Pediatric Palliative Care:
Neonatal Specifics

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Neonatal care:
where we are coming from & where we are going

- Elevated mortality rates
- High rates of outborn patients
- Aggressive intensive care, based on oxygen and mechanical ventilation
- Standardized decisions
- Withdrawing & withholding care; +/- active ending of life

Improved survival and intact survival
Regional organisation of care, antenatal transfer
Antenatal steroids
CPAP & exogenous surfactant
Developmental, family based care
Individualized care and medical decisions
Neonatal palliative care
Neonatal patients

- Particularly vulnerable,
- Totally dependent,
- Unable to express any demands or consents
- Facing an uncertain long term prognosis, starting antenatally
- Perserved consciousness, including with severe brain damage
- Possibly not in an end of life situation when an extremely poor prognosis becomes available
- Repeatedly involved in situations of ethical dilemmas during their hospital stay (premature infants)
Short-term challenges of preterm birth

Delivery room stabilisation

Respiratory distress syndrome (RDS)

Haemodynamic, kidney, metabolic disorders

Intra-periventricular haemorrhage (IVH)

Apneas

Persistence of ductus arteriosus (PDA)

White matter disease (WMD-PVL)

Necrotizing enterocolitis (NEC)

Broncho-pulmonary dysplasia (BPD)
  - Chronic Lung Disease (CLD)

Retinopathy of prematurity (ROP)

Sepsis (early)

Sepsis (late, nosocomial)
# Ethical Dilemmas – Perinatal Medicine

<table>
<thead>
<tr>
<th>Fetus: a patient; Mother</th>
<th>Newborn infant: a patient, a person (by law)</th>
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<tbody>
<tr>
<td><strong>Termination of pregnancy</strong></td>
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<tr>
<td>Active ending of life</td>
<td>Comfort care</td>
<td>Artificial nutrition</td>
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<tr>
<td>Intention: Patient’s death</td>
<td>Palliative care</td>
<td>Withholding, limiting, withdrawing curative treatments</td>
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<td>Intention: to avoid medical treatment futility (survival possible)</td>
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**LAW**

**ETHICS**
Neonates are treated differently

Percentage of respondents who thought it was in a patient's best interest to be resuscitated and transferred to intensive care (gray bars) and the percentage of those who would accept withholding care from the same patients (black bars).

Parental conditions and end of life decision making:

Percentage of respondents who would always or generally comply with parental decision to resuscitate in the 9 scenarios.

aP = .001. bP = .02.

Active euthanasia in neonatal care

Cuttini et al, ADC 2004
Neonatal care: subjective context

- Parents and health care professionnals emotions
- Historical subjectivity linked to the threshold of birth and of viability
  - A particular moral status in the society
- Societal views on, and tolerance of handicap
Why are newborn infants considered differently?

• The newborn infant:
  • Absence of perceived personal or familial history?
  • A dependent individual; the law of nature?
  • Absence of perceived self-awareness, reasoning, limited perceptions of pleasure or suffering?
  • Absent memories of the neonatal period in adult individuals?
The emergence of human consciousness

• Consciousness: a sensory awareness of the body, the self, the world

• Fetus: maybe aware of the body (pain), reacts to smell, touch, sounds, facial expressions reactive to stimuli, asleep most of the time
  • Subcortical nonconscious origin?

• Newborn infant: basic consciousness: can be awake, shows sensory awareness of the body, processes memorized mental representations, differentiates between self and non self-touch, express emotions, signs of shared feeling
  • Yet unreflective, present oriented, little reference to the concept of him/herself

• Related to thalamocortical connexions establishment.
### Humanizing the fetus

- Development of fetal & perinatal medicine: the fetus as a patient
  - Scientific studies
  - Prenatal diagnosis & screening
  - Fetal pain
  - Fetal therapy & surgery
- Emotions and psychology in pregnancy (mothers, parents, health care providers)
- Publicly available 3D US fetal imaging
- Debate about abortion and limits to be allowed to medically justified termination of pregnancy
- France: August 22, 2008 decrees on stillborn infants:

### Fetalizing the newborn

- Extensive indications of life support withholding or withdrawl in neonatal care
- Neonatal euthanasia/deliberate ending of life
- Grey zones exactly defined, category-based, non individualized life/end of life decision making in extremely preterm babies
- Arbitrary limits vs preservation of newborn infants’ individual rights
- Medically-induced extreme preterm birth clashing with late terminations of pregnancies

* A misleading continuum between the fetal and the neonatal condition?*
From ancient to current representations

The Venus from Willendorf (Naturhistorisches Museum Wien, 30,000 b.c.)

Prenatal 3D ultrasounds, 2012

Birth, a symbolic threshold in the majority of cultures
Opposing philosophies

• Personalism:
  • Persons have unique value
  • Roman-christian tradition (Aristotle, Augustine, Thomas Aquinas,…)
  • Kant: deontological approach.
  • By law, human life to be respected; taking or compromising the newborn infant’s life is prohibited, contrary to taking a fetus life: a greater ontologic consistance for the newborn infant

• Utilitarianism:
  • The greatest good for the greatest number; the balance for preferences (pleasure and pain)
  • « Killing a newborn baby is never equivalent to killing a person, that is, a being who wants to go on living » (P. Singer, ‘Should the baby live?’ 1985): Individuals are different from persons. Then the newborn is not a person, and the suffering of parents becomes the next issue.
  • Consent of individuals is needed (no sacrifice).

(JS Mills, J Bentham)
Phenomenology?
(P Le Coz)

• Phenomenology suspends interpretations and focuses on concrete perceptions (Husserl)

• Meeting the other one’s face, a major existential event in which the demands of ethics have roots (Levinas, 1984)

• The visible infant’s face:
  • bears an inhibiting force, which prohibits violence
  • the basis for empathy: perceiving and sharing the other one’s emotions; the newborn can be touched, caressed, cradled; the fetus cannot.
Neonatal palliative care: situations

- Palliative care following limitations/interruption of intensive care
- Lethal or severe, life-limiting malformations discovered postnatally, or prenatally in the absence of demand of termination of pregnancy
- Birth at the threshold of viability in the absence of intensive intervention.
Planning a neonatal palliative care project

• A comprehensive and integrative approach

• Sequence:
  • Identification of futility of intensive/curative care:
    • Among known eligible situations
    • Identification of futile or disproportionate therapeutic options
  • Withdrawl or withholding of undesired curative care measures
  • Start of palliative care
  • Flexible care choices through the whole procedure

• Procedure for decision making:
  • Parents opinion after complete, clear, loyal, adapted information
  • Multidisciplinary, team planning; external consultant opinion
  • Transparency of communication and documentation in the patient’s chart
Elaboration of neonatal palliative care approach

• Building the project with the family
  • In the neonatal unit or in the delivery room
  • In relationship with pediatric palliative care teams
  • Information sharing with care teams
  • Transparency on intentionality
  • Awareness of evolutivity and flexibility of the project
  • Anticipation of the terminal phase
  • Bereavement
Elaboration of neonatal palliative care approach

• Difficulties encountered by families
  • Tense prenatal decisions
  • Demands of treatment perceived as futile
  • Possible demands of euthanasia
  • Parental depression
  • Divergence and pressures among/from the family members
  • Emotions
Elaboration of the palliative care approach

- Difficulties encountered by care givers teams
  - Conflicting values behind the medical decisions to be made, specific to the neonatal/perinatal context
  - Uncertainty about patient’s prognosis
  - Questions about practical application of the palliative care project
    - e.g. gastric tube feeding withdrawal
  - Difficulties in identifying therapeutic obstinacy and futility
Neonatal palliative care
Practical issues

• In the delivery room
  • Start of palliative care oriented by clinical signs (vital functions)
  • In the case of respiratory distress: sedatives (dyspnea, gasps)
    • Ideally IV (ensures biodisponibility of drugs)
  • In situations when a decision has been anticipated antenatally (malformations, unviable extreme preterm birth):
    • Comfort care, warming, treatment of pain
    • Humanization of the environment
In the neonatal unit

Management of pain and comfort

- Limitation of uncomfortable or painful interventions
- Pain scoring, step by step analgesics
- Sedatives
- Modes of mechanical ventilation withdrawal:
  - Progressive reduction of MV under sedatives titration, preceeding tracheal extubation
  - Tracheal extubation with consequent use of sedatives
Pain and comfort

• Morphinic Analgesics
  • Morphine chlorhydrate
    • Orally or intra-rectal: 0.2 – 0.5 mg/kg/d (every 4-6h)
    • IV, SC: 0.05-0.1 mg/kg/4-6h or 0.01-0.02 mg/kg/h
  • Morphine derivatives

• Sedatives, anxiolytics
  • Midazolam
    • IR: 0.2-0.3 mg
    • IV: 0.03-0.1 mg/kg, or 0.05 mg/kg/h

• Symptomatic treatment: diuretics, anticonvulants, anti-gastro-oesophageal reflux drugs
Human and material environment

• Location:
  • Neonatal unit
  • Delivery room, Obstetric clinic
  • Home

• Importance of the relational role of the parents and of health care professionnals
Neonatal palliative care vs prenatal diagnosis/screening:

- In the absence of a demand of pregnancy termination, an approach based on follow-up of pregnancy, with application of a neonatal palliative care project can be proposed.

- But malformations likely to be lethal at or shortly after birth are rare. Palliative approach cannot be considered a true alternative to termination of pregnancy, in many situations.

- The nature of the discontinuity between the fetal and neonatal situations is:
  - legal,
  - pathophysiological,
  - therapeutic,
  - psychologic and emotional

- Appropriate information of the pregnant woman and future parents is of utmost importance.
Neonatal Palliative Care: Needed Advances

• Education, CME, and pluri-professionnel appropriation of the palliative culture by perinatal centres and perinatal networks

• Interdisciplinary support of palliative care networks, mobile pediatric palliative care teams.

• Promotion of research in neonatal palliative care.
Individualization of care