Pain Management and Palliative Care in the Newborn

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Disclosures:

Vanderbilt CME has determined that there are no conflicts of interest.

I have no conflicts of interest to disclose.
Objectives

1. To present the rationale & means for assessing newborn pain.
   • Give an overview of the varied measures of neonatal pain.
   • To educate staff about signs indicating a need to tailor the individual patient’s analgesia.

2. Introduce palliative care precepts to staff and share their potential incorporation into care for patients & families in the ICU.
Neonatal Pain

Old School of Thought:
1. Newborns do not feel pain because their nervous systems are too immature.
2. Even if newborns do feel pain, they cannot remember it.
3. Even if they feel or remember pain, it doesn't cause them harm.
4. Even if newborns feel or remember pain, and, even if it is harmful to them; we cannot safely give them local or systemic analgesia or anesthesia.
Neonatal Pain...Evidence

2. Research and anecdotal experience show that newborns react with distress behaviors to actions that have preceded painful interventions in the past.
3. Untreated pain has physiologic effects and can increase morbidity, post-operative healing, and even mortality.
4. Analgesia, sedation, and anesthesia can be safely provided to newborns in most circumstances.
5. Newborns are as sensitive to pain as adults, AND preterm infants are more sensitive to pain.
   - Neurotransmitters in the dorsal horn of the spinal cord are associated with nociception and increased somatosensory excitability in the preterm spinal cord.
   - On the other hand, neurotransmitters in descending inhibitory nerve fibers are only present at term.
   - Thus, there is diminished inhibition of pain in premature infants.
Developmental Effects of Unrelieved Pain

- Increased behavioral and physiologic responses to pain
  - Altered temperaments
- More somatization – emotional problems expressed as physical symptoms
  - More distress behaviors
- Possible altered development of the pain conduction system
- Increased vulnerability to stress disorders, addictive behavior, & anxiety states
  - Lowered pain threshold
Errors in Pain Management

I. Errors in Assessment and Documentation
   A. Discrepancy by Age
   B. Discrepancy by Gender
   C. Discrepancy by Ethnicity
   D. Documentation Failures

II. Errors in Treatment and Management
    A. Scheduling
    B. Analgesic Choice
    C. Route Choice
    D. Inadequate Use of Adjuncts

III. Errors in Patient Education
     A. Patient/Family Education
     B. Patient Satisfaction
     C. Myths/False Beliefs
Multilayered Pain Response

Pain Assessment Scales

Behavior

Perception

Sensation

Nociception

PK/PD

CNS

Peripheral Tissue
Key Concepts and Assumptions in Newborn Pain Management

Assumptions:

1. Infants experience pain
2. Untreated pain leads to cardiovascular, endocrine, metabolic, immune, neurological, and psychological problems
3. Pain interferes with optimal growth and healing
4. Infants cannot report pain
5. Anticipate pain & provide preemptive analgesia

- It takes less medicine to prevent pain than to treat already existing pain.

- Pain that is well-controlled after a procedure will likely be of shorter duration than pain that is poorly controlled.
Pain Management Concepts

6. Steady state analgesia is best
Pain happens in a social context, must be communicated, and then acted upon.

Non-Pharmacologic Interventions

1. Reduction of environmental stimuli
   - Light
   - Noise
   - Too much touch
2. Swaddling
3. Pacifier/non-nutritive suckling
4. Minimizing restraints
1. **Sucrose is safe & effective for reducing procedural pain from single painful events (heel lance, venipuncture).**
   - The use of sucrose is effective (dose range 0.012 g to 0.12 g).
   - The use of repeated administrations of sucrose in neonates needs has now been investigated & is effective.
   - Sucrose in combination with other behavioral (e.g., facilitated tucking, kangaroo care) and pharmacologic (e.g., morphine, fentanyl) interventions is effective.
   - The use of sucrose in VLBW neonates even while ventilated is effective.

2. **Mechanism:** orogustatory response (sweet taste -> endogenous opioid). Suckling alone is mediated through orotactile response.

   **Pacifier + sucrose > sucrose alone > pacifier > nothing**


Opioids...morphine, fentanyl (80x more potent than morphine)

1. Newborns receiving an opioid must be monitored (HR, RR, BP, SpO2)
2. Narcan must be available to reverse any serious side-effect (e.g., respiratory depression/apnea) of an opioid
3. Doses:
   - Morphine 0.05-0.10 mg/kg/dose IV, or SC q 2-4 hrs (bolus dosing may be associated with hypotension)
   - Fentanyl 0.5 – 3.0 mcg/kg/dose IV q 1-2 hrs (may be associated with chest wall rigidity)
Acetaminophen

1. It may decrease the total dose of opioid needed
   - Dose of 10-15mg/kg given q 6 hourly

2. It may be sufficient for mild-to-moderate pain

3. Best to schedule “Around the Clock” until pain is judged to no longer be present

4. May be given PO/OG to infants
   - Well absorbed from GI tract
   - Only contraindication for rectal route anal atresia
   - Difficult to administer PR in ELBW; Erratic absorption
   - Withhold from those with liver disease
7. Pain medication dosages should be individualized

- Dosage should be titrated at the bedside to patient response
- Infants should get the dose they need to be comfortable – not the dose we think is “normal” or “right”
Pain Management Concepts

8. There is no ceiling to the amount of opioid that *can* be given *if* pain persists

- Example of chronic pain patient, or when opioids are used for weeks
- The dose *is* limited when side effects outweigh effective pain relief
- Opioid withdrawal may need to be addressed
Procedural Pain: Circumcision

- Use of comfortable swaddling on restraint board, pacifier, sucrose
- AAP recommendations
- EMLA < DNPB < Ring Block

http://aappolicy.aappublications.org/cgi/reprint/pediatrics;103/3/686.pdf
Pain Assessment Must Address

• Location
• Characteristics
• Onset / duration
• Frequency
• Quality
• Intensity / severity
• Precipitating Factors
Pain Assessment

- Self-report is what we rely upon in adults & older children
  - Type, intensity, location, timing, scale
- Observations may be by parent, nurse or physician
  - Vocalization, verbalization, facial expression, body language (avoidance), emotional state
- Physiologic parameters...HR, RR, BP, \( S_{\text{PO}_2} \)
Pain Assessment: Heel-Lance & Heart Rate
The Face Of Pain

**Figure 14.1** Facial expression of pain.

Facial Score for Pain with Heelstick

Facial Expression of Pain

- The facial expression most often associated with pain is a **grimace**.
- Characterized by:
  - brow lowering
  - eyes squeezed shut
  - deepening of the nasolabial furrow
  - open lips and mouth
Pain may be remembered

Fig. 2. Former ELBW male infant (birth weight 750 g at 26 weeks gestation) undergoing blood collection by finger poke at age 8 months 6 days CCA.
Coding tips for using CRIES

**Crying...** The characteristic cry of pain is high pitched.
- If no cry or cry which is not high pitched score 0.
- If cry high pitched but baby is easily consoled score 1.
- If cry is high pitched and baby is inconsolable score 2.

**Requires O2...** Look for changes in oxygenation. Babies experiencing pain manifest decreases in oxygenation saturation.
- For Sat > 95%, if no oxygen is required score 0.
- If < 30% O2 is required score 1.
- If > 30% is required score 2.
  (Consider other causes of changes in oxygenation: atelectasis, pneumothorax, over sedation, etc.)

**Increased vital signs...** *Note: Take blood pressure last as this may wake child causing difficulty with other assessments. Use baseline pre-op parameters from a non-stressed period. Multiply baseline HR x 0.2 then add this to baseline HR to determine the HR which is 20% over baseline. Do likewise for BP. Use mean BP.*
- If HR and BP are both unchanged or less than baseline score 0.
- If HR or BP is increased but increase is <20% of baseline score 1.
- If either one is increased >20% over baseline score 2.

**Expression...** The facial expression most often associated with pain is a grimace. This may be characterized by: brow lowering, eyes squeezed shut, deepening of the naso-labial furrow, open lips and mouth.
- If no grimace is present score 0.
- If grimace alone is present score 1.
- If grimace and non cry vocalization grunt is present score 2.

**Sleepless...** This parameter is scored based upon the infant's state during the hour preceding this recorded score.
- If the child has been continuously asleep score 0.
- If he/she has awakened at frequent intervals score 1.
- If he/she has been awake constantly score 2.
Neonatal Infant Pain Scale (NIPS)

- **Facial expression** – relaxed; grimace
- **Cry** – no cry; whimper; vigorous
- **Breathing patterns** – relaxed; changed
- **Arms** – relaxed; flexed/extended
- **Legs** – relaxed; flexed/extended
- **State of arousal** – sleeping; awake; fussy
## FLACC Pain Scale

### FLACC Behavioral Pain Assessment Categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Scoring</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Face</strong></td>
<td>0</td>
<td>No expression or smile</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Occasional grimace or frown, withdrawn, disinterested</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Frequent to constant quivering chin, clenched jaw</td>
</tr>
<tr>
<td><strong>Legs</strong></td>
<td>0</td>
<td>Normal position/relaxed</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Uneasy, restless, tense</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Kicking, or legs drawn up</td>
</tr>
<tr>
<td><strong>Activity</strong></td>
<td>0</td>
<td>Lying quietly, moves easily</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Squirming, shifting back &amp; forth/tense</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Arched, rigid or jerking</td>
</tr>
<tr>
<td><strong>Cry</strong></td>
<td>0</td>
<td>No cry, (awake or asleep)</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Moans or whimpers; occasional complaint</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Cries steadily/screams or sobs, frequent complaints</td>
</tr>
<tr>
<td><strong>Consolability</strong></td>
<td>0</td>
<td>Content, relaxed</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>Reassured by occasional touching, hugging/being talked to, distractible</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Difficulty to console/comfort</td>
</tr>
</tbody>
</table>

Each of the five categories is scored from 0-2, resulting in a total score between 0 and 10.

The FLACC scale was developed by Sandra Merkel, MS, RN, Terri Voepel-Lewis, MS, RN, and Shobha Malviya, MD, at C. S. Mott Children’s Hospital, University of Michigan Health System, Ann Arbor, MI.

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# N-PASS:
**Neonatal Pain, Agitation, & Sedation Scale**

Pat Hummel, MA, RNC, NNP, PNP & Mary Puchalski, MS, RNC

<table>
<thead>
<tr>
<th>Assessment Criteria</th>
<th>Sedation</th>
<th>Normal</th>
<th>Pain / Agitation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Crying Irritability</strong></td>
<td>-2</td>
<td>-1</td>
<td>0</td>
</tr>
<tr>
<td>No cry with painful stimuli</td>
<td>Moans or cries minimally with painful stimuli</td>
<td>Appropriate crying</td>
<td>Irritable or crying at intervals</td>
</tr>
<tr>
<td>No arousal to any stimuli</td>
<td>Arouses minimally to stimuli</td>
<td>Not irritable</td>
<td>Consolable</td>
</tr>
<tr>
<td>No spontaneous movement</td>
<td>Little spontaneous movement</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Behavior State</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mouth is lax</td>
<td>Minimal expression with stimuli</td>
<td>Appropriate for gestational age</td>
<td>Restless, squirming</td>
</tr>
<tr>
<td>No expression</td>
<td></td>
<td></td>
<td>Awakens frequently</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Facial Expression</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No grasp reflex</td>
<td>Weak grasp reflex ↓ muscle tone</td>
<td>Relaxed hands and feet</td>
<td>Intermittent clenched toes, fists or finger splay</td>
</tr>
<tr>
<td>Flaccid tone</td>
<td>Normal tone</td>
<td></td>
<td>Body is tense</td>
</tr>
<tr>
<td>Vital Signs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HR, RR, BP, SaO₂</td>
<td>No variability with stimuli</td>
<td>&lt; 10% variability from baseline with stimuli</td>
<td>Within baseline or normal for gestational age</td>
</tr>
<tr>
<td>Hypoventilation or apnea</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Premature Pain Assessment
+ 3 if < 28 weeks gestation / corrected age
+ 2 if 28-31 weeks gestation / corrected age
+ 1 if 32-35 weeks gestation / corrected age
Always Assess Causes for Agitation Do Not Assume it is Due to Pain

- Rule out respiratory cause - increase support
  - Calming occurs
  - Agitation/Pain continues
  - Look for pain source - provide analgesia
  - Assess environment - reduce stimulation
    - Calming Occurs
    - Calming Occurs
  - Agitation Continues
- Provide Sedation
Improving Pain Management for Newborns...next steps

- **Staff Education...multimodal**
  - Core competency
  - Case-based
- **Realization and response to the fact that pain assessment & management may be:**
  - Procedure dependant
  - Developmental/gestational age dependent
  - Physician dependant
  - Staff assessment dependant
What’s Going on at Vanderbilt?

- Updated Housestaff Manual
  - Add “Pain Management” to routine/daily notes
- Staff education
  - Web-based learning/core competencies
  - Point of care (bedside) instruction
  - Case of the week
- Improved management of opioid weaning: methadone
- Addressed reduced sedation in the chronically ventilated patient
- Refined NICU procedural pain management
References


Perinatal Palliative Care
Case 1: Mrs. Q

- Iraqi Kurdish woman, G3P0T2L2 non-English speaking
  - Presents at 22 0/7 weeks’ EGA with ‘silent’ cervical dilation & hour glass membranes
    - Husband speaks English, brings her to hospital and sees her through admission process, then returns home to care for young children
    - Meets with OB, MFM, Neonatology to gather facts
  - OB/MFM team considers:
    - Circlage...risks incl. ROM, delivery, infection
    - Expectant management...risks of delivery & non-viability
    - Induction & delivery
Case 2: Mrs. S

- Prenatal diagnosis of congenital high airway obstruction syndrome (CHAOS)
- Center for Advanced Maternal-Fetal Care
  - Further elucidation of lesion by US, MRI
  - Discussion of delivery & DR options
    - Resuscitation
    - Tracheostomy
    - Assisted ventilation
    - ECMO
    - Or palliative care
Case 3: Mrs. H

- Prenatal Dx of oligo/anhydramnios at 19 wks
- Options: terminate or carry to near-term?
  - Met with OB, MFM, Neonatology, Nephrology
  - US diagnosis consistent with PUV
- Delivered at 34 weeks’ EGA, an AGA male
  - Small bell-shaped chest, some positional deformation but not ‘classic’ Potter’s sequence
  - Initially ‘comfort only’ ... but, baby breathed
- HFOV, iNO, vasopressors, Urology & Nephrology consults, post-natal renal US: Rt. atresia & Lt. cystic/dysplastic
- DNR & compassionate extubation with support at <48hrs
Case 4: Mrs. G

- Twins at 33 weeks ... one with anencephaly
  - Anencephalic born alive & receives comfort care with mother who receives supportive care in LDRP
    - Not admitted to NICU
    - Dies in 8 hours
  - Twin is in NICU on ventilator with RDS
    - Discharged to home in 3 weeks

We Must Recognize Special Bereavement Concerns

What kinds of pregnancies are we talking about?

- Women with recurrent loss
- Women with multifetal gestations
- Women with genetic/metabolic disease
- Women carrying a fetus with:
  - Congenital heart disease
  - Complicated birth-defect syndromes
    - Anhydramnios, anencephaly, holoprosencephaly, hydrops (multiple causes), thanatophoric/campomelic dwarfism, OI
  - Genetic or metabolic disease
  - Extremely low birth weight/early gestation
A perinatal hospice program helped Jill Kilibarda prepare for the birth of her severely ill daughter Alaina (with tris 18).

Photos by Ruth Fremson, *NY Times*

When Mike and Janel Newell learned the child she was carrying was fatally ill, they briefly considered abortion. They displayed an ultrasound photograph of the child, named Joseph, with that of their first son, William.
Perinatal Palliative Care

- Prenatal Diagnosis
  - Discovery
- Questions & Research
- Coping & Choices
  - Anticipatory Grief
  - Support
- Birth
- Life & Love
  - Learning What is Needed
  - Letting Go
- Bereavement
Palliative-EOL-Bereavement Care

Adapted from Betty Ferrell, RN, PhD
NIH State of the Art Palliative Care Consensus Conference, December 2004

Structure & Process of Care

Ethical considerations

The Imminently Dying Patient

Cultural aspects

Physical Aspects
- Pain
- Symptom Mgmt

Psychological & Emotional

Social aspects

Spiritual & Existential Aspects

Palliative-EOL-Bereavement Care...
AAP Palliative Care Statement

Pediatrics 2000;106:351

- Respect for the dignity of patients & families
- Access to competent & compassionate care
- Support for the caregivers
- Improved professional and social support
- Continuing improvement through research and education
Characteristics of Care in the NICU

- Inherent hope & anticipation
- Expectation of miracles
- Intensive & Invasive care
- Implications of prenatal diagnoses & postnatal iatrogenic sequela:
  “The NICU: tomorrow’s PICU patients, today”
- Inconceivable not to do “everything”
  - What does everything mean?

Environment of the ICU

Personnel
- medical & nursing staff, “technicians”
- parents as “visitors?”

Prevailing philosophy...treat & cure
- risk averse vs risk seeking?
- often invasive & painful
- rarely private or quiet

Pressure of time?

Support?
Conditions Around Death

- Locale/environment...the ICU
- Personnel...medical & nursing staff, "technicians," parents as "visitors?"
- Prevailing philosophy...treat & cure
  - risk averse vs risk seeking?
  - often invasive & painful
  - rarely private or quiet
- Pressure of time?
- Support?
While life prolongation is often an appropriate goal, acknowledging eventual lethality is necessary.

- Ensure physical, psychosocial, spiritual ramifications and readiness
  - infant, family (incl. siblings), and community
- An abrupt transition from curative mode to purely comfort care may be impossible.

Bereavement Care

- Continuing care of the survivors who have experienced loss
  - Survivors may include parents, siblings, grandparents, other relatives, friends, nurses, physicians, and other staff members who have cared for the patient

- Anticipatory grief work may help with an ultimate transition through loss and into bereavement care
  - It isn’t always possible to predict when death will occur
  - Hope is powerful & important
    * "Hoping for the best while preparing for the worst"

http://grievingforbabies.org/

RTS: Resolve Through Sharing
http://www.bereavementprograms.com/
Bereavement Training in Early Pregnancy Loss, Stillbirth & Newborn Death

* See also, KJ Gold: Navigating care after a baby dies. J Perinatology 2007;27:230
Hearing the lethal Dx...
“All your family may pull together with support. But the truth is, they will probably say the stupidest things or stay away entirely.” – Chaplain Peter Lund

- Have they told others?
- Have prior losses?
- How do they tell family & friends that their child has a life-threatening problem?
  - If they tell, what response will they get?
  - Isolation often follows
    - Some will encourage abortion
    - Others wax political

“I can’t tolerate people who think this is anything but a gut-wrenching choice,” Mr. Newell said. “By the same token, it was our choice to make, and if you had tried to restrict that in any way, it would’ve been very upsetting.”
What is Perinatal Palliative Care?

- **Palliative care** is both a philosophy of care & an organized, highly structured system of delivering care.
  - It begins with diagnosis of a life-threatening/limiting condition
  - It continues throughout the course of illness regardless of the outcome
  - **The focus is upon enhancing the quality of life** in the face of an ultimately terminal condition.
    - Relief of symptoms (pain, respiratory distress)
    - Relief of emotional distress (fear, anxiety, isolation)
    - It is *early* and ongoing
    - It seeks to add life to the time the child has left, not to add time to the child's life
    - In the case of newborns, many of the healing components of palliative care (those meeting the cognitive, psycho-social, emotional, and spiritual needs) are geared more toward the infants' family members

- **Perinatal palliative care** emphasizes the importance of planning for the limited amount of time families may have with their baby. *(Sumner, et al. J Perinat Neonat Nurs, 2006)*

- **Perinatal hospice** is a newly developing model of hospice care *(Ramer-Chrastek, Internat J Pall Nursing, 2005)*
  - offered to the family in the prenatal period
  - provides support, guidance and comfort to families who make the difficult choice to continue a pregnancy after the diagnosis of a fatal fetal anomaly
  - The model is based on the hospice philosophy of living life fully and enjoying each moment.
Each year in the US there are 25-27,000 infants who die before their first birthday with causes that may relate to the perinatal period:
- Birth defects (~20%)
- Prematurity & LBW (~17%)
- SIDS (~8%)
- Maternal Conditions (~6%)
- Accidents (~4%)

Palliative Care Invokes Family-Centered Care Principles

- Families need to feel cared for & connected to HCP
- They need to retain the rights & responsibilities of parents to their infant, even when dying
  - Allowing them to have control whenever possible during a situation of overwhelming powerlessness is important in supporting their role as parents
  - Focusing on the human experiences of families strengthens connections between caregivers and families
  - Provide information
  - Offer choices
  - Discuss both sides of all options

- Give families time to make difficult decisions or to be with their baby before &/or after death
  - Create a space for privacy/intimacy
  - Be sensitive to room location/activities going on near baby's bedside
  - Be present/absent when needed
- Strive for seamless continuity between areas of care/changes of shift
- Call the baby by name
- Use gentle touch and tone of voice
- Offer to contact supportive persons (chaplain, clergy, SW, friend)
- Be familiar with protocol for fetal/infant death
- Preserve keepsakes
"The nurses and technicians did all they could—I just wasn’t into it."
The Question Most Clinicians Dread Being Asked:

“*If this were your child, what would you do?*”

- While there is room for debate about the range of ways one might respond to this question depending on the context, it is valuable for practitioners to ponder the implicit existential question:

  - How would this be for you, if you were going through it?

  - “I am a different person than you, but based on the values that affect my decisions, I imagine I might be thinking... (followed by your own thoughts and feelings.)

- Others?

AA Kon. Pediatrics 2006;118:393
Neonatal Palliative Care Attitude Scale Measures Barriers to & Facilitators of Palliative Care in Neonatal Nursing

**Facilitators**
1. Support for a neonatal palliative model of care by the health care team
2. A health care team that can express values, opinions, and beliefs
3. The availability of counseling support for caregivers
4. The presence of at least some clinical guidelines to support practice, and
5. The support of parents by the health care team.

**Barriers**
1. Inadequate staffing to support palliative care practice
2. A physical environment that is not conducive to palliative care practice, and
3. Technological imperatives and parental demands.

Suggested Reading


• Gale G, Brooks A: Implementing a Palliative Care Program in a NICU. *Adv Neonatal Care* 2006;6(1):37.e1-37.e21
