- If not able to cure the disease, will it prevent progression of the disease?
- Will it improve the way the child feels?
- Could it make the child feel worse?
- What is the likely impact of this decision on the family?

(lan Anderson EOL Care, Module 12)

(lan Anderson EOL Care, Module 12)

**Explore Care Goals:** 

**o**Cure

Slowed progression

•Remission

• Contribution to research

• Prolonged life span

Achieving life goals

Maximizing periods of lucidity/comfort

Having care and/or death occur in a preferred location

(lan Anderson EOL Care, Module 5)

Prepare for Patient's & Family's Responses:

⊙ Guilt

**⊙Shock** 

Denial

**⊙Grief** 

Anger

**⊙Fear** 

Bargaining

**⊙Over-dependency** 

Depression

# Communication & decision-making Engage Children in the Process:

Competence or capacity, rather than age (minor) or life experience (mature minor), is becoming the standard when deciding an individual's ability to make healthcare decisions.

This has led to increased involvement of children and adolescents in health care decision-making. (lan Anderson EOL, Module 12)

Earlier communication may open the door for the child to express wishes & achieve goals like:

- Preference for location of care
- Meaningful & reassuring dialogue
- Making special memories

(lan Anderson EOL Care, Module 12)

Earlier communication may:

- O Allow child to participate when most able
- Contribute to a trusting relationship
- Provide time to process & integrate information with their values & beliefs

(lan Anderson EOL Care, Module 12)

My Wishes booklets help children express how they want to be treated when very sick:

• How I want people to treat me

• How comfortable I want to be

O What I want my loved ones to know

O What I want my doctors and nurses to know www.agingwithdignity.org/about.php

When siblings know about and participate in the care of their terminally ill brothers and sisters, they cope better in the weeks leading up to the death and months after.

(Korones, 2007; Spinetta, 1999)

Making it better or curing disease:

When the possibility of making it better or curing disease is small and the burden of treatment high, decisions can be very difficult.

(lan Anderson EOL Care, Module 12)

Patients and their families struggle with myriad choices concerning medical treatments that often precede death, including:

• When is intubation and mechanical ventilation reasonable?

O When do they increase suffering without offering hope of prolonged life of reasonable quality? (Tulsky, 2005; Mack & Wolfe, 2006)

Discussions regarding "do not attempt resuscitation (DNAR)" and "allow natural death (AND)" are often not undertaken until death is close at hand.

This, in turn, can lead to guilt and regret that extend long past the death of the child.

(lan Anderson, EOL Care, Module 12)

Although continued hope can be an important coping mechanism, avoidance,

or resistance

to addressing a difficult prognosis can lead to delays in the start of appropriate palliative options.

(lan Anderson EOL Care, Module 12)

Written advance directives formalize goals and preferences articulated by patients and include:

Living wills or other statements of patient preferences

**⊙Durable power of attorneys for health care** (Tulsky, 2005)

Orders are written by physicians to operationalize the preferences, and include:

O DNAR: Do Not Attempt Resuscitation

O AND: Allow Natural Death

 POLST: Physician Order for Life Sustaining Treatment

(Tulsky, 2005)

Advance directives are not the same as <u>orders</u> written by physicians and generally do not provide instructions for specific situations.

## Rather, they should facilitate:

- Discussions of goals of care
- Consideration of quality at end of life
- O Agreement on goals while patient has decision-making capacity (Tulsky, 2005)

A decision to forgo a specific treatment should not lead to abandonment of all active therapy, but may lead to careful review of all current and planned interventions.

Early discussion can lead to better understanding, fewer inappropriate CPR attempts, & improved coping.

(lan Anderson EOL Care, Module 12)

When both the physician and parent recognized earlier that the child had no realistic chance for cure:

- Elements of palliative care were more likely integrated into the child's care
- Hospice was introduced earlier
- The child was less likely to receive cancerdirected therapy in the last month of life
- The primary goal of treatment was to lessen suffering (Wolfe, et al, 2000)

When a psychosocial clinician (psychologist or social worker) was involved in the child's care there was greater concordance in the timing of physicians' and parents' understanding that the child had no realistic chance of a cure.

Interventions that focus on <u>strengthening</u> interdisciplinary interactions could be one way to enhance communication around palliative care. (Wolfe, et al, 2000)

In a study of bereaved parents of children with cancer, parents were more likely to consider care as of a higher quality if:

- The physician communicated what to expect in the end-of-life care period
- The parents felt prepared for the circumstances surrounding the child's death

(Mack & Wolfe, 2006)

# Communication & ethics HCPs self-evaluation

- Am I adequately treating pain/other symptoms?
- Am I helping patients and families set goals?
- Am I inappropriately prolonging dying?
- Am I helping patients and families achieve a sense of control, relieving burdens and strengthening relationships?

(Singer, PA et al, 1999; Ian Anderson EOL, Module 4)

The fundamental belief that the purpose of grief is to let go of the deceased in order to move on and form new attachments is the antithesis of many bereaved people's experience.

(Horgan, 2009; Klass, et al, 1996))

Klass (1996) found that "continuing bonds" or remaining connected to their deceased loved ones seemed to:

- Facilitate both adults' and children's ability to cope with the loss and the changes in their lives
- Provide solace, comfort and support
- Ease the transition from the past to the future

Ann Finkbeiner (1998) found that after a child dies, the parent's world changes entirely:

- Changed marriages and relationships with children, friends and relatives
- Drastically changed priorities
- Attempts to make sense of the death
- O How they move on through grief, get on with their lives, and never let go of their children

If families perceive that their child's death was "good," have few or no regrets, and feel their child received high quality care, then the bereavement process can be less complicated.

(Painter, 2011; Mack & Wolfe, 2006)

### **An important study found that:**

- Of bereaved parents who discussed death with their children, nobody regretted having done so.
- 27% of parents who did not discuss death with their children did regret not having done so.
- O Physicians who are willing to enter into such conversations with their pediatric patients may ease the burden parents face of initiating such discussions (Mack & Wolfe, 2006)

Complicated bereavement involves additional barriers (such as regret) that slow or prohibit each unique grieving process.

With most cases where there is complicated grief, the theme of forgiveness is a key component.

# Communication, loss, & grief Helpful interventions for families

- Provide presence
- Active listening, touch, silence, reassurance
- Identify support systems

- Use bereavement specialists and resources
- Actualize the loss and facilitate living without the deceased

(ELNEC-PPC, Module 9)

# Communication, loss, & grief in HCPs

"To cure sometimes. To relieve often. To comfort and support always."

Edward Trudeau

I doubt any medical education can generate sustainable patient-centered physicians, capable of procuring endless comfort and assistance to their patients, while being void of dedicated resources intended to support their own physical and mental health. (Jennings, 2011)

# Communication, loss, & grief in HCPs

The critical endeavor lies in not forgetting that behind each evidence-based, scientifically apt physician is a human being with frailties, flaws, fears and doubts alongside astounding proficiency and skillfulness.

(Jennings, 2011)

## Grief interventions for HCPs

(ELNEC-PPC, Module 9; Jennings, 2011))

Physician's Health Programs (PHP)

Health Enhancing Programs (HEP)

Develop managerial skills

Social and peer support

Spiritual reflection, exploration & replenishment

Organizational Engagement

# PEDIATRIC END-OF-LIFE CASE STUDIES

Be like the bird that, pausing in her flight awhile on boughs too slight, feels them give way beneath her, and yet sings, knowing that she hath wings.

~Victor Hugo

# PEDIATRIC END-OF-LIFE CASE STUDIES

## **Explore Other LION Modules:**

Siblings Stories
Cancer Health Disparities
Childhood Cancer & School Issues
Childhood Cancer Survivorship Stories
Case Studies in Spirituality & Childhood Cancer
Nurse-Patient-Relationships in Childhood Cancer

Aquarius Health Care Media (www.aquariusproductions.com)