NEONATAL PALLIATIVE CARE

ICPCN Children’s Palliative Care Conference
10 – 12 February 2014, Mumbai, India

Transforming Children’s Palliative Care – from ideas to action
DRA. RUT KIMAN

Head CPC Team. Hospital Nacional “Prof. A. Posadas”. Buenos Aires-Argentina

Department of Pediatrics. Faculty of Medicine.

University of Buenos Aires
Milena was the sixth daughter...

What would be your advice in this situation?
The aim of this presentation is to provide an overview of palliative care in the neonatal period in order to enhance care of babies with no curative options.
Over the next few minutes...

- Introduction
- What we know
- What we do
Pediatric palliative care is considerably younger than its adult counterpart.
Key issues in the development of Neonatology

- Apgar score
- Management of perinatal hypoxic-ischemic brain injury
- Thermoregulation
- Nutrition
- Respiratory distress syndrome
- Setting up artificial ventilation
- Neonatal surgery
- Neonatal nursing as a subspecialty
Newborn deaths account for 43% of all deaths among children under age 5

3 million newborn babies die every year due to preventable causes

2.6 million stillbirths

1 million per year die on their day of birth

2 million per year die in their first week.

60% of infant deaths occur in the first month
The infant mortality rate is 4 per thousand, neonatal 3%. Every year 80,000 babies are admitted to NICU and an average of 2109 neonatal death each year from causes likely to require CPC.

The infant mortality rate is 6 per thousand, neonatal mortality 4 per thousand. An estimated 11,300 babies die on the day they are born each year. Complications of preterm birth cause of 35% of newborn deaths.

The infant mortality rate is 11.7 per thousand, neonatal deaths from avoidable causes represent 60% of the total (8%).
Palliative care

• Palliative care principles may be applied in the NICU, where they can be integrated into patient and family care plans, regardless of whether the treatment goal is obtaining a cure, prolonging life, or exclusively palliation and comfort until an expected death

Carter B. Providing palliative care for newborns.
Pediatric Ann, 2004
Palliative care for a fetus, neonate or infant with a life limiting condition is an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, at the time of death and beyond.

It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the neonatal infant and support for the family.

It includes the management of distressing symptoms, the provision of short breaks and care through death and bereavement.

*The Neonatal Care Pathway (2009)*
*Together for short lives*
PRENATAL DISCUSSION OF PALLIATIVE CARE

✓ Choosing who will deliver the baby
✓ Where the delivery will take place
✓ Who will be present
✓ Notifying all members of the obstetric and neonatal team that palliative care will be offered
✓ Delineation of resuscitation status
✓ Planning for comfort measures immediately at birth
✓ Having on-hand availability of medications to treat symptoms buccally if IV access is not available
✓ Deciding which diagnostic interventions
✓ Arranging for spiritual/cultural care
✓ Planning for family support
Eligible babies for Neonatal Palliative care

Infants who are born too early, who are too sick, who are not responding to intensive care efforts, who are suffering to the point of therapies being a burden or whose condition will not allow any kind of meaningful life are offered palliative care.
End-of-life decision making for newborns with adverse prognosis is an ethical challenge and the ethical issues are controversial ...
Considerations of diagnostic and prognostic certainty

✓ **Diagnosis and prognosis is certain**: Trisomy 13, 15, or 18; anencephaly, complex congenital heart disease, renal agenesis/dysgenesis

✓ **Diagnosis and prognosis uncertain**: Dwarfism, oligohydramnios, hydranencephaly, extreme prematurity <23 weeks

✓ **Prognosis is uncertain**: Mild oligohydramnios including prolonged rupture of membranes, hypoplastic left heart syndrome, multiple anomalies, diaphragmatic hernia

*Leuthner SR.*

Fetal palliative care, 2004
Morbidity replaces mortality
Around the world most neonatal deaths occur in hospital settings and few parents are allowed to take their babies to die at home with appropriate support or to a children's hospice.
The model of palliative care in the perinatal setting: a review of the literature

Albert Balaguer1,2*, Ana Martin-Ancel3, Darío Ortigoza-Escobar3, Joaquín Escribano4 and Josep Argemi2

1Antenatal period also considered
2Integrative care started early (including bereavement)
3Comprehensive (including psychological, social, spiritual aspects...)
4Family centered care
5Maternal bond (& emotional aspects)
6Comfort (multisensorial)
7Pain relief
A Paradigm of Integrative Care: Healing with Curing Throughout Life, "Being with" and "Doing to".

Jay Milstein
Journal of Perinatology; 2005
Neonatal palliative care guidelines

- British Association for Perinatal Medicine (BAPM)
- Together for Short Lives (U.K. Association for children's palliative care and children hospices)
- Neonatal End-of-Life Palliative Care Protocol (USA)
- Recommendations for decision-making and end of life care in neonatology (Spain)
Palliative care (supportive and end of life care)
A framework for clinical practice in Perinatal medicine

Stages of palliative care planning

A. Establish eligibility of fetus or baby for palliative care

B. Family care
   - Communication & documentation
   - Flexible parallel care planning

C. Pre birth care
   - Transition from active postnatal care to supportive care
   - End of life care
   - Post end of life care

D. Routine pre birth care plan
   - Routine post natal plan
   - Survival or end of life by natural causes
Data shows 53 babies died during the first week:

- 35 with severe malformations
- 14 premature
Hospital Posadas 2012

PPCT: 12 patients

7 died in NICU: sequelae of hypoxic ischemic encephalopathy, undifferentiated brain tumour, hydrocephaly, thanatophoric dwarf, multiple malformations, cerebral infarction and one with neonatal leukaemia

5 patients were able to return home: holoprosencephaly, Steinert disease, neurological sequelae, multiple malformations and pulmonary malformation
145 babies with congenital heart disease were admitted for surgery

17 died

CICU demanded support for 29 patients and 10 died
DECISION MAKING FOR COMPROMISED NEWBORNS

What happened to Milena?
DECISION MAKING FOR COMPROMISED NEWBORNS

Elective tracheostomy and gastrostomy on a patient in a deep coma...

Life support limitation in a patient whose neurological damage was severe...
Losing a baby is a devastating experience and every mother experiences grief in her own way...
Working in the Neonatal Intensive Care Unit allows us to witness not only the birth of a baby with a life-threatening disease but also the birth of the earliest relationship between a baby and his parents in adverse circumstances, posing the threat of "psychosocial risk".
The Palliative Care Team interventions point towards enrolling this “real baby” in a family history to be accepted as a person beyond its survival prognosis...
From ideas to action...
What can you do to make a difference?
Thank you so much for your attention!!

rkiman@gmail.com
palipepos@hospitalposadas.gov.ar
http://www.hospitalposadas.gov.ar