

# **PEDS, EPIDURAL, SPIRITUALITY, AND GRIEF**

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# PROGRAM DETAILS

- **Title:** Peds, Epidural, Spirituality, and Grief
- **Dates/Term of offering:** This activity was released on May 31, 2023 and is valid for one year. Requests for credit must be made no later than May 30, 2024.
- **Joint Providership:** This activity is jointly provided by Global Education Group and Hospice and Palliative Board Review.com.



- **Target Audience:** The educational design of this activity addresses the needs of Physicians, NPs, Nurses, and health care professionals interested in learning more about hospice and palliative medicine and those who want to earn continuing education credits and/or prepare for board certification in hospice and palliative medicine.

# PROGRAM DETAILS

- **Program Overview:** Clinicians and health care professionals are unaware of best practices to be utilized when having advanced care planning discussions with patients and family. As such, they do not know how to adequately counsel patients and families on appropriate goals of care (from a holistic point of view) and advanced care planning given the patient's disease trajectory and wishes.
- **Faculty:** Eric Bush, MD, RPh, MBA
- **Physician Accreditation Statement:**

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of Global Education Group (Global) and Hospice and Palliative Board Review.com. Global is accredited by the ACCME to provide continuing medical education for physicians.

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  - **Fee Information:** There is a fee for this educational activity.
  - **System Requirements:**
    - **PC:** Microsoft Windows 2000 SE or above, Flash Player Plugin (v7.0.1.9 or greater), Internet Explorer (11.0 or greater), Chrome, Firefox, Adobe Acrobat Reader\*
    - **MAC:** MAC OS 10.2.8, Flash Player Plugin (v7.0.1.9 or greater), Safari, Chrome, Adobe Acrobat Readers\*, Internet Explorer is not supported on the Macintosh.
- \*Required to view printable (PDF) version of the lesson.

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# LEARNING OBJECTIVES

- Describe how to perform symptom management in the palliative and hospice setting.
- Describe how to counsel patients and caregivers on interventions in this setting and the applicable risk versus benefit for appropriate interventions.
- Describe how to perform goals of care and advanced care planning discussions with patients and family.
- Describe how to counsel patients and caregivers on appropriate goals of care and advanced care planning given the patient's disease trajectory and wishes.
- Describe how to discuss utilization of appropriate personnel allocation in the hospice and palliative care setting.
- Describe how to counsel patients and families on appropriate personnel allocation in the hospice and palliative care setting and the benefits for patients and families undergoing this type of care.
- Describe how to perform discussions differentiating between hospice and palliative care services with patients and family.
- Describe how to counsel patients and caregivers on differentiating between hospice and palliative care services and appropriate level of care for the patient and family given current best practice.

# Pediatrics, Ethics, Spirituality & Grief

# Features of Pediatric Palliative

- Epidemiology
- Rare genetic disorders complicate prognosis
- Distinct needs of infant vs child vs adolescent
- Ethical and legal issues
- Impact of terminal illness on family, peers & healthcare providers
- Bereavement implications (often complicated)

1. Papadatou D et al. Education and Training Curriculum for Pediatric Palliative Care. Alexandria, Va.: Children's International project on Palliative/Hospice Services, NHPCO, 2003

# 10 Leading Causes of Death by Age Group, United States – 2017

Rank	Age Groups									
	<1	1-4	5-9	10-14	15-24	25-34	35-44	45-54	55-64	65+
1	Congenital Anomalies 4,580	Unintentional Injury 1,267	Unintentional Injury 718	Unintentional Injury 860	Unintentional Injury 13,441	Unintentional Injury 25,669	Unintentional Injury 22,828	Malignant Neoplasms 39,266	Malignant Neoplasms 114,810	Heart Disease 519,052
2	Short Gestation 3,749	Congenital Anomalies 424	Malignant Neoplasms 418	Suicide 517	Suicide 6,252	Suicide 7,948	Malignant Neoplasms 10,900	Heart Disease 32,658	Heart Disease 80,102	Malignant Neoplasms 427,896
3	Maternal Pregnancy Comp. 1,432	Malignant Neoplasms 325	Congenital Anomalies 188	Malignant Neoplasms 437	Homicide 4,905	Homicide 5,488	Heart Disease 10,401	Unintentional Injury 24,461	Unintentional Injury 23,408	Chronic Low. Respiratory Disease 136,139
4	SIDS 1,363	Homicide 303	Homicide 154	Congenital Anomalies 191	Malignant Neoplasms 1,374	Heart Disease 3,681	Suicide 7,335	Suicide 8,561	Chronic Low. Respiratory Disease 18,667	Cerebro-vascular 125,653
5	Unintentional Injury 1,317	Heart Disease 127	Heart Disease 75	Homicide 178	Heart Disease 913	Malignant Neoplasms 3,616	Homicide 3,351	Liver Disease 8,312	Diabetes Mellitus 14,904	Alzheimer's Disease 120,107
6	Placenta Cord. Membranes 843	Influenza & Pneumonia 104	Influenza & Pneumonia 62	Heart Disease 104	Congenital Anomalies 355	Liver Disease 918	Liver Disease 3,000	Diabetes Mellitus 6,409	Liver Disease 13,737	Diabetes Mellitus 59,020
7	Bacterial Sepsis 592	Cerebro-vascular 66	Chronic Low. Respiratory Disease 59	Chronic Low Respiratory Disease 75	Diabetes Mellitus 248	Diabetes Mellitus 823	Diabetes Mellitus 2,118	Cerebro-vascular 5,198	Cerebro-vascular 12,708	Unintentional Injury 55,951
8	Circulatory System Disease 449	Septicemia 48	Cerebro-vascular 41	Cerebro-vascular 56	Influenza & Pneumonia 190	Cerebro-vascular 593	Cerebro-vascular 1,811	Chronic Low. Respiratory Disease 3,975	Suicide 7,982	Influenza & Pneumonia 46,862
9	Respiratory Distress 440	Benign Neoplasms 44	Septicemia 33	Influenza & Pneumonia 51	Chronic Low. Respiratory Disease 188	HIV 513	Septicemia 854	Septicemia 2,441	Septicemia 5,838	Nephritis 41,670
10	Neonatal Hemorrhage 379	Perinatal Period 42	Benign Neoplasms 31	Benign Neoplasms 31	Complicated Pregnancy 168	Complicated Pregnancy 512	HIV 831	Homicide 2,275	Nephritis 5,671	Parkinson's Disease 31,177

# Definitions

- Neonate: Birth to 28 days old
- Infant: Birth to 1 year old
- Child: 1-18 years old

# Statistics

- About 50,000 deaths annually (~2% all US deaths)
- Children represent 25% US population
- Half of childhood deaths are in first year of life
- Half of infant deaths are in the first month of life

# Symptoms in Dying Children

- Most common reported symptoms:
  - Pain
  - Fatigue
  - Dyspnea

# Concurrent Care

The “Concurrent Care for Children” Requirement (CCCR) of the Patient Protection and Affordable Care Act stipulates that a child who is eligible for and receives hospice care may concurrently receive all other services that are related to the treatment of the child’s condition. That means that, in addition to curative measures, a child’s care may also focus on enhancing the quality of life, minimizing suffering, optimizing function and providing opportunities for personal and spiritual growth. As that realization has taken root, the healthcare culture and referral sources, as well as patients and their families, are beginning to embrace a dual approach to caring for terminally ill children.



# Causes of Deaths

## All Infants

1. Congenital malformations
2. Short gestation / LBW
3. Sudden Infant Death Syndrome
4. Maternal complications
5. Complications of placenta, cord, or membranes
6. Accidents/unintentional injury

# Causes of Deaths

## Infants with Complex Chronic Conditions

1. Cardiovascular
2. Congenital / genetic
3. Respiratory
4. Neuromuscular

# Causes of Death Children 1-19

1. Accidents
2. Assault
3. Malignancy
4. Suicide
5. Congenital malformations, deformations
6. Chromosomal anomalies
7. Heart disease
8. Cerebrovascular diseases

# Causes of Death

## Children 1-19 with Complex Chronic Condition

1. Malignancy
2. Neuromuscular
3. Cardiovascular

# Diagnoses in Pediatric Palliative Care

- Genetic/Congenital
- Neuromuscular
- Oncologic
- Respiratory
- Gastrointestinal
- Cardiovascular

Some children with multiple diagnoses

# Advanced Care Planning

- Children should participate to the fullest extent possible, based on experience of illness, developmental capacities, and level of consciousness.
- Regardless of the prognosis, respect for the child requires that he or she be given a developmentally appropriate description of the condition along with the expected burdens and benefits of available management options, while soliciting and listening to the child's preferences.

# Identifying presence of pain

Behaviors seen in validated pain assessment tools for nonverbal children with neurologic impairment

- Vocalizations (crying, moaning)
- Facial expression (grimacing, fussy)
- Consolability
- Interactivity (withdrawn, less active)
- Movement (pulls legs up)
- Tone and posture (arching, stiffening)
- Physiological responses (sweating)

# FLACC scale

**Behavioral Observation Pain Rating Scale**

Categories	Scoring		
	0	1	2
Face	No particular expression or smile; disinterested	Occasional grimace or frown, withdrawn	Frequent to constant frown, clenched jaw, quivering chin
Legs	No position or relaxed	Uneasy, restless, tense	Kicking, or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
Cry	No crying (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or talking to; Distractable	Difficult to console or comfort
Each of the five categories (F) Face; (L) Legs; (A) Activity; (C) Cry; (C) Consolability is scored from 0-2, which results in a total score between 0 and 10.			



**Faces Pain Scale** The **scale** shows a close linear relationship with visual analog **pain scales** across the age range of 4-16 years.

## Wong-Baker **FACES**® Pain Rating Scale



**0**

No  
Hurt



**2**

Hurts  
Little Bit



**4**

Hurts  
Little More



**6**

Hurts  
Even More



**8**

Hurts  
Whole Lot



**10**

Hurts  
Worst

CRIES assesses crying, oxygenation, vital signs, facial expression, and sleeplessness. It is often used for infants six months old and younger and is widely used in the neonatal intensive care setting

DATE/TIME						
<b>Crying</b> - Characteristic cry of pain is high pitched. 0 – No cry or cry that is not high-pitched 1 - Cry high pitched but baby is easily consolable 2 - Cry high pitched but baby is inconsolable						
<b>Requires O<sub>2</sub> for SaO<sub>2</sub> &lt; 95%</b> - Babies experiencing pain manifest decreased oxygenation. Consider other causes of hypoxemia, e.g., oversedation, atelectasis, pneumothorax) 0 – No oxygen required 1 – < 30% oxygen required 2 – > 30% oxygen required						
<b>Increased vital signs (BP* and HR*)</b> - Take BP last as this may awaken child making other assessments difficult 0 – Both HR and BP unchanged or less than baseline 1 – HR or BP increased but increase in < 20% of baseline 2 – HR or BP is increased > 20% over baseline.						
<b>Expression</b> - The facial expression most often associated with pain is a grimace. A grimace may be characterized by brow lowering, eyes squeezed shut, deepening naso-labial furrow, or open lips and mouth. 0 – No grimace present 1 – Grimace alone is present 2 – Grimace and non-cry vocalization grunt is present						
<b>Sleepless</b> - Scored based upon the infant's state during the hour preceding this recorded score. 0 – Child has been continuously asleep 1 – Child has awakened at frequent intervals 2 – Child has been awake constantly						

# Opioid dosing basics

- Dosage initially based on weight
- Same escalation principles as in adults
- No upper dose limits
- Taste can be a limiting factor (chocolate syrup hides flavor-generally safe for drug)

# Morphine

- Gold standard for moderate or severe pain
- Increased half-life and diminished clearance in neonates.
- Starting doses for infants ~50% of older children.
- Infants more sensitive to respiratory depression.

# Conditions Appropriate for Palliative Care

- Conditions for which curative treatment is possible but may fail (Cancer)
- Conditions requiring long-term treatment aimed at maintaining the quality of life (Cystic Fibrosis)
- Progressive conditions in which treatment is exclusively palliative after diagnosis (Trisomy 13)
- Conditions involving severe, non-progressive disability (Hypoxic Brain Injury)

# Barriers

- Psychological
- Religious
- Fragmented Health Care System
- Financial & Regulatory
- Ethical & Legal
- Research
- Educational

# Research

- Limited
- Systematic data are often not available
- Results in decision making about the care of children with little guidance regarding potential burdens versus benefit of medical interventions

Field MF, Behrman R, eds. When Children Die. Washington, D.C.: National Academies Press, 2003

# AAP Recommendations

Residency, fellowships, and continuing education Programs should include topics on:

- Palliative Medicine
- Communication Skills
- Grief and Loss
- Managing prognostic uncertainty
- Spiritual Care
- Decision to forgo life sustaining medical treatment
- Alternative medicine



# Ethics

- Autonomy
- Beneficence
- Non-maleficence
- Justice
- Quality of life (like beauty, in the eye of the beholder)
- All the above based on principle of respect

# Ethical Issues Arise Due to

- Clinical decisions
- Technology
- Decision maker viewpoints/perspectives/differences
- Transference/countertransference
- Lack of planning (ie no advanced directives in acutely ill pt, pt w/out capacity)

# Ethical Challenges

- Informed consent
- “Futile treatments” & medicolegal implications(regional variation)
- Nutrition & end-of-life care
- “Suffering”
- Assessing capacity for decision making
- Laws of surrogacy
- Advanced Directives
- Secondary gain issues
- Need for guardianship
- Advancing medical technology vs what would the patient want?
- Religious and cultural context/implications

# Autonomy

Individual's right and ability to decide for him - or  
- herself according to their beliefs, values and life  
plan

# Beneficence

- Doing good on behalf of the patient
- Interpretational differences, whose good?

# Non-maleficence

- Primum non-nocere (first do no harm)
- Risk vs benefit vs pt trajectory of illness, wishes & family desires/understanding of disease process

# Justice

- Concept of fairness or what is deserved
- Describes what individuals are legitimately entitled to and what they can claim
- Sometimes justice may serve to limit autonomy; what the individual wishes, chooses, or feels entitled to may not be possible or allowable in the context of the society

# Spirituality

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.

Christina Puchalski, M.D., M.S., F.A.P.C., et. al. Improving the Quality of Spiritual Care as Dimension of Palliative Care: The Report of the Consensus Conference. *Journal Of Palliative Medicine*. Volume 12, Number 10, 2009.

Spirituality refers to the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual.

Reed, P.G. (1992) An emerging paradigm for the investigation of spirituality in nursing. *Research in Nursing & Health*, 15(5), 349-357.



# Religion

Religion has specific behavioral, social, doctrinal and denominational characteristics because it involves a system of worship and doctrine that is shared within a group.

Multidimensional Measurement of Religiousness / Spirituality for use in Health Research: A Report the Fetzer Institute / National Institute on Aging Working Group. Kalamazoo, MI: Fetzer Institute 2003 (1999).

# Spiritual Traits

- Meaning
- Value
- Transcendence
- Connecting
- Becoming

Sanders, C. Challenges for spiritual care-giving in the millennium. *Contemporary Nurse* 2002 April; 12(2): 107-11

# Spiritual Care

Interventions, individual or communal, that facilitate the ability to express the integration of the body, mind, and spirit to achieve wholeness, health, and a sense of connection to self, others, and[/or] a higher power.

American Nurses Association, & Health Ministries Association. (2005). Faith and community nursing: Scope and standards of practice. Silver Spring, MD: American Nurses Association.

# Screening Tool

- F-Faith
- I-Importance
- C-Community
- A-Address (Need to address)

# Spiritual Distress

“Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.”

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# Common Causes of Spiritual Distress

- Grief
- Concerns about death and afterlife
- Conflicted or challenged belief systems
- Loss of faith
- Concerns with meaning/purpose of life
- Concerns about relationship with deity
- Isolation from religious community
- Guilt
- Hopelessness
- Conflict between religious beliefs and recommended treatments
- Ritual Needs

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# Addressing Spiritual/Religious Needs & Outcomes

- Improved pt/family coping, comprehension of illness and disease trajectory
- Improved care planning
- Improved clinical outcomes
- Provision of care that is holistic and patient-centered

# Grief

- Grief is the response to any loss and is therefore a common human experience.
- Terminal illness or chronic illness may be replete with losses and grief.
- Losing your own life is associated with grief (self-anticipatory).
- Losing a loved-one is also associated with grief
- Grief may start at the time of diagnosis
- Good end-of-life care has incorporated the concept of good grief (*i.e. a healthy expression of our life force*)



# Important Definitions/Delineation

- Grief-psychological, social & somatic reactions to the perception of loss.
- Mourning-cultural response to grief.
- Bereavement-state of having suffered a loss.
- Grief work-grief response requiring the expenditure of physical and emotional energy.

# Coping/Grief Response/Bereavement Pearls

- Highly individual
- Supports beneficial (family, community, faith based)
- Many hospice programs offer bereavement services (individual/group)
- Role of faith/spirituality
- Complicated w/loss of a child
- Transference/countertransference
- Substance abuse, mental health issues & prior losses often make more complex
- Many elderly patients/spouses with long marriages may make more complex

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<https://www.sonohs.com/sono-it-all-blog/2017/10/17/methadone-dosing-for-chronic-pain>

<https://www.palliativedrugs.com/download/030911Methadone.pdf>

Opioid Deaths: Trends, Biomarkers, and Potential **Drug Interactions** Revealed by Decision Tree Analyses. Saad MH, Savonen CL, Rumschlag M, Todi SV, Schmidt CJ, Bannon MJ. Front Neurosci. 2018 Oct 23;12:728

**Methadone** Metabolism and **Drug-Drug Interactions**: In Vitro and In Vivo Literature Review. Volpe DA, Xu Y, Sahajwalla CG, Younis IR, Patel V. J Pharm Sci. 2018 Dec;107(12):2983-2991

Management of opioid withdrawal symptoms. Med Lett Drugs Ther. 2018 Aug 27;60(1554):137-141

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- [Multidisciplinary Pain Management for Pediatric Patients with Acute and Chronic Pain: A Foundational Treatment Approach When Prescribing Opioids](#). Wren AA, Ross AC, D'Souza G, Almgren C, Feinstein A, Marshall A, Golianu B. *Children (Basel)*. 2019 Feb 21;6(2).

# APPENDIX

# Methadone - Pg 15: Notes

I want to call your attention to methadone. Methadone has garnered the reputation of being the opioid of choice for neuropathic pain because not only is it an opioid that works at all of the receptors, it's also a serotonin reuptake inhibitor and an NMDA blocker. So theoretically, this ought to be a good drug for neuropathic pain.

# Statistics – Pg 42: Notes

- 0.06% children die

# Causes of Death Children 1-19 with Complex Chronic Condition – Pg 48: Notes

- Looking at the pediatric population as a whole, total
- Preventable deaths (accidents/unintentional injuries, assault/homicide) account for 27% of deaths



# POSTTEST/QUIZ

Please click on the link below to be taken to this activity's quiz. After successful completion, you can then fill out an evaluation and application for CME credit.

[Peds, Epidural, Spirituality, and Grief](#)