

SYMPTOM MANAGEMENT AND APPROACH TO CARE 2

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PROGRAM DETAILS

- **Title:** Symptom Management and Approach to Care 2
- **Dates/Term of offering:** This activity was released on May 26, 2021 and is valid for one year. Requests for credit must be made no later than May 26, 2022.
- **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:** This educational activity will dive a bit deeper into the best practices for clinicians and health care professionals to utilize when performing symptom management, and managing its interventions, for patients in the palliative and hospice care setting.
- **Faculty:** Eric Bush, MD, RPh, MBA
- **Physician Accreditation Statement:**

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PROGRAM DETAILS

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- **Global Contact Information:** For information about the accreditation of this program, please contact Global at 303-395-1782 or cme@globaleducationgroup.com.
- **Fee Information:** There is a fee for this educational activity.

PROGRAM DETAILS

- **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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The *faculty* have the following relevant financial relationships with ineligible companies:

- **Eric Bush, MD, RPh, MBA:** Nothing to disclose

The *planners and managers* have the following relevant financial relationships with ineligible companies:

- **Lindsay Borvansky:** Nothing to disclose
- **Andrea Funk:** Nothing to disclose
- **Liddy Knight:** Nothing to disclose
- **Ashley Cann:** Nothing to disclose
- **Eric Bush:** Nothing to disclose

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LEARNING OBJECTIVES

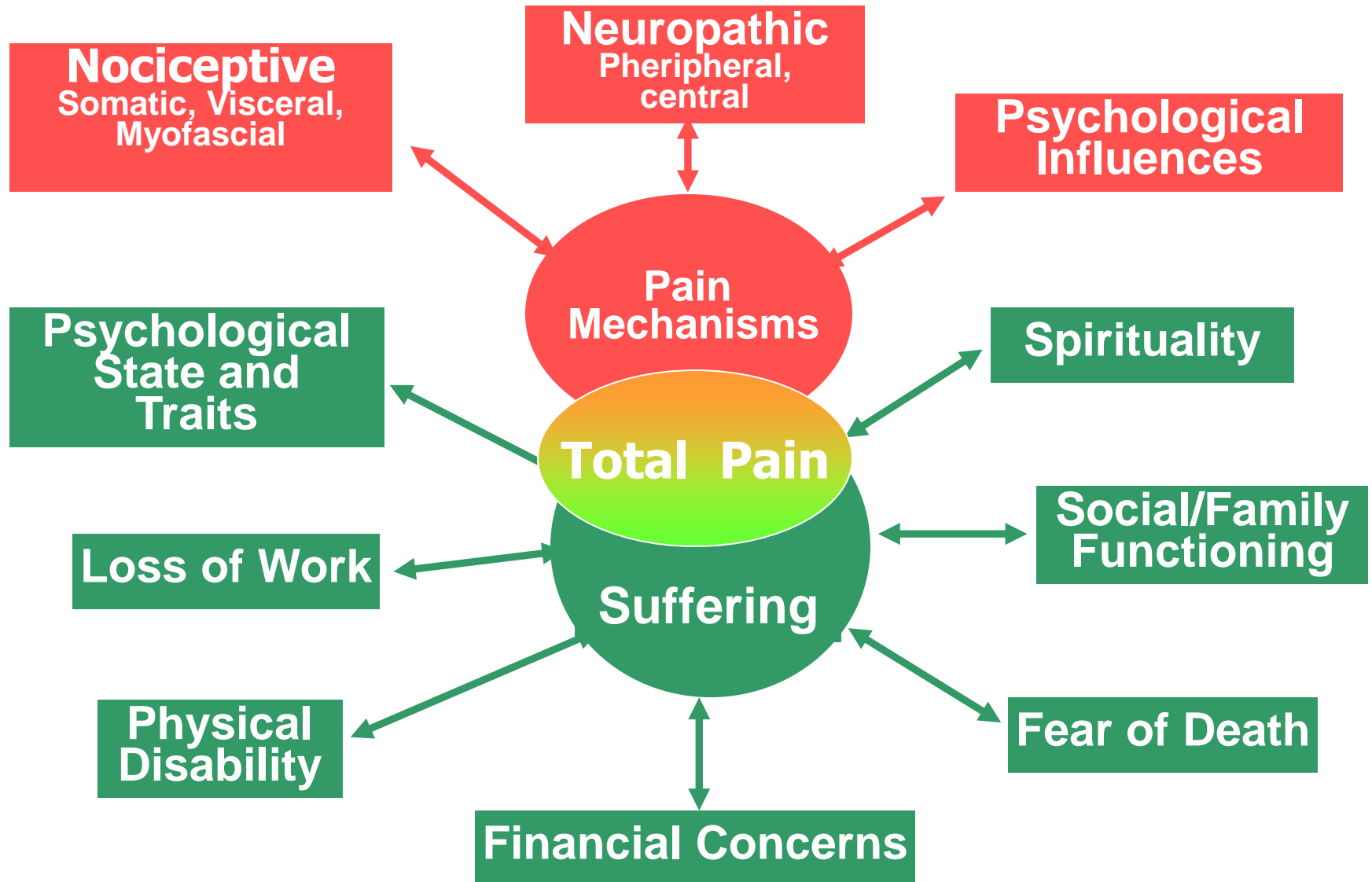
- Describe how to perform symptom management in the palliative and hospice setting
- Describe how to counsel patients and caregivers on interventions in this setting and the applicable risk versus benefit for appropriate interventions
- Describe how to perform goals of care and advanced care planning 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 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

PAIN, OPIATE CONVERSION & TITRATION

Definition of Pain

- An unpleasant sensation that can range from mild, localized discomfort to agony. Pain has both physical and emotional components. The physical part of pain results from nerve stimulation. Pain may be contained to a discrete area, as in an injury, or it can be more diffuse, as in disorders like [fibromyalgia](#). Pain is mediated by specific nerve fibers that carry the pain impulses to the brain where their conscious appreciation may be modified by many factors.
- The word "pain" comes from the Latin "poena" meaning a fine, a penalty.

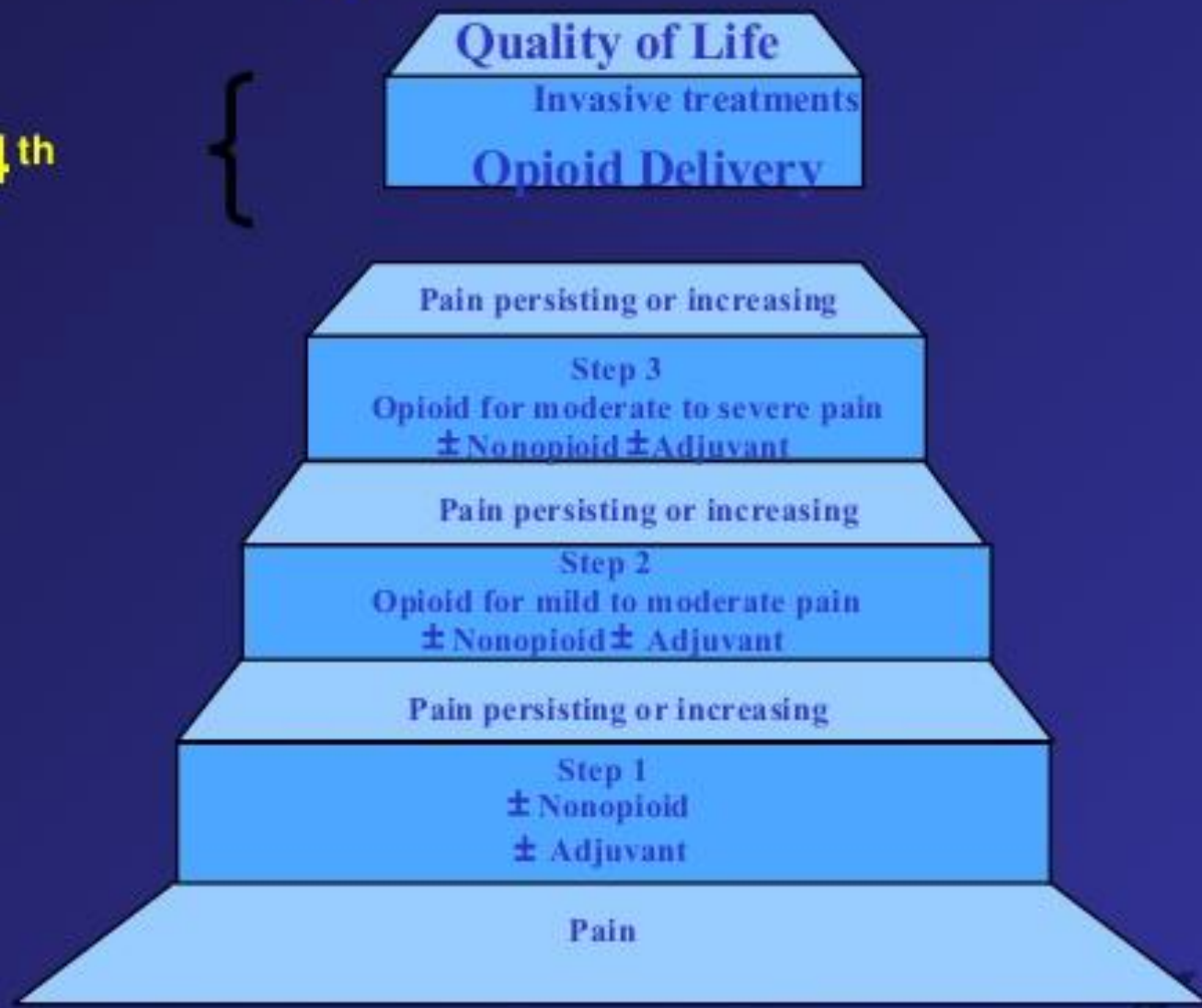
Nature of Pain/QOL



Modified WHO Analgesic Ladder

**Proposed 4th
Step**

**The WHO
Ladder**



Opioid Titration

- Goal of care is management of pain with long acting pain medications (overall goal of pain management is **ALWAYS** OPTIMIZE FUNCTIONALITY)
- Use of 3 or more breakthrough doses/24 hour period may be an indication of the need to increase the long acting medication (dose/frequency or both)
- Knowing how to safely titrate pain medications is a core competency for hospice nurses
- Opioid naïve < 30mg DOME (Daily Oral Morphine Equivalents);
High dose opiate >90MG DOME

Opioid Rotation

Consider when:

- Lack of therapeutic response - Patient develops tolerance to their current narcotic
- Formulary issues - Change from Oxycodone Extended Release to a preferred narcotic(ie Long Acting Morphine)
- Change from IV/SQ to po or po to IV/SQ
- Changing to Methadone
- Development of adverse effects
- Change in patient status
- Other considerations
 - Opioid/formulation availability
 - Patient/family health care beliefs

Physician and/or Pharmacist oversight required:

- When changing to or from IV/SQ
- When changing to or from Methadone

COMMUNICATING THE RATIONALE

Explaining WHY to patients, families, caregivers (and other practitioners):

- Improved pain management
 - Fewer Peaks/Troughs
 - LA oral, transdermal fentanyl and buprenorphine
- Enhanced adherence to opioid therapy
- Improved patient outcomes
 - Better analgesic effects
 - Better functional status
 - Fewer adverse effects

CONVERSION CONVERSATIONS

- Same opioid, one formulation to a another



- Same opioid, one route of administration to another



- From one opioid to another



- Conversions to/from transdermal opioids



EQUIANALGESIC TERMINOLOGY

- Opioid responsiveness
 - The degree of analgesia achieved as the dose is titrated to an endpoint defined either by intolerable side effects or the occurrence of acceptable analgesia
- Potency
 - Intensity of the analgesic effect of a given dose
 - Dependent on access to the opioid receptor and binding affinity
- Equipotent doses = equianalgesic

EQUIANALGESIC OPIOID DOSING

- Use the equianalgesic chart
- Convert current total daily opioid to morphine equivalence (DOME in a 24 hr time period)
- For TD Fentanyl, double the strength of the patch i.e, 100mcg patch is approximately 200mg/day of oral morphine
- Always consider 25% reduction in dose when rotating opiate itself (incomplete cross tolerance)

EQUIANALGESIC OPIOID DOSING

Drug	Equianalgesic Doses (mg)	
	Parenteral	Oral
Morphine	10	30
Buprenorphine	0.3	0.4 (sl)
Codeine	100	200
Fentanyl	0.1	NA
Hydrocodone	NA	30
Hydromorphone	1.5	7.5
Meperidine	100	300
Oxycodone	10*	20
Oxymorphone	1	10
Tramadol	100*	120

LIMITATIONS OF EQUIANALGESIC CHARTS

- Based on single dose studies
- Patient-specific variables
 - Weight, adipose layer available, temperature

DETERMINING AN APPROPRIATE DOSE ADJUSTMENT

- Determine 24 hour total of long acting medications actually taken
- Determine 24 hour total of breakthrough doses actually used = DOME
- Determine pain trajectory with the aforementioned
- Is the pain opiate responsive? Are there better alternatives? Adjuvants? Complementaries?

COMFORT ACHIEVED - WITHOUT OPIOID ROTATION

- If the patient reached comfort with the breakthrough dosing taken in the last 24 hours:
- Total the medication used in the past 24 hours (TDD)
- Adjust the LA Opiate accordingly

COMFORT NOT ACHIEVED - WITHOUT OPIOID ROTATION

If patient did not reach comfort with breakthrough dosing in past 24 hours:

- Total opiate use in last 24 hrs (DOME)
- **Increase the total dose by 25% for moderate pain.**
- **For severe pain, 50% increase may be indicated. Requires close monitoring.**
- Adjust LA opiate appropriately
- Breakthrough/Rescue dose is 25% of the new 12 hour long acting dose

MEDICATION CHANGE/ROUTE NECESSARY

Common scenarios:

- Cannot swallow the oral tablet / solution
- No longer has the fatty layer or body temperature to absorb a transdermal patch
- Has lost IV access and does not wish to restart
- Consider using the same drug in a new route
- Consider using a different drug in a new route

SAME DRUG: DIFFERENT ROUTE

- Bioavailability
 - The rate and extent to which the active ingredient is absorbed from a drug product and becomes available at the site of action
- Oral bioavailability
 - Morphine 30-40% (range 16-68%)
 - Hydromorphone 50% (29-95%)
 - Oxycodone 80%
 - Oxymorphone 10%

CONVERSION EQUATION

Same Drug : Different Route

- Set up the conversion equation
 - Use the same drug but determine the conversion fraction based on an alternate route
 - (Morphine is 30 Oral to 10 IV or equation of $10/30$)
- Cross multiply and solve for “X”
- Obtain the total dose for the new route
- Divide the total dose by 2 for every 12 hour dosing or by 3 for every 8 hour dosing
- Breakthrough dose is 25% of the 12 hour long acting dose
- Individualize for your patient
- HAVE YOUR MATH DOUBLE CHECKED!!!

OPIOID CONVERSION

Same Drug : Different Route

Am is 84 yo with Multiple Myeloma and is admitted to the hospital w/ cord compression and is made npo awaiting corpectomy by neurosurg. Pain previously well controlled on la morphine 30 MG PO Q8H. What is the equivalent IV dose?

- A. Morphine 5 MG IV every 4 hours
- B. Morphine 10 MG IV every 4 hours
- C. Morphine 15 MG IV every 4 hours
- D. Morphine 30 MG IV every 4 hours
- E. Morphine 45 MG IV every 12 hours

Answer is choice A

OPIOID CONVERSION

Changing to a Different Drug

- AM (same pt) now develops renal failure (preferred agents Hydromorphone, Fentanyl, Methadone) convert pt to equianalgesic IV Hydromorphone regimen
- Use the conversion fraction for the old drug and the new drug in the new route
 - (Morphine is 30mg Oral to Hydromorphone 1.5MG IV or equation of $1.5/30$)
- Cross multiply and solve for “X”
- Obtain the total dose for the new opioid or route
- HAVE YOUR MATH DOUBLE CHECKED!!!

Calculations

- $1.5/30=x/90$, therefore $30x=135$, $x=4.5$ MG of IV Hydromorphone over 24hrs
- Change pt to Hydromorphone 0.75MG IV q4h ATC

Change in Drug and Route

56 yo M with ES CHF and COPD receiving 5MG po/sL Morphine q4h atc for dyspnea (controlled), now for d/c from GIP to home, major adherence concerns. What dose TD Fentanyl:

- A) Fentanyl 25MCG TD q48hr
- B) Fentanyl 25MCG TD q72hr
- C) Fentanyl 12MCG TD q72hr
- D) Fentanyl 50MCG TD q72hr

Answer is choice C

Conversion to PCA (IV OR SUBCUT)

JC is 59 yo F with stage 4 NSCLC. Family desires to keep pt at home on hospice. Pain well controlled but now w/significant EOL Dysphagia. Prior regimen is LA Morphine 100 MG PO Q12H and MSIR 30MG PO Q4H PRN (avg 3 BTP dose/24hr). What is PCA Morphine Basal and Bolus dose?

- A) Morphine Basal 1 MG/hr Bolus 1mg Q10MIN
- B) Morphine Basal 2 MG/hr Bolus 1mg Q10MIN
- C) Morphine Basal 3 MG/hr Bolus 2mg Q10MIN
- D) Morphine Basal 4 MG/hr Bolus 2mg Q10MIN
- E) Morphine Basal 8 MG/hr Bolus 4mg Q10MIN

Answer is choice D

CHANGE IN OPIATE, SAME ROUTE

FY is 74 yo F with stage 4 Breast Ca. Now admit to Hoc, pain stable on oxycodone extended release (non-formulary) 20MG PO Q8H ATC and oxycodone immediate release 10mg PO Q3H PRN BTP (not utilizing); change to long acting (LA) morphine (do not account for cross tolerance).

- A) LA Morphine 15 MG PO Q12H
- B) LA Morphine 15 MG PO Q8H
- C) LA Morphine 30 MG PO Q12H
- D) LA Morphine 30 MG PO Q8H
- E) LA Morphine 60 MG PO Q12H

Answer is Choice D

Methadone - Benefits

Mu agonist, synthetic opioid

- Has two non-opiate analgesic receptor activities:
 - Prevents MAO reuptake in periaqueductal gray
 - Prevents N-methyl-d-aspartate (NMDA) receptors
- Lacks neuroactive metabolites
- High bioavailability (79 +/-11 hours)
- Long half life (30 +/- 16 hours)
- Highly lipophilic
- Fecal excretion - safe in ESRD
- Very inexpensive

METHADONE

When converting to Methadone:

- Assess the appropriateness of converting in the home
- Educate to side effects and responses
- Process takes 3-5 days to reach full therapeutic effect
- Breakthrough dosing with another opioid is imperative for transition
- Know the assessment findings that indicate overdose or under dosing

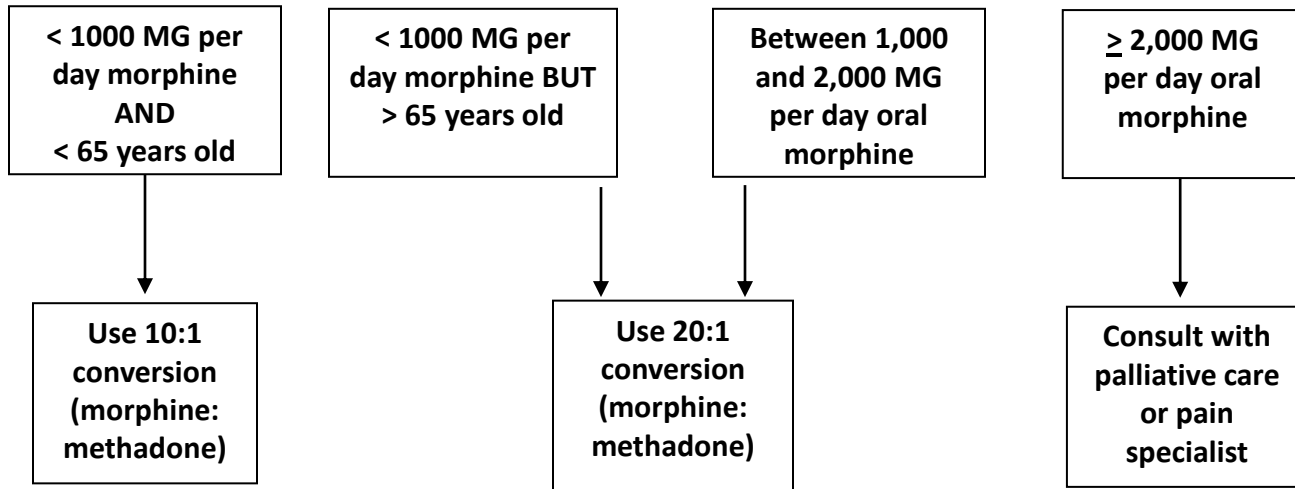
Methadone Precautions

- Lack of caregiver(s) to monitor the patient
- Very limited prognosis
- Increased risk of QT prolongation in patients with known bradycardia or heart failure, patients with hypokalemia or those taking drugs which potentiate QT prolongation.
- Patients with OSA, hypercarbia.

METHADONE DOSES

- Initial dose for opioid naïve patients: 1-2.5MG at bedtime or twice a day
- Use their previous opioid or morphine for breakthrough pain
- With careful oversight, can use methadone for breakthrough(rare) in case of allergies etc..

Conversion from Morphine to Methadone



Methadone

- Analgesic and plasma $t_{1/2}$ differ
- Onset of 15 min with peak in 1 to 2 hrs
- Analgesic $t_{1/2}$ of 4 to 6 hrs
- Plasma $t_{1/2}$ of ~24hrs
- Clinical implications of pharmacokinetic properties
- IV methadone is twice as potent as oral

Dosing Dilemmas

- Half life (30+/- 16 Hours)
- Recommended dosing intervals (3-24 hours)
- Duration of analgesia for a single dose (4-6 hours)
- Rapid absorption-distribution
- Accumulates in tissues-initial q4hour dosing may stretch to bid

Clinical Uses

- Neuropathic pain and/or mixed nociceptive pain not responding to morphine and co-analgesic
- End-stage renal failure
- True morphine allergy
- Cost

What is an Adjuvant Analgesic?

Any drug that has a primary indication other than pain, but is known to be analgesic in specific circumstances

What are the Indications to Use an Adjuvant Analgesic?

- Poor response to optimal opioid therapy
- Type of pain experienced is more responsive to the adjuvant
- Patient has a marked predisposition to opioid toxicity

What Types of Pain are Adjuvants Indicated?

- Neuropathic pain
- Bone pain
- Visceral pain
- Myofascial

Is The Patient Experiencing Neuropathic Pain?

- Etiology
 - Injury along the afferent and efferent pathways
 - Tumor infiltration
 - Treatment: chemotherapy, radiation, surgery
- Description
 - Burning, electrical, pinching, shooting; numbness, tingling, “pins & needles”

What Sensory Disturbances Does The Patient Experience?

- Hyperalgesia: increased perception of painful stimuli
- Allodynia: exaggerated pain induced by non-painful stimuli
- Hyperpathia: exaggerated pain response
- Dysesthesia: deep aching, pressure, cramping, painful sensations
- Hypesthesia: numbness, decreased feeling
- Paresthesia: tingling, spontaneous, non-painful sensation

Neuropathic Pain: What To Do?

- Anticonvulsants
- SNRI for co-morbid depression
- Tricyclic antidepressants
- Benzodiazepines
- N-Methyl-D-Aspartate receptor antagonists
- Corticosteroids
- Alpha₂ adrenergic agonist
- Antiarrhythmics
- Topical anesthetics

Refractory Pain

- 57 yo F with widely metastatic breast ca
- Intractable pain on Oxycodone Extended Release 80MG po q6h atc with Oxy IR 30MG po q3h prn(taking ATC)
- What to do?

A)Methadone 10MG po tid,oxy ir 30MG po q3prn

B)Methadone 40MG bid,oxy ir 45MG po q3prn

C)Methadone 40MG tid,oxy ir 45MG po q3prn

D)Methadone 60MG bid,oxy ir 45MG po q3prn

Answer is B

Knowledge Check

- 38 yo F with cervical CA
- On Hydromorphone PCA with basal 18MG/hr
- On gabapentin as adjuvant, pain poorly controlled, primarily neuropathic

Knowledge Check (continued)

Start methadone PCA at basal of 9mg/hr with upward titration based on symptoms

Clinical Pearls

- Methadone safe and effective when used judiciously
- Consider when failing other opioids/difficult to control pain
- QTc issues can be concern in conjunction w/other agents affect cardiac conduction(TCA's etc.)

Summary

- Works well for bone pain, neuropathic pain pt who have failed multiple other opiates and refractory pain, co-morbid addictions (Etoh, etc), patients with ESRD, patients who cannot afford other opiates
- Be careful of pt with OSA, sedation on day 4/5, withdrawal on day 7+, drug interactions, QTc issues, ESLD

Final Thoughts

1. Be alert for clinical scenarios that may indicate opioid switching should be recommended
2. Always consider adjuvants/complementaries and other elements of pain (is the pain opioid responsive?)
3. Understand/consider principles of opioid responsiveness, potency, equivalence and bioavailability
4. Follow approved labeling for switching in opioid tolerant patients
5. Use a fair balance equianalgesic dosing chart and understand limitations (approach these systematically)
6. Consider timing of switches
7. Document your interventions and EDUCATE patients and practitioners

BEST PRACTICES

- Dosage calculations should be double checked by another practitioner (nurse, pharmacist, MD)
- Know your dose prior to calling the MD for orders
- Understand that you are responsible for the dose you give, even if the MD order was not prudent
- Patients who have pain meds increased or medications changed should have a check in call and/or skilled nursing visit 24 hours after the change

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						
Crying - 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						
Requires O₂ for SaO₂ < 95% - 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						
Increased vital signs (BP* and HR*) - 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.						
Expression - 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						
Sleepless - 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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APPENDIX

Methadone – Pg 39: 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 59: Notes

- 0.06% children die

Causes of Death Children 1-19 with Complex Chronic Condition – Pg 65: 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.

[Symptom Management and Approach to Care 2](#)