INTRODUCTION TO PEDIATRIC PALLIATIVE CARE

Pediatric Pain Resource Nurse Curriculum

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The MAYDAY Fund

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Objectives

- Describe different populations of children who benefit from pediatric palliative care
- Explain the benefits of pediatric palliative care for children suffering from serious life limiting or life-threatening illness and their families.
- Discuss palliative care pain and symptom management strategies for children with serious illness and at end of life.

Is treatment causing more suffering than relief?

To Cure Sometimes, Relieve Often and Care Always.

What can you cure?
When have you relieved?
How do you Care Always?
And
When should you consult a palliative care specialist or team?

Type your answer here

Pediatric and Neonatal Mortality & Morbidity

42,328 USA children aged 0-19 died in 2013

55% of these deaths were neonates & infants

- Congenital heart disease (4.2%)
- Congenital/chromosomal anomalies
- Gestational age/Low birth weight
- Sudden infant death
- Unintentional injury
- Birth complications

Ages 1-24:

- Congenital anomalies
- Malignant neoplasms
- Assault
- Unintentional injury
- Cardiac disease

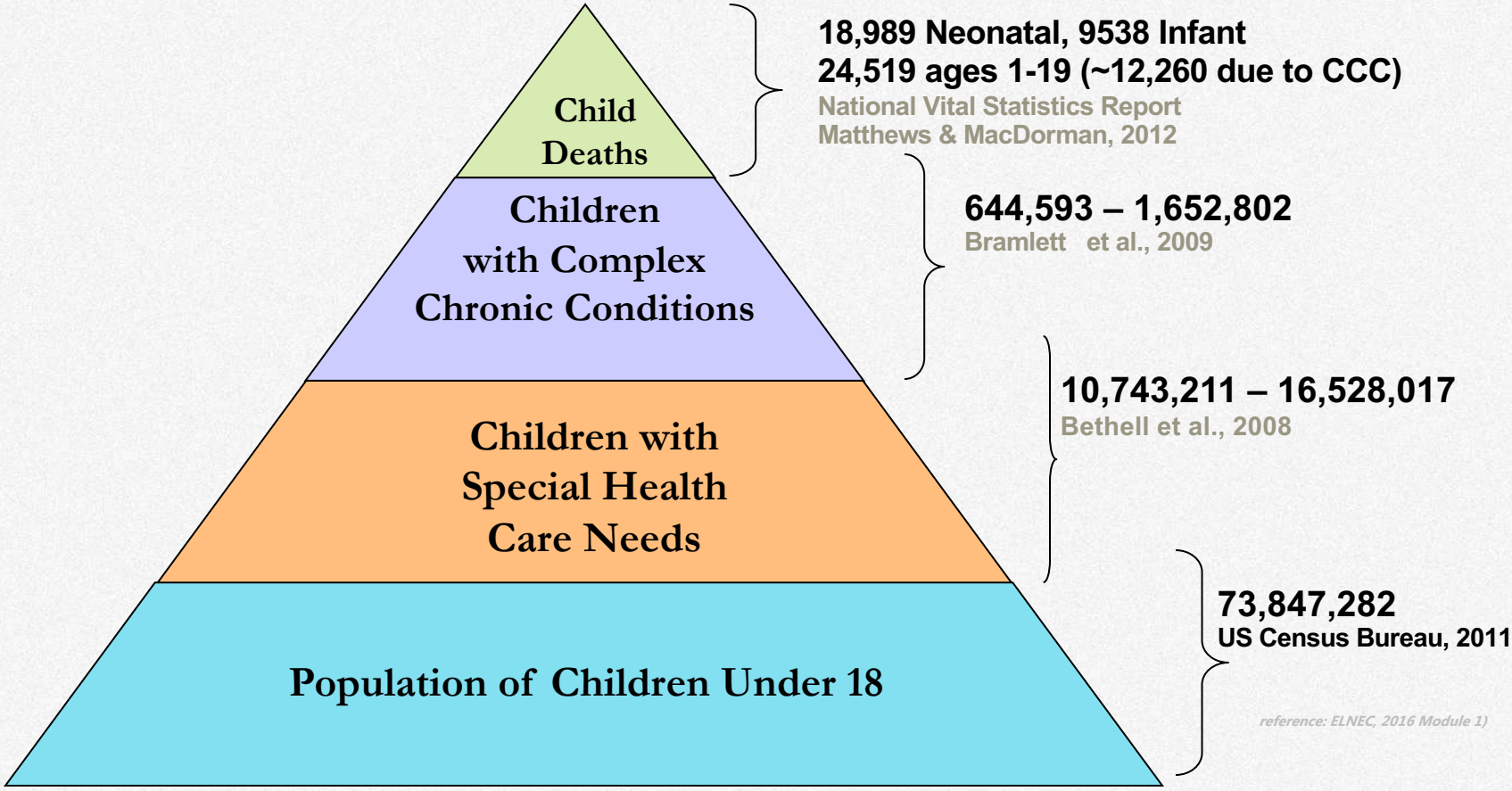
Neonatal mortality rate (0-30 days) = 4.2/1000 live births

Infant mortality rate= 6.42/1000 live births

- 15,000 children born annually are not likely to survive their first year of life
- 20% of these deaths are attributed to congenital malformations
- Other causes include:
  - Extreme prematurity/low birth weight,
  - Maternal complications,
  - Neonatal hemorrhage,
  - Sudden infant death, or
  - Unintentional injury

reference: Freibert & Williams, 2015; CDC, 2016, Gilboa et al, 2010 , Hoyert & Zu, 2012)

Child Health Sub-populations



Which of these families need pediatric palliative care?

1. A Young, single mother whose prenatal ultrasound and genetic studies just revealed congenital heart disease and Trisomy 13
2. A 16 year old football player who has relapsed leukemia after a bone marrow transplant
3. A 6 year old living with a progressive mitochondrial disorder
4. A Newborn infant in the NICU after life threatening e. coli bacterial meningitis now with a tracheostomy, gastrostomy tube and severe neurological deficits
5. A 13 year old boy living with nephrotic syndrome that is resistant to routine treatments
6. An 8 month old boy waiting for a liver transplant due to biliary atresia
7. A 10 year old boy, congenital heart patient, whose Fontan is failing and is suffering with protein losing enteropathy
8. A 17 year old girl with severe combined immune deficiency and advanced bronchiectasis, recurrent systemic CMV, and multiple hospitalizations

What is Palliative Care?

What is Palliative Care?

Palliative care is an interdisciplinary team approach to optimize symptom management and physical, psychosocial, and spiritual needs, quality of life, and patient/family preferences.

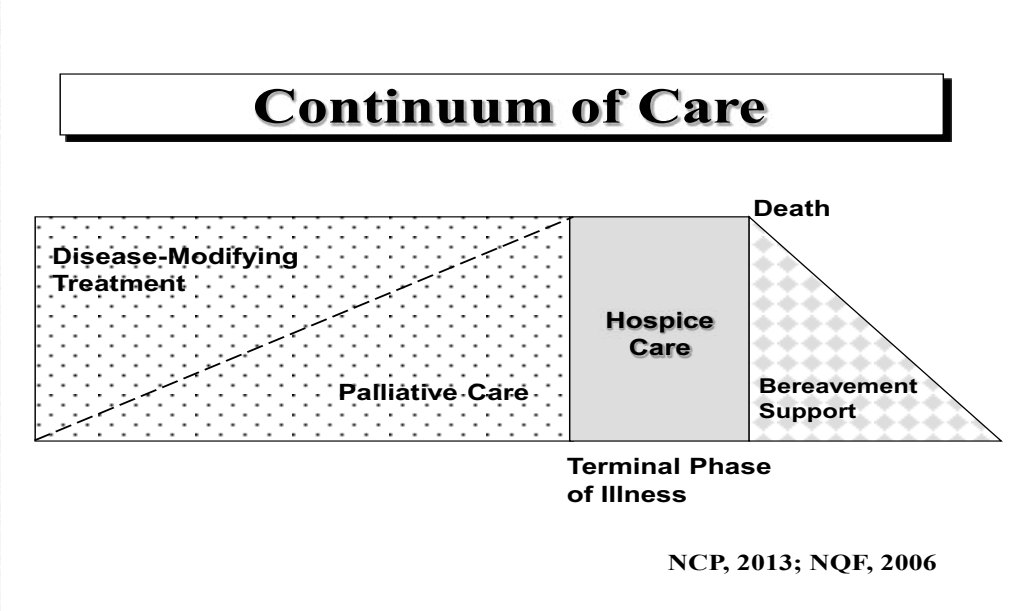
Palliative care does not exclude any medical therapy or life-prolonging treatment.

Goal for both the patient and the family is a good quality of life for as long as possible

Used when a patient has a life-limiting or threatening illness

Supports patient and family's hopes for peace and dignity throughout the course of illness, during the dying process, and after death.

Works collaboratively with the primary care team who provides an added layer of support.



What is Palliative Care?

Interdisciplinary care providers who add an extra layer of support for children who suffer from serious, complex, chronic and sometimes terminal diseases and their families.

- Consult or primary services
- Inpatient, outpatient, home, hospice.
- Partner with primary & subspecialty providers
- Provide care throughout the illness trajectory, NOT just at end of life
- Expert in pain and symptom management
- Coordinate care between services and systems.
- Advocate for advanced care planning and continual re-assessment of goals of care.
- Help keep the focus of care on total quality of life and symptom management
- Provide emotional, social, and spiritual support that respects cultural and family values.
- Provide support for providers and staff caring for seriously ill children
- Trained in facilitating difficult conversations and decision making
- Provide bereavement care as needed.

Palliative care planning: Where do you start?

ALL palliative care is interdisciplinary

Remember the principles of ethics

Autonomy of the patient and family

Justice and equality in care

Beneficence

Non-maleficence

(reference: Sundean, L. J. & McGrath, J. M., 2013, NPHCO, 2009)

Parents want:

- The best quality of life for as long as possible for their child
- Their child to be comfortable even in the face of serious illness and death
- Someone to advocate for them and their family– to achieve their wishes for their child
- Recommendations to come from a place of compassion and understanding
- To be able to look back 1 day, 6 months, 5, and 10 years later and know they did the best for their child.

Why Early Referral?

Integrating pediatric palliative care at diagnosis of a life threatening, limiting illness improves the care of the children and helps their families.

Early Referral

- Helps families live with the uncertainty of a life limiting or threatening illness over an unknown period of time
- Gives the team time to assess and understand goals of care
- Helps the team fully understand family dynamics and values
- Allows for Advanced Care Planning···before the crisis

IOM Report: When children die: Improving palliative and end-of-life care for children and their families (2003)

Early Referral Requirements

Automatic

Conflicts regarding use of medical nutrition/hydration in cognitively impaired, seriously ill or dying child

Suggested

- New diagnosis of life-limiting or life-threatening disease
- 3 or more admissions within 6 months
- Difficult pain/symptom management
- Patient, family or physician uncertainty regarding prognosis
- Family with limited social support
- Allow Natural Death/DNR order
- Ethical conflicts
- Complex care coordination and/or ongoing special needs
- Prolonged hospitalization for more than 3 weeks
- Need for hospice resources

Diagnosis Specific

- New diagnoses with suspected poor outcomes and/or uncertain outcomes
- Suspected to have significant symptom burden and diminished quality of life for the child and family.

(Freibert and Osenga, Center to Advance Palliative Care, 2012)

Barriers to Pediatric Palliative Care?

Multifactorial

- Individual beliefs
- Misunderstood in both public and healthcare community
- Providers, nursing and staff, parents and patients lack understanding on how Pediatric Palliative Care helps
- Lack of training and education of providers and staff with pediatric palliative care expertise
- Financial and insurance , lack of reimbursement
- Geographic unavailability, poor access to services
- Health care policy does not place an emphasis on palliative care

(reference: Linton & Feudtner, 2011; Thienprayoon et al, 2013)

Decision making in the NICU: The "GREY ZONE"

Ethical decision-making should consider

- Expected prognosis and potential treatments
- Neurocognitive deficits–quality of life expected
- More technology available for congenital heart and other diseases- Burden of interventions versus quality of life

What is quality of life?

- Quality of life is what the family perceives
- This is a continual conversation with families

Diagnoses considered incompatible with life?

- For instance a child with Trisomy 13 with congenital heart disease has an expected shortened life-span of ≤1 year.
- But in one study almost 20% of children survived through their first birthday

(reference: Lantos, J. D, 2016)

What are the Differences Between Palliative and Hospice Care?

Children with complex medical conditions

A 2016 study of children with complex medical needs showed a need to focus on quality of life and symptom management

Of children with a median of 5 different complex chronic condition categories. Most had:

- Neurological disorders and were
- Technology dependent (Gastrostomy, tracheostomy, ventilators)
- a shortened life span due to complications and/or progressive disease

Struggle with multiple, sometimes difficult to assess and treat symptoms, such as seizures, spasticity, dysautonomia, pain, respiratory distress

Suffer from frequent emergency department visits, hospitalizations and increased amount of intensive care admissions , especially as their disease progresses toward end of life

Require expert attention to comprehensive, complex care coordination that is not the "norm" in general pediatrics

Over 80% of these families suffer from at least one "hardship"

- 68% financial and 46% social. Most commonly:
  - Missing house or rent payments,
  - Changes in income
  - lack of family or other support.

(reference – Thomson et al, 2016)

Pediatric Palliative Care: Diminish TOTAL Pain & Improve Quality of Life

Physical symptom management needs

Psychological needs

Anxiety, depression in both the child and within the family

Social

Financial stress, loss of income, family counseling needs

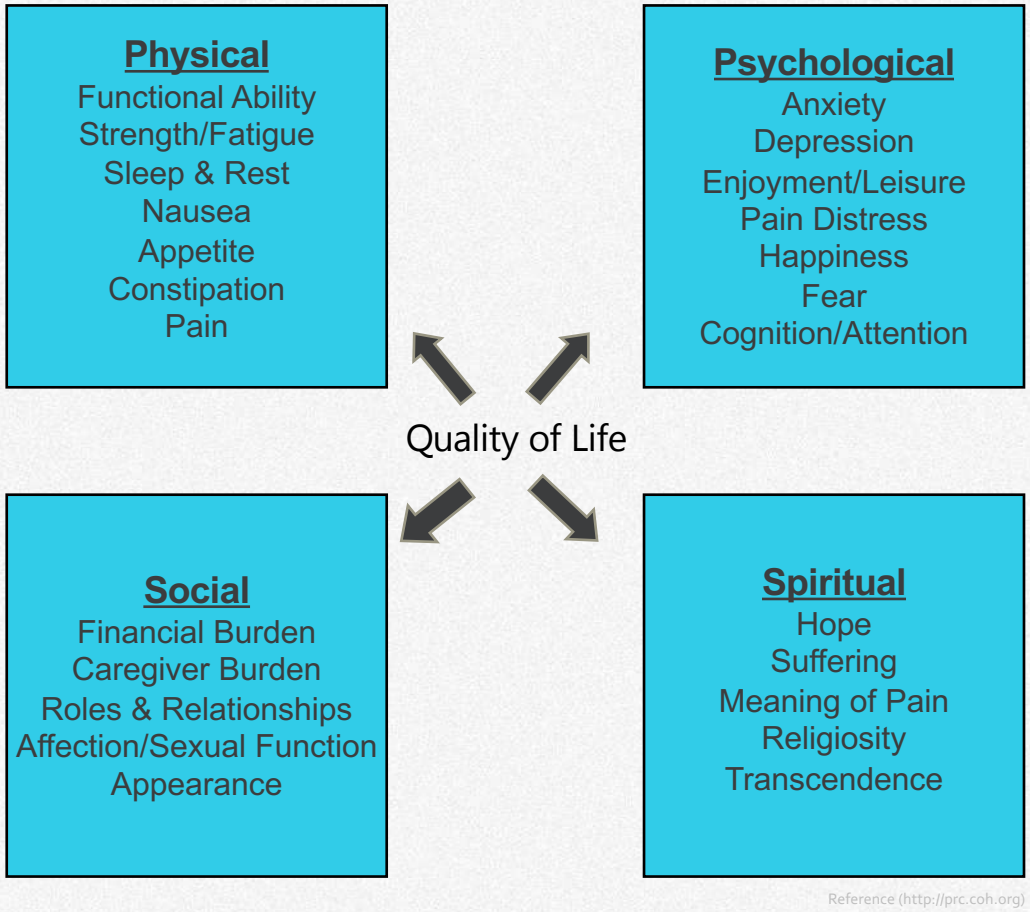
Spiritual

Grief and bereavement

Questioning faith

Developmental needs of the patient, siblings, and/or other young family members

The whole family suffers…



Reference (http://prc.coh.org)

Symptom Management

Symptom Management: Pain

World Health Organization 2 step pain management

Step 1 = Mild Pain = *Non opioids*

Step 2 = Moderate to Severe Pain= *Opioids*

Use age appropriate pain assessment tools and parent report

Neonates and infants < 6 months old start with 25-50% lower dose than usual opioid weight-based recommendation

Monitor for sedation and depressed respiratory rate

Side effects are the ONLY reason for non-escalation of opioid dosing.

Opioid rotation remember to adjust for cross tolerance

Constipation is the ONLY side effect that will not resolve with chronic opioid use

Treat prophylactically

Adjuvant medications can treat specific types of pain, work synergistically with other pain medications to improve pain management or treat symptoms that increase pain

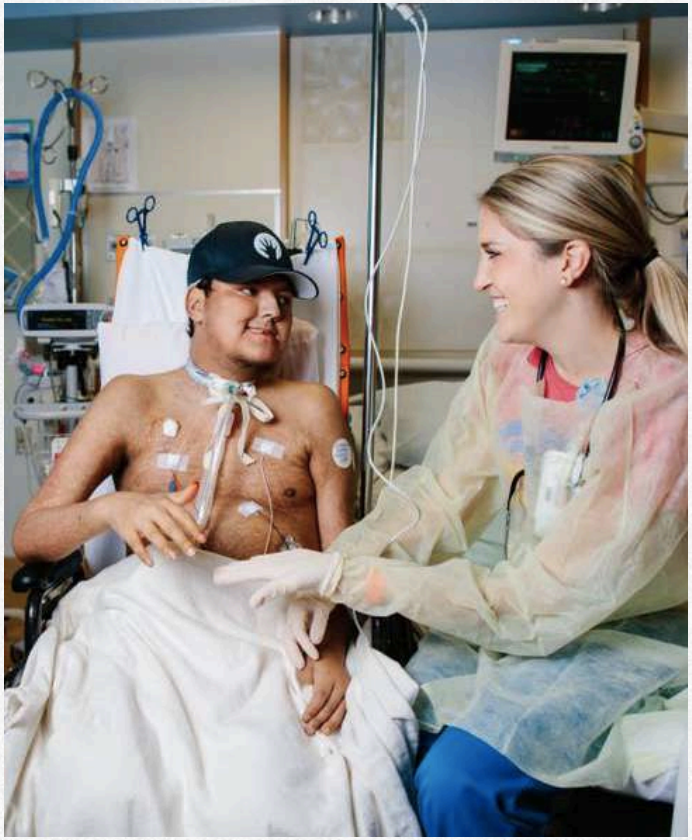
Steroids, anticonvulsants, anti-depressants, bisphosphonates and radiation therapy

Don't forget about integrative methods such as aromatherapy, guided imagery, hypnosis

(references: Hauer, J, 2014; Collins, Berde & Frost, 2011; Hain, Zeltzer, Hellsten, Cohen, Orloff & Gray, 2011)

(references: Hauer, J, 2014; Collines, Berde & Frost, 2011; Hain, Zeltzer, Hellsten, Cohen, Orloff & Gray, 2011)

Symptom Management: Pain Opioid PEARLS



Keep it simple

Always give major opioids as scheduled and as needed for breakthrough pain

Make sure the breakthrough dose is appropriate taking into account scheduled dosing and tolerance

KNOW the opioids: how they work, onset of action and how they differ from morphine

KNOW the adjuvants: use them as often as possible to improve pain control

Think "outside of the box", be "creative" and recognize other approaches to pain management that might work for your patient

Review the plan regularly accounting for steady state

Have a plan for dealing with side effects

Be confident. Opioids and other medications are safe and effective. Your confidence will help the child and parents

(Adapted from WHO Approach to Management of Pain in Palliative Care, Hain & Freidrichsdorf, 2012, p. 228)

Symptom Management: Respiratory

Dyspnea is described as a subjective "feeling" of shortness of breath

It can not be determined by objective data like pulse oximetry.

Morphine or other opioid is a primary treatment for this symptom

Lorazepam, Midazolam

Gentle fan blowing in the face triggers the trigeminal nerves to provide decreased sense of discomfort

Secretions – consider ease of route

Glycopyrrolate

Sublingual Atropine drops

Scopolamine (adolescents and older)

Hyoscyamine

(references: Hauer, Duncan & Fowler-Scullion, 2014; Collins, Berde & Frost, 2011; Hain, Zeltzer, Hellsten, Cohen, Orloff & Gray, 2011)

Symptom Management: Neurological Impairment or Disease

Neurological Pain "ladder"

Step 1 – Gabapentin or Pregabalin
Step 2 – Clonidine or Tricyclic antidepressant
Step 3 – Methadone
Always consider and treat possible sources of nociceptive pain
Always consider use of adjuvants

(reference: Hauer, Duncan & Fowler, Scullion, 2014; Hauer & Faulkner, 2012, p. 301-302

Spasticity

Baclofen, benzodiazepine
Clonidine as needed

Myoclonus

Clonazepam

Seizures

Lorazepam, Midazolam
Diazepam rectal gel

Anxiety, agitation, delirium

Lorazepam, clonazepam
Haloperidol, Risperidone, Olanzapine, Quetiapine

These children may have suffered a hypoxic-ischemic injury, brain injury, degenerative brain condition or have a neurological oncology diagnosis

Experience pain "without a clear cause" sometimes

They suffer from spasticity, muscle spasms, dysautonomia, dystonia, chorea, seizures, myoclonus and sleep disturbances

Assess pain with revised FLACC, INR, NCCPC or other pain scale that allows the addition of individual indicators of pain to best assess non-verbal children

Listen to their parents and family.

They know what is "typical" for their child and are typical signs that the child is in pain

Dysautonomia and neurological "storms"

Clonidine start once a day and increase scheduled dosing to effect

PRN dosing as needed

Gabapentin

Morphine

Cyproheptadine if have cyclic vomiting or retching symptoms

Propranolol

Neuropathic pain and neuro-irritability

Gabapentin start small and escalate to effect with scheduled dosing

Pregabalin, Tricyclic Antidepressants are 2nd and 3rd line medications

Start small dose and escalate to effect

Symptom Management: End of life

Pain, dyspnea and other symptoms are what most parents fear most as the child nears end of life

Poor control of symptoms is one of the biggest regrets that parents have later

Poor appetite, fatigue, and inability to "be" with the family are very distressing

Pain and symptom management theory is the same at end of life as it is throughout the trajectory of illness

Focus on comfort and quality of life

Manage side effects

Remember that there is no ceiling in opioid management except side effects

Rotate opioids as needed

Differentiate between anxiety, agitation, and delirium

Morphine is used to treat BOTH pain and dyspnea

Educate families about the principle of double effect, especially if they are in a home setting administering medications themselves.

(references: Hauer, J., Duncan, J. & Fowler-Scullion, 2014, ; Wolfe, J., 2011, p. 371; LaFond, Hinds et al,)

Pain control may require rapid opioid escalation

- Rapid escalation requires vigilance and good coordination between nursing, providers to obtain good pain control
  - Bolus administration every 10-15 minutes of opioid equal to 10-20% of total daily opioid dose
  - Increase bolus dose by 30-50% after third dose if no good effect on pain
  - When pain controlled calculate new 24 hour total dose and set scheduled/breakthrough dosing based on the new calculation
- There is no ceiling dose except for side effects
  - If need to rotate opioid, remember to reduce dose by 30-50% of calculated equinalgesic dose
  - If pain is not well controlled do not reduce equianalgesic

Don't forget the other symptoms that can cause distress and increase pain.

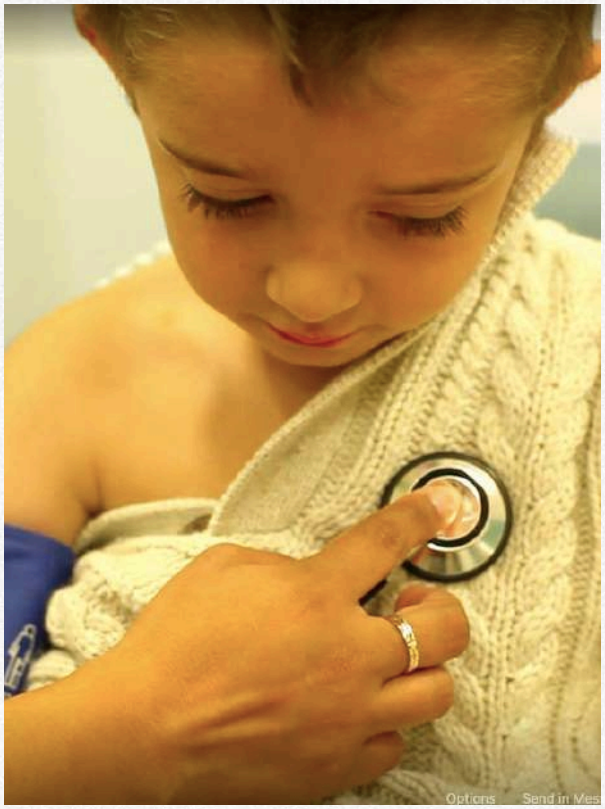
Adjuvants for pain, dyspnea, agitation, seizures

- Lorazepam, Midazolam, Haloperidol, Ketamine, Phenobarbital, Steroids, nonsteroidal anti-inflammatory medications

Consider other routes such as rectal, transdermal, and trans mucosal

- Antiepileptics that can be given rectally include carbamazepine, lamotrigine, phenobarbital, valproic acid

The Principle of Double Effect



All healthcare providers worry about cause and effect; risks and benefits to treatments and procedures

But some interventions can have both good and bad effects

Example: The good benefit of medication for pain; seizure control, outweighs the possible side effect of respiratory depression

The treatments that we use to decrease suffering sometimes have side effects that could be considered "dangerous".

INTENT is important

It is ethically allowed to give medication if the INTENT is to relieve suffering not to cause death

We give the medications such as opioids and anti-epileptics to relieve suffering not to end life.

There will always be a last dose.

But it is the disease taking the child's life not the medication, parent or provider.

Managing withdrawal of intensive support

Inter-disciplinary care

Chaplain, Child Life, Social Work & Medical interpreter as needed.

Memory-making with Child Life if able to do so

Coordinate with the parents wishes and comfort level

Allow and encourage family involvement with infant or child

Quiet and serene environment

Communicate with family throughout

Symptom management

Anticipate dyspnea, pain

Morphine is first choice for pain and dyspnea

Have medications ready at the bedside

(reference: Curtis, J.R. and Rubenfeld, G. D., 2001)

In Summary…

Key Points

Curing:
Making the problem go away.
Healing:
Giving someone the resources to deal with problems that will not go away.

- Rabbi Harold Kushner

More than 2 of 3 patients referred to pediatric palliative care are still alive a year after referral

There is no reason to be afraid of palliative care!

Children and their families in the care of palliative care teams report higher quality of life

The concept of TOTAL PAIN is an important way that these teams frame the care they give

EARLY referral to pediatric palliative care is the right thing for so many children and their families.

Eric Cassel (1982) said "Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself…"

(reference: Cassel, NEJM, 1982; Kaufman et al, 2011)

Medical care today has even more treatment options for patients

But is what you have to offer going to cause more suffering than relief?

Pediatric palliative care teams help redirect goals of care and address questions regarding the "right thing" for each child and family suffering with serious illness.

(reference: Cassel, NEJM, 1982)

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