Neonatal Pain in the End of Life

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Abstract

Neonatal palliative care is a person and family centered care for the neonate with a progressive, advanced, life-limiting disease. Its goal is to optimize the whole group’s quality of life. The general objective of the present review is to update neonatal end of life pain treatment and the specific objective is to answer: a) How to recognize pain in neonatal end of life and b) How to treat pain in neonatal end of life.

Keywords: Neonatal Pain; Neonatal End of Life; Neonatal Palliative Care.

Introduction

Pain Management is a fundamental Human Right (Declaration of Montreal) [1]. Neonatal palliative care is a person and family centered care for the neonate with a progressive, advanced, life-limiting disease. Its goal is to optimize the whole group’s quality of life [1].

- NEONATAL death: happens during the first 28 days of life, early deaths between 0 and 7 days - late deaths after 7 days to 28 days [1].
- PERINATAL death: happens between 22 weeks of gestation (or weighing 500 g) and 7 days after birth (Fetal death: before delivery and intrapartum) [1].

The first application of neonatal palliative care concept 1982 In 2019, 47% of all deaths in children under 5 years of age occurred during the neonatal period [2]. Most neonatal deaths happen in the first week after birth. (UNICEF) In Uruguay 153 newborns died in 2020; mostly due to congenital anomalies and preterms [1]. Up to 3% of pregnancies complicated by a fetal life-limiting conditions [2].

Objectives

The general objective is to update neonatal end of life pain treatment. The specific objective is to answer:

- How to recognize pain in neonatal end of life?
- How to treat the pain in neonatal end of life?

Methods

A bibliographic review with PubMed, Scielo, Google Scholar and Medline. Included during a period from 2016 to 2021. Was selected accessible full text and indexed articles. Excluded: duplicate or non-relevant article based on title and abstract.

Ethics questions: The author has no conflict of interest.

Results

The PubMed research show: Neonatal palliative care 284 results and end of life pain 19 results; Neonatal end of life care 327 results and pain 37 results. It was selected 14 papers as it is shown in table one.
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<tr>
<th>S.NO</th>
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<tr>
<td>1</td>
<td>Veldhuijzen van Zanten S, et al.</td>
<td>2021</td>
<td>Medications to manage infant pain, distress and end-of-life symptoms in the immediate postpartum period.</td>
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<td>2</td>
<td>Haug S, et al.</td>
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<td>End-of-Life Care for Neonates: Assessing and Addressing Pain and Distressing Symptoms.</td>
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<td>3</td>
<td>Cortezzo DE, et al.</td>
<td>2020</td>
<td>Neonatal End-of-Life Symptom Management.</td>
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<td>4</td>
<td>Walters A, et al.</td>
<td>2020</td>
<td>This My Home? A Palliative Care Journey Through Life and Death in the NICU: A Case Report.</td>
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<td>5</td>
<td>Garten L, et al.</td>
<td>2019</td>
<td>Pain and distress management in palliative neonatal care.</td>
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<td>Cortezzo DE, et al.</td>
<td>2019</td>
<td>Birth Planning in Uncertain or Life-Limiting Fetal Diagnoses: Perspectives of Physicians and Parents.</td>
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<td>7</td>
<td>ACOG committee</td>
<td>2019</td>
<td>Perinatal palliative care: ACOG committee opinion</td>
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<td>8</td>
<td>Carter BS, et al.</td>
<td>2018</td>
<td>Pediatric Palliative Care in Infants and Neonates.</td>
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<td>9</td>
<td>Xavier D, et al.</td>
<td>2017</td>
<td>EPIPAGE-2 Extreme Prematurity Writing Group. Delivery room deaths of extremely preterm babies: an observational study.</td>
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<td>11</td>
<td>Carter BS, et al.</td>
<td>2017</td>
<td>Neonatal pain management.</td>
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<td>13</td>
<td>Ligia M., et al</td>
<td>2016</td>
<td>Analysis of death and palliative care in a neonatal intensive care unit</td>
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<td>2016</td>
<td>Delivery room deaths of extremely preterm babies: an observational study</td>
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**Discussion**

**A. How to Recognize Pain in Neonatal End of Life?**

**Barriers**
- The current definition of pain (IASP) excludes newborns (11).
- The methods and tools cannot be translated to this population (3).
- Few studies specifically focus on symptom management in the delivery room (1).

**Results**
- No EOL scale has been validated (2).
- It is recommended use a tool and experienced with it to increase the reliability of the reported results (3).
- 2017- EPIPAGE 2 study (from Extreme Prematurity Writing Group) Included 73 preterm. Median gestational age of 24 (23-24) weeks (9). Median duration of life was 53 (20-82) min. Pain was assessed for 72%, although without using any scale.

**Point to Mark**
- Many neonates still receive curative and aggressive practices at the end of life (2, 13).
- It’s necessary decreasing noxious stimuli (2).
- It is the most common symptom in EOL is pain (10).
- The analysis of death and palliative care in a neonatal intensive care unit shows the therapeutic on the day of death of 49 newborns included: mechanical ventilation 44, vasoactive drugs 37 (13), parenteral nutrition 26, peritoneal dialysis 6 and others: (2).
B. How to Treat the Pain in Neonatal End of Life?

- **First Step: Non-Pharmacological**
  Swaddling, facilitated tucking, kangaroo care/skin-to-skin care, non-nutritive sucking with or without oral sucrose, and breastfeeding (2).
  
  Combining measures enhances comfort (2).

- **Second Step: Pharmacological**
  Common medications are grouped into non-opioid opioids and adjuvants. Non-opioid medications are recommended for mild pain (2, 3).
  Opioid medications with or without adjuvant therapies for moderate to severe pain (2). Considered off label uses (3).

  Compassionate extubation and withdrawing artificial nutrition and hydration (4).

  The access to palliative care team improves newborn quality of life (5, 10, 2).

  Algorithm for a practical approach to EOL symptom management in the NICU (2).

  Route of administration in extremely preterm babies (14). In this study the most used administration via was the Umbilical via followed by Transrectal Nasal Transdermica and Via Venous Periphery (14).

  Comfort medication administration in delivery room in extremely preterm babies: Pain was assessed 72%, although without using any scale. Gasping was described for 66% (14). Comfort medications were administered to 50%, significantly more frequently to babies with gasping (p=0.001). Mother-child contact was reported for 78%.

**Conclusions**

It is required to study and validate an EOL scale. Pain control requires non pharmacologic and pharmacologic treatment. Non opioid for mild pain and opioid and coadjuvants for moderate a severe pain. Neonatal palliative care programs must begin in the antenatal period. The birth plan must include plans for assessment and care of the newborn. Provides parents with comprehensive, holistic support. It is important training for nurses and residents. The intervention of the palliative care team is recommended.

**References**

3. World Health Organization (WHO)
5. UNICEF

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