

END OF LIFE CARE

Introduction

Paediatric palliative care is defined as an active and total approach to care embracing physical, emotional and spiritual elements. It focuses on quality of life for the child and support for the family and includes management of distressing symptoms, provision of respite and care through death and bereavement'.

Causes of Paediatric Mortality (Malaysian State Hospitals)

- Approximately 70% of deaths are in the neonate group; 30% in older children.
- A small proportion deaths are due to acute illnesses where death is sudden; the rest are lethal congenital malformations or one of the following broad groups of life limiting conditions (i.e. where there is no reasonable hope of cure, from which children will die):
- conditions where potentially curative treatment has failed. (e.g. malignancy)
Note: excludes children in long term remission, or following successful treatment
 - conditions where intensive treatment may prolong life but premature death occurs. (e.g. cystic fibrosis)
 - progressive conditions where treatment is exclusively palliative (e.g. Duchenne's muscular dystrophy)
 - non progressive neurological conditions which result in an increased susceptibility to complications and premature death (e.g. cerebral palsy).

There is a perception that most deaths are due to malignancy but < 50% of paediatric deaths are due to malignancy. Congenital abnormalities, chromosomal disorders and neurodegenerative disorders are common causes.

Impact of the lost of a child

- one of the differences highlighted by Papadatou between the care of dying adults and dying children is that the dying process of a child affects many individuals with grief over the loss that is more intense, long lasting and complicated. This is because children are generally expected to outlive their parents. Parental grief is the most severe form of grief; with an associated increase in morbidity and mortality. It often intensifies in 2nd or 3rd year (when friends and relatives expect them to be 'over it').
- for parents who have lost a child , there is an increased risk of first psychiatric hospitalisation for any disorder compared with parents who did not lose a child. This risk is higher in bereaved mothers than bereaved fathers, the risk being highest during the 1st year following their child's death, and remains elevated for ≥ 5 years
- care related factors may influence parents' psychological outcomes. Among factors that continued to affect parents 4-9 years following their child's death were the child having had unrelieved pain and experienced a 'difficult moment of death'. Parental interviews suggest that the child's physical pain and circumstances at the moment of death contributed to parents' long term distress.

Quality of End of life care

Parents associate the quality of end of life care with physicians:

- giving clear information about what to expect in the end of life period
- communicating with care and sensitivity
- communicating directly with child where appropriate
- preparing the parent for circumstances surrounding the child's death

As healthcare providers we have the unique opportunity to proactively provide good symptom control and supporting the child through a "good death".

End of life Care for Paediatric Patients .

When the disease trajectory of a patient has reached the final days, and the family or caregivers understand the situation, the following are steps that can be taken to help the patient/family. Medical management in such instances needs a review of existing orders and management strategies with the goal of enhancing comfort and decreasing noxious and invasive interventions.

Aspects of care that should be addressed are

- discontinuation of parenteral nutrition. Enteral feeding reduced, discontinued or offered as comfort measure; breastfeeding may be offered if desired by mother and baby; a lactation referral for breastfeeding mothers to stop milk production
- tests and treatments usually discontinued to minimize noxious or painful procedures
- intravenous access maintained for medications to decrease pain, anxiety or seizures. Alternatives to IV access are the use of oral, sublingual or rectal medications.
- antibiotics may be discontinued.
- cardiac medications e.g. dopamine, adrenaline may be discontinued.
- ventilator support: parents must be included in the decision to stop ventilator support and should be provided with information about the expected sequence of events surrounding removal from the ventilator as well as the infant's physical response, including the possibility that the infant may not die immediately.
- moral/ethical issues e.g. do not resuscitate status; Do not resuscitate (DNR) orders should be explicit and developed collaboratively with the family.
- pain management; comfort measures e.g. discontinuing non essential investigations, observations for pain, agitation, nausea and vomiting; appropriate management to improve the quality of life; give additional morphine for breakthrough pain.
- communication with care givers ; their understanding of what to expect, choice of place where they prefer the child to die; how the rest of the family is coping or understands; patient's desire/wish list ; organ donation
- religious /spiritual needs
- for the child dying in hospital, whether the family wants to take the body home, how will the body be transported; are there any specific religious requirements, and does the family want symbolic memorials (e.g. handprints, hair lock).
- transitional care ,family support, sibling support, staff support, organ donation, follow up support for family

End of life care for infants with lethal anomalies

The goal of palliative care is the best quality of life for patients and their families.

The following is a list of lethal congenital anomalies:

- *Genetic*
Trisomy 13 or 18, triploidy, thanatophoric dwarfism or lethal forms of osteogenesis imperfecta; inborn errors of metabolism that are lethal even with available therapy
- *Renal* (with oligo/anhydramnios and pulmonary hypoplasia)
Potter's syndrome / renal agenesis, multicystic / dysplastic kidneys, polycystic kidney disease, renal failure that requires dialysis
- *Central nervous system*
Anencephaly, holoprosencephaly, complex, severe meningomyelocele, large encephaloceles, hydranencephaly. Congenital severe hydrocephalus with absent or minimal brain growth; neurodegenerative diseases, e.g. spinal muscular atrophy

- *Cardiac*
Acardia, Inoperable heart anomalies, hypoplastic left heart syndrome, pentalogy of Cantrell (ectopia cordis)
- *Other structural anomalies*
certain cases of giant omphalocele, severe congenital diaphragmatic hernia with hypoplastic lungs; inoperable conjoined twins

Some of these conditions may be prenatally diagnosed – thus allowing the paediatric palliative care team to be activated immediately. Others may need further evaluation to ensure certainty – in these cases it is advisable to do what is medically necessary to support the baby. The life sustaining medical support can be withdrawn once a definitive diagnosis or prognosis is established.

In the event of child's survival to homegoing, Hospice services should be offered. Hospice admission must occur on the day of discharge to coordinate for continuity of care from hospital to home.

NEONATAL PALLIATIVE CARE PLAN: INFANT WITH LETHAL ANOMALIES

Mother's name: _____

Father's name: _____

Infant's name: _____

Date, time of birth: _____

Discussion for palliative care done by: _____

in the presence of _____

Comfort measures for babies

- dry and warm baby, provide warm blankets
- provide hat
- allow mothers to room in
- minimize disruptions within medically safe practice for mother
- lower lights if desired
- allow presence of parents and extended family as much as possible without disruption to work flow in the unit
- make siblings comfortable; they may wish to write letters or draw for the baby
- begin bereavement preparation and memory building, if indicated, to include hand and footprints, pictures, videos, locks of hair.
- encourage parent/child bonding and interaction: bathe, dress baby; feeds, diaper change

Selected medical interventions

- humidified oxygen (_____ %)
- nasal cannula oxygen (_____ L/min)
- suction
- morphine sublingual 0.15 mg/kg or iv 0.05 mg/kg as needed
- buccal midazolam or oral clonazepam as needed
- artificial hydration or nutrition : _____
- natural hydration or nutrition : _____

Avoid distressing delays in treating symptoms by making medications available in all available concentrations and doses.

Spiritual care:

- religious preference: _____
- identified religious leader: _____
- religious ritual desired at or near time of death: _____

In the event of child's death in hospital

- diagnostic procedures: _____
- autopsy preference: _____
- tissue/organ procurement preferences: _____

Funeral home chosen by family: _____

Rituals required for body care: _____

Please notify: _____