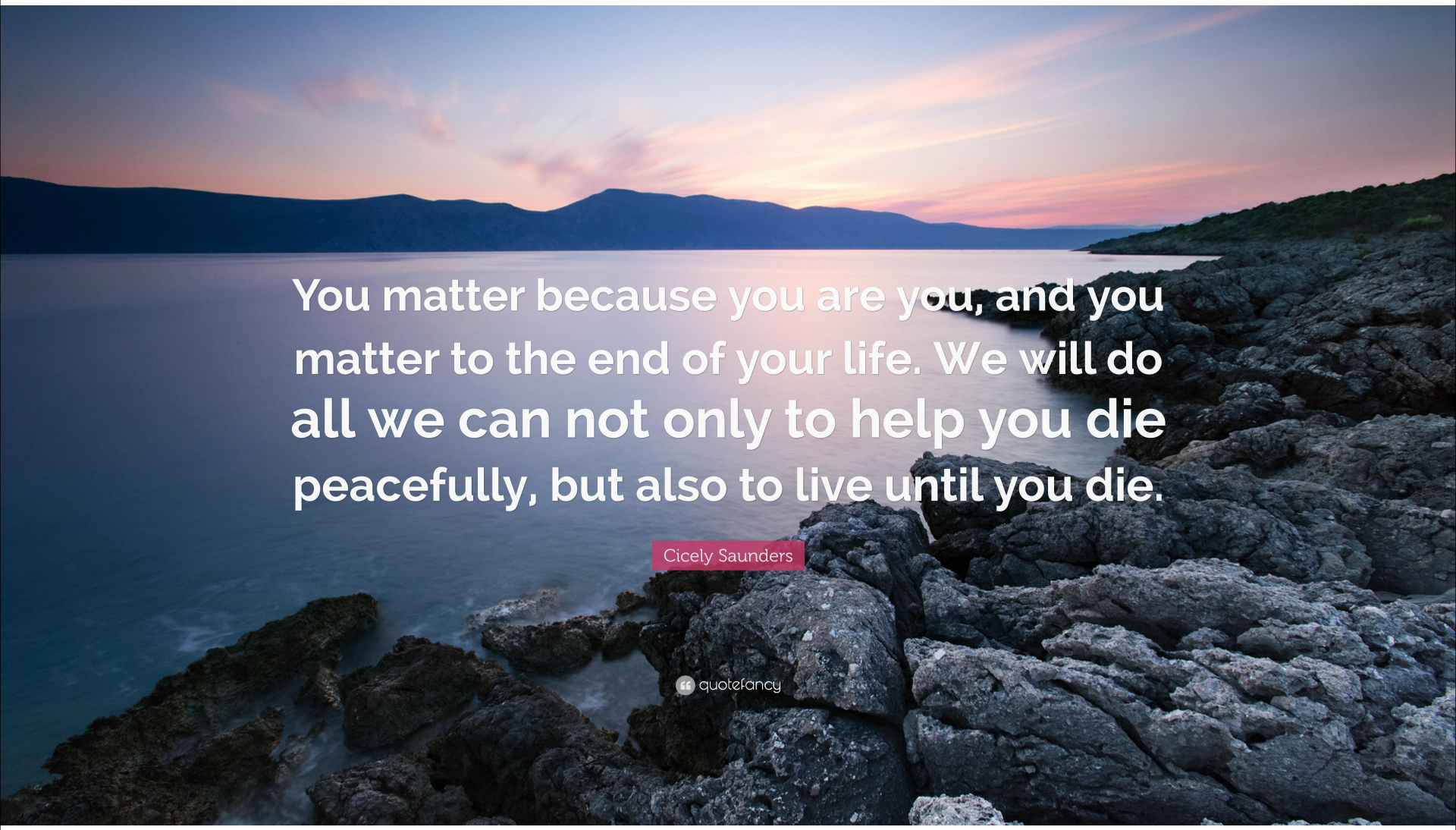
15th Malaysian Hospice Council Congress

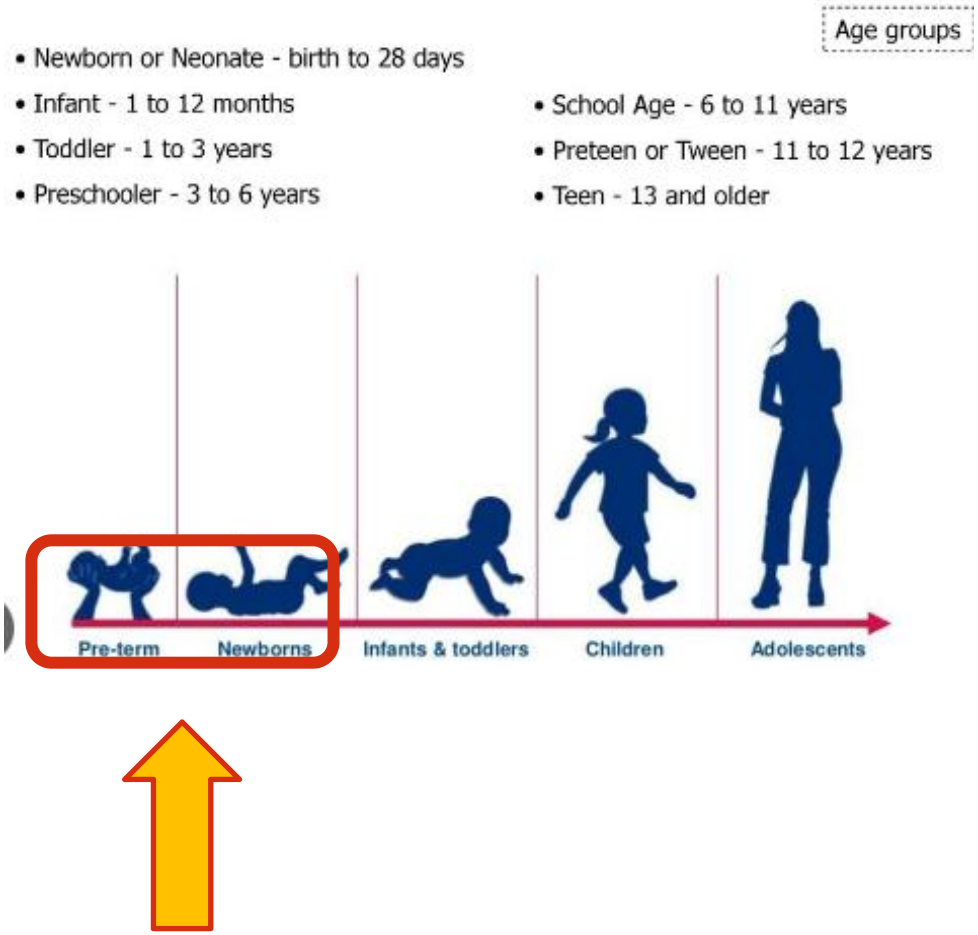
PERINATAL & NEONATAL PALLIATIVE CARE

Fahisham Taib, Universiti Sains Malaysia


You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.
Cicely Saunders
quotefancy

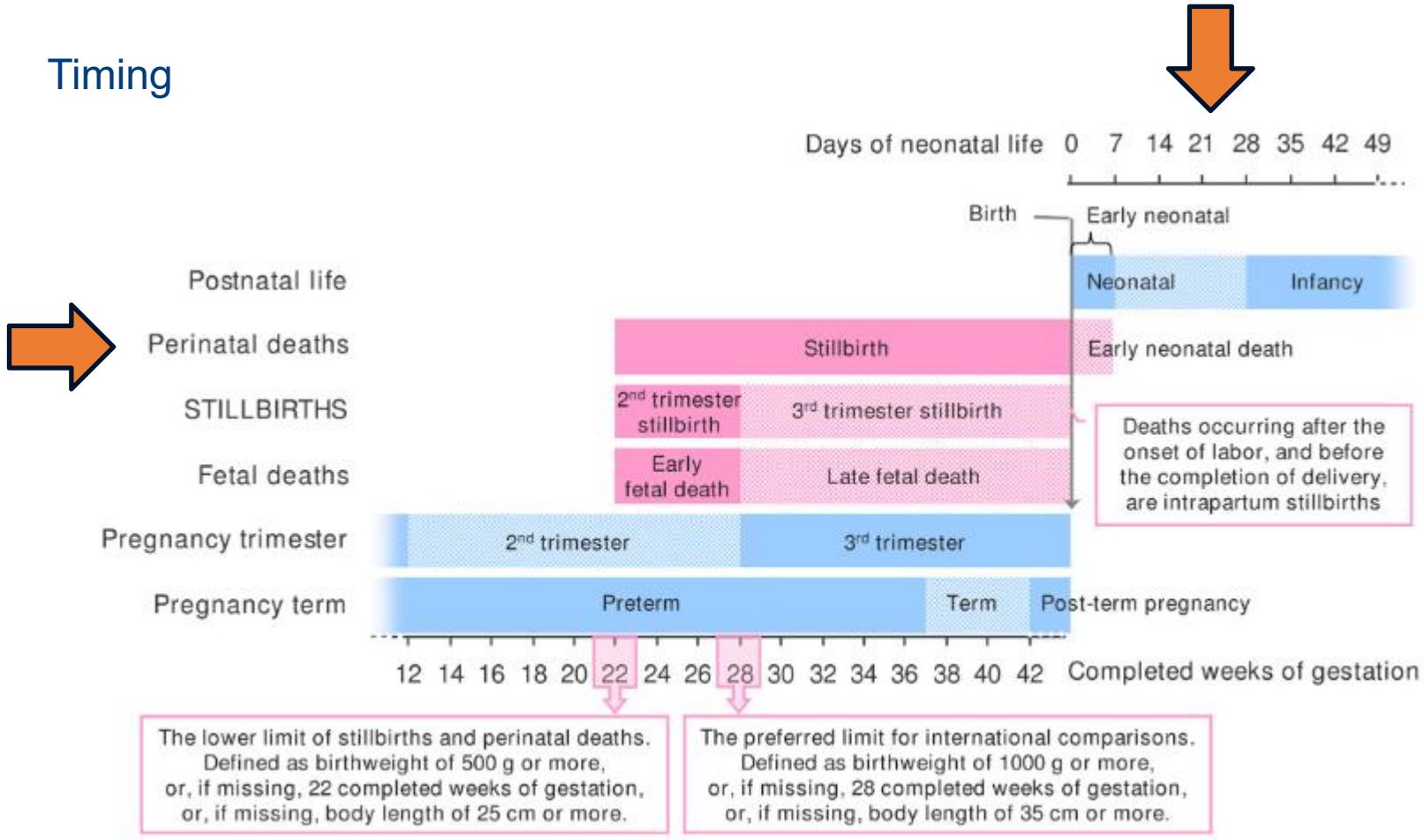
Outline

1. Definition
2. Literature
3. Components
4. Illustration
5. Conclusion



1. Definition

Timing



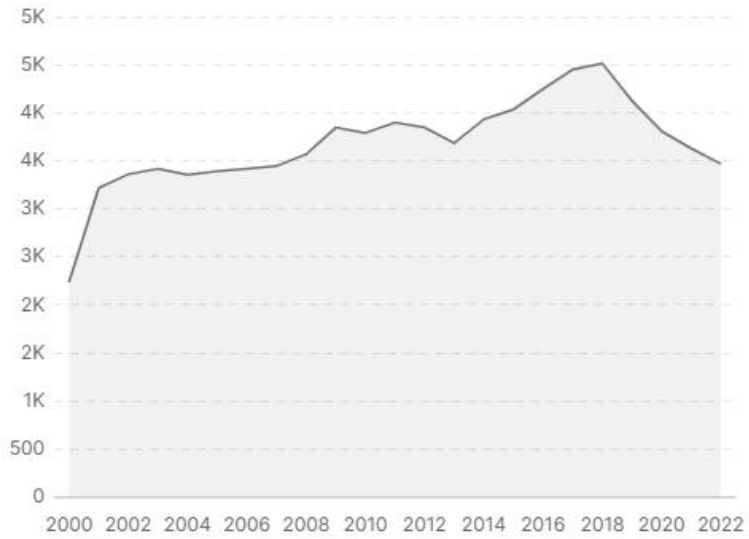
Frøen, J.F., Gordijn, S.J., Abdel-Aleem, H. *et al.* Making stillbirths count, making numbers talk - Issues in data collection for stillbirths. *BMC Pregnancy Childbirth* **9**, 58 (2009). https://doi.org/10.1186/1471-2393-9-58

Why important – Perinatal vs Neonatal

Statistics from DOSM

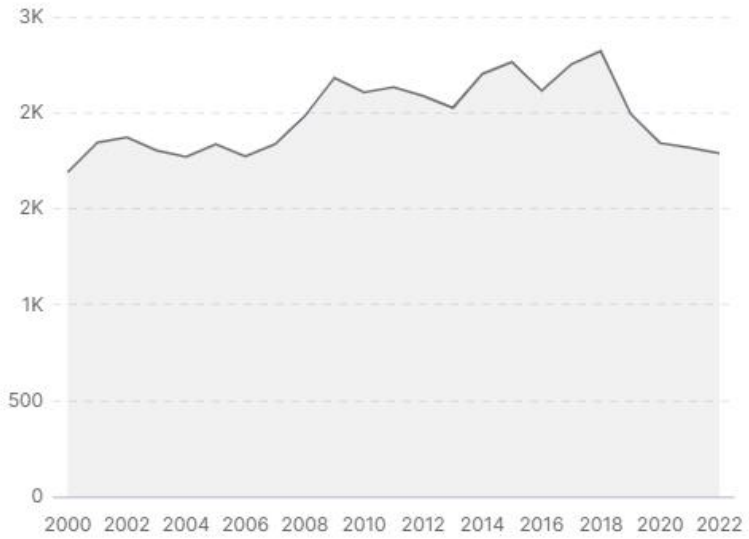
Perinatal Deaths

Latest (2022)	Rate (per 1000 births)
3,468	8.2



Neonatal Deaths

Latest (2022)	Rate (per 1000 live births)
1,789	4.2



issues during pregnancy and childbirth [maternal health conditions, obstetric complications, and fetal anomalies.]

issues that arise immediately after birth, [birth asphyxia, infections, and prematurity]

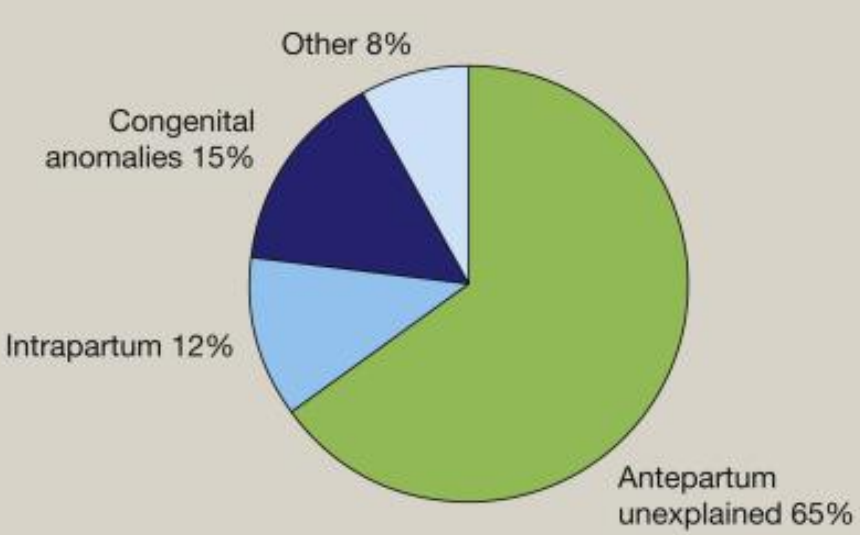
Obstetrics, Gynaecology & Reproductive Medicine
Volume 30, Issue 3, March 2020, Pages 65-71

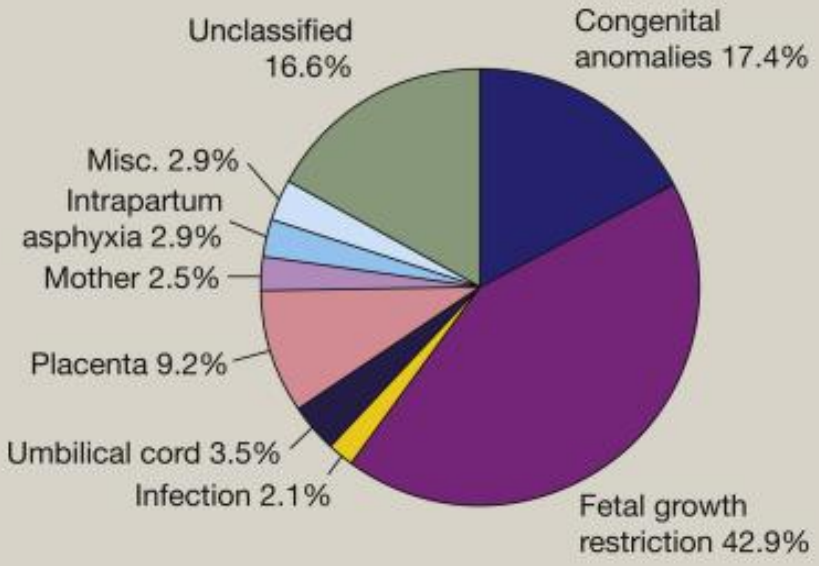
Review

Understanding perinatal mortality

Jess McMicking, Matias C Vieira, Dharmintra Pasupathy

Causes of stillbirth according to Wigglesworth (left) and ReCoDe (right) classifications





Obtained from Gardosi J, *et al.* Public Health. 2014;128(8):698–70

Causes of death in Malaysia

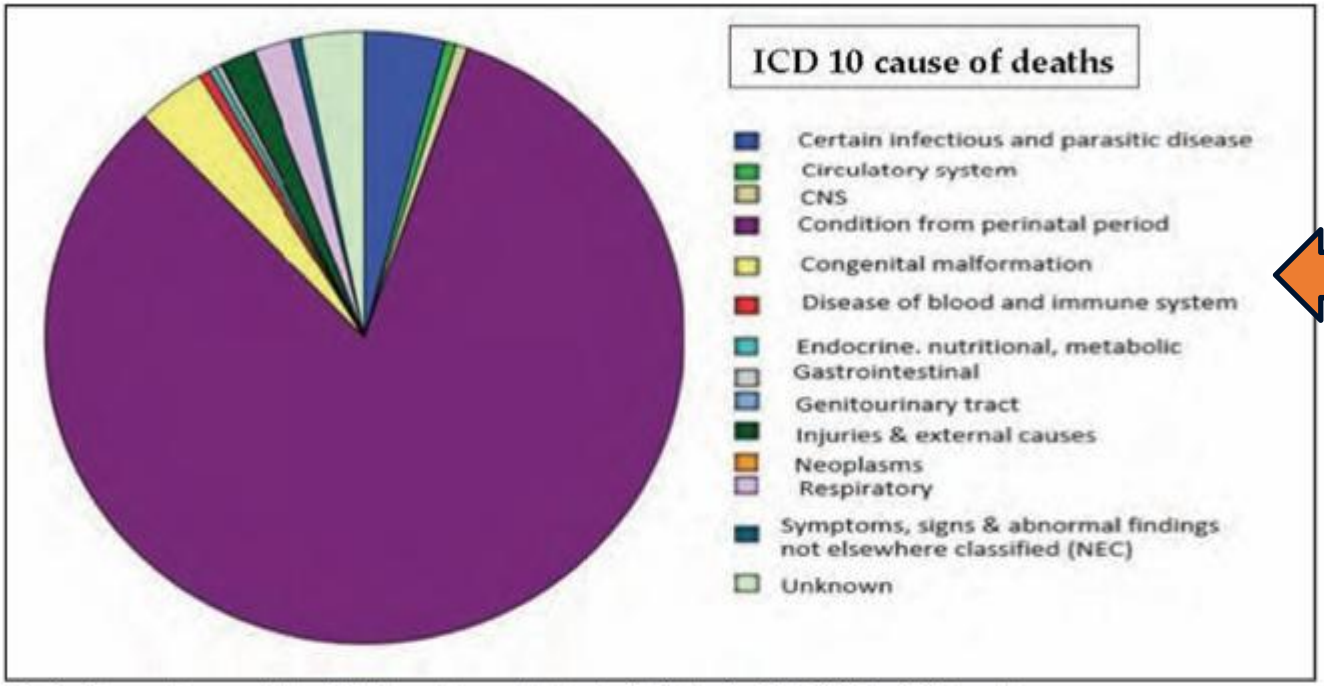


Fig. 1: Causes of preventable stillbirths and neonatal deaths in Malaysia, 2015–2017 (n=3242 cases)

Preventable stillbirths and neonatal deaths in Malaysia: An analysis of the under-five mortality surveillance data 2015–2017

Norain Ahmad, DrPH[1,2], Rosnah Sutan, PhD[1], Azmi Mohd Tamil, MPH[1], Rozita Ab Rahman, MPH[3]

Med J Malaysia Vol 78 No 1 January 2023

MALAYSIA

DOSM Report: Perinatal And Neonatal Mortality Rates In Malaysia Down By 9% And 2.9% Between 2020 And 2022

Definition (WHO)	**Perinatal deaths - foetal deaths of at least 28 weeks of gestation and/or 1,000g in weight and newborn deaths (up to and including the first seven days after birth)**	**Neonatal death - death after birth and within the first 28 days of life.**
Causes	Prematurity and low birth weight (21.6%) Syndrome (7.8%) Cardiovascular (7.3%) Others - premature birth, hydrocephalus, milk aspiration, and liver disease.	Prematurity (16.3%) Low birth weight (16.4%) Syndrome (7.4%) Cardiovascular 7.4% Others- premature birth, hydrocephalus, milk aspiration, liver disease, road accidents, tumours

Local study

International Medical Journal Vol. 15, No. 3, pp. 193 - 198 , July 2008

PEDIATRICS

A Five-Year Review of Perinatal Deaths at Pasir Mas District

Norsa'adah Bachok[1)], Norhayati Mohd Nor[2)], Tengku Norbanee Tengku Hamzah[1)], Wan Norlida Ibrahim[2)], Aziah Daud[2)]

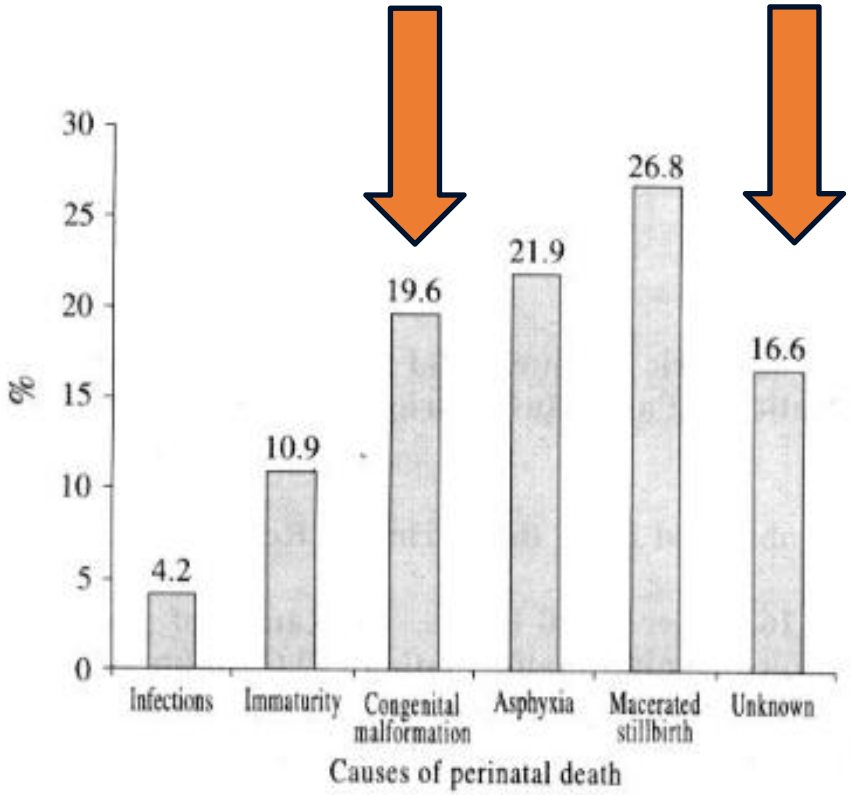


Figure 1. The causes of 265 perinatal deaths in Pasir Mas district in year 1999-2003

Definition: Perinatal vs Neonatal Palliative care

Perinatal PC

"Care strategy that comprises options for **obstetric and newborn care** that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy."

“Life-limiting” --> lethal fetal conditions

Care PP. ACOG committee opinion. Obstetrics Gynecol. 2019;134:e84-9.

Neonatal PC

"Palliative care for the **neonate 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, death and beyond."

It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the baby and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

ACT 2009.

Citation:
Wang Y, Shan C, Tian Y, Pu C and Zhu Z (2022) Bibliometric Analysis of Global Research on Perinatal Palliative Care. Front. Pediatr. 9:827507. doi: 10.3389/fped.2021.827507

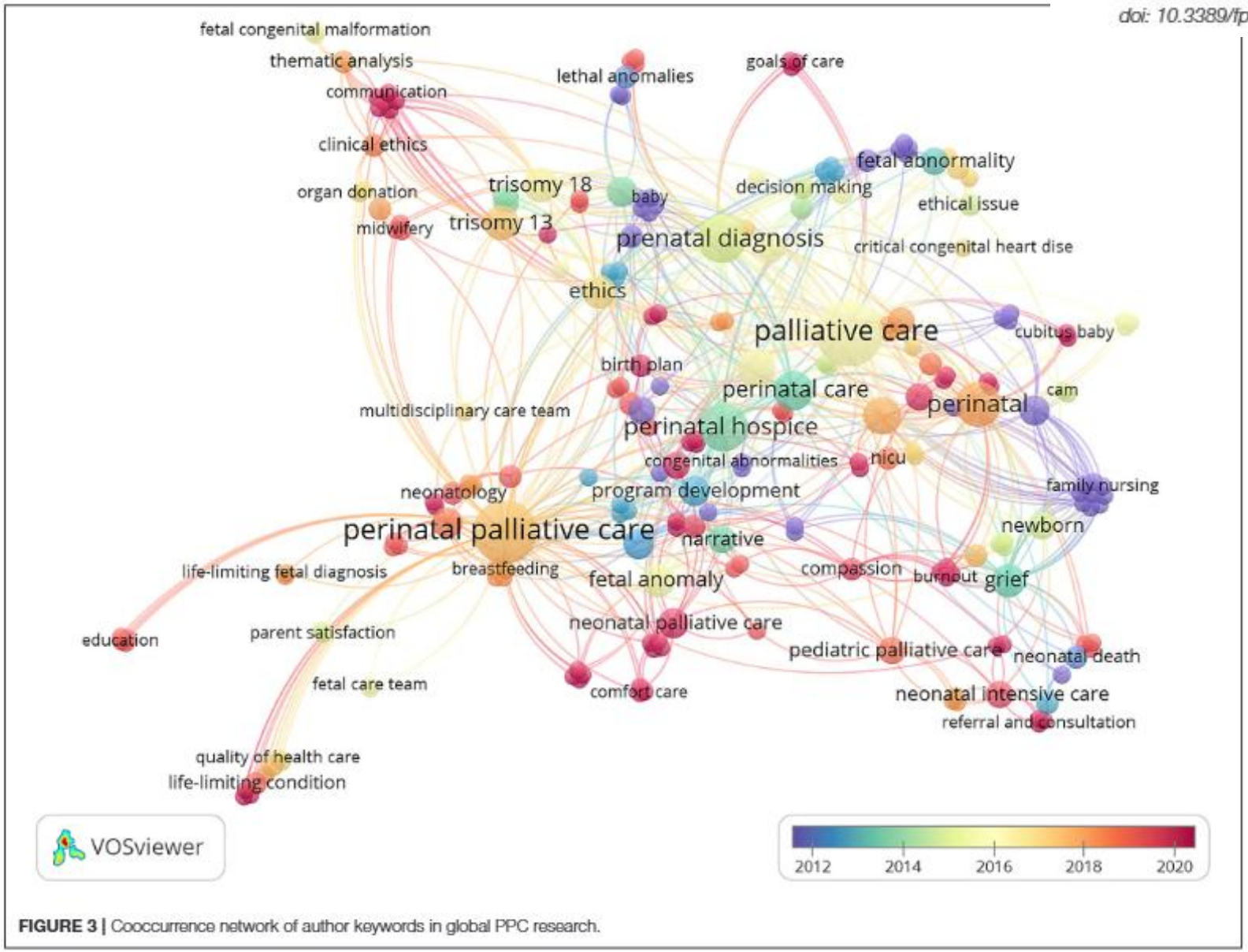


FIGURE 3 | Cooccurrence network of author keywords in global PPC research.

Findings

a) 159 referrals over 14 years
b) Diagnoses - cardiac (29%), Trisomy (28%)
c) 129 referrals had contact with the PPC team prior to birth and 60 had a personalised symptom management plan
d) Place of death - home (n = 10), hospice (n = 6) hospital (n = 72)

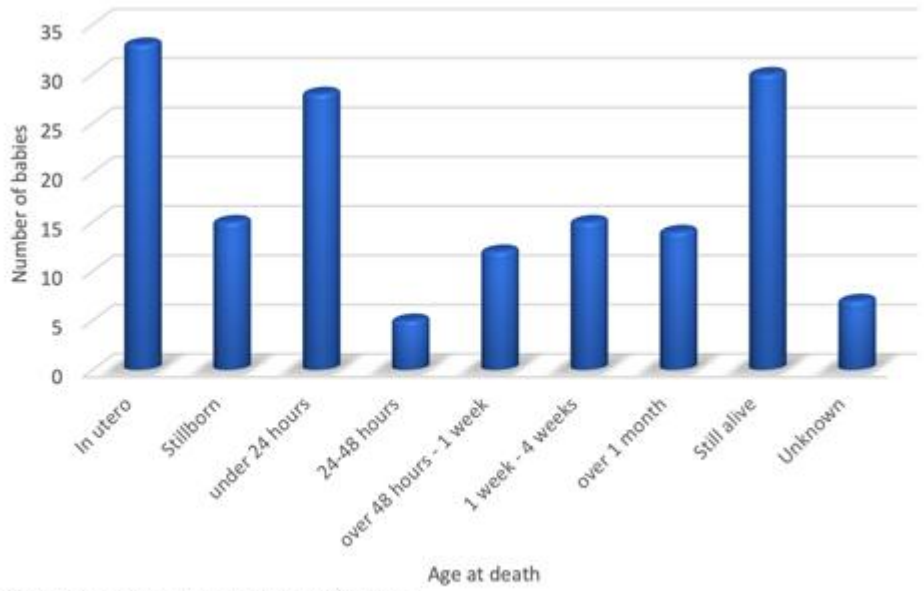


Fig. 2 Age at death for babies referred antenatally to the PPC team

Table 3 Characteristics of surviving children (at the time of the study) for babies referred antenatally to the PPC team

Diagnosis	Number of cases	Age or age range for children at the time of the study
HLHS	8	8 m to 8y 10 m
Holoprosencephaly	3	1y to 4y 6 m
Dandy-Walker malformation	3	11 m to 4y
Complex congenital heart disease	3	10 m to 1y 3 m
Tricuspid atresia with VSD	2	11 m to 1y 6 m
Trisomy 18	1	8y 2 m
Spina bifida	1	8y 1 m
Arthrogryposis	1	5y 3 m
Microcephaly	1	2y 4 m
Epstein's anomaly	1	2y 1 m
Unbalanced AVSD	1	1y 11 m
Hypoplastic right heart syndrome	1	1y 10 m
Suspected coarctation of the aorta, severe ventriculomegaly	1	1y 9 m
Pulmonary atresia	1	1y 1 m
Multiple congenital abnormalities including renal and gut issues	1	1y
Double inlet left ventricle	1	1y

HLHS Hypoplastic Left Heart Syndrome, *VSD* Ventricular Septal Defect, *AVSD* Atrioventricular Septal Defect, *y* years, *m* months

Specialist perinatal palliative care: a retrospective review of antenatal referrals to a children's palliative care service over 14 years

Sophie Bertaud[1,2*], Georgina Brightley[2], Nicola Crowley[3], Finella Craig[2] and Dominic Wilkinson[1]

Reference	Country	Study Design	Targeted Population	Aims/Research Questions	Outcomes and Effect Evaluation
Bolognani et al. [26]	Italy	Retrospective chart review	Perinatal	To describe the model build up to take care of fetuses and newborns eligible for perinatal palliative care	Facilitated decision making and consensus building, improvement of therapeutic alliance, better flow of information.
Callahan et al. [27]	US	Prospective cohort study of parents of neonates with congenital heart disease	Neonatal	To test the hypothesis that an innovative method of early palliative care reduces psychological distress in parents of neonates with congenital heart disease	The study demonstrated that early PC reduced parental stress. Parental depression and anxiety did not decrease with the intervention.
Jalowska et al. [28]	Poland	Retrospective chart review	Perinatal	To demonstrate the role of perinatal palliative care in case of severe developmental disorder in the fetus with a potentially lethal prognosis	All mothers in the perinatal hospice program wanted to see and hug their child. All families wanted to participate in memory making and many of them expressed the importance of these memories to the team.
Loyet et al. [29]	US	Survey after start of a fetal care team	Perinatal	Improvement in quality of care for women carrying a fetus with a suspected or known fetal anomaly	Patients receiving fetal perinatal palliative care were highly satisfied and felt that support was valuable. Enhanced patients' feelings of their knowledge of the condition or diagnosis of their fetus.
Parravicini et al. [18]	US	Prospective mixed method self-report survey	Neonatal	Assess the perception of parents concerning the state of comfort maintained in their infants affected by life-limiting conditions when treated by the neonatal comfort care program	Parents felt that their baby was comfortable and treated with respect, care and compassion by professionals. The environment was perceived as mostly peaceful, private and non-invasive.

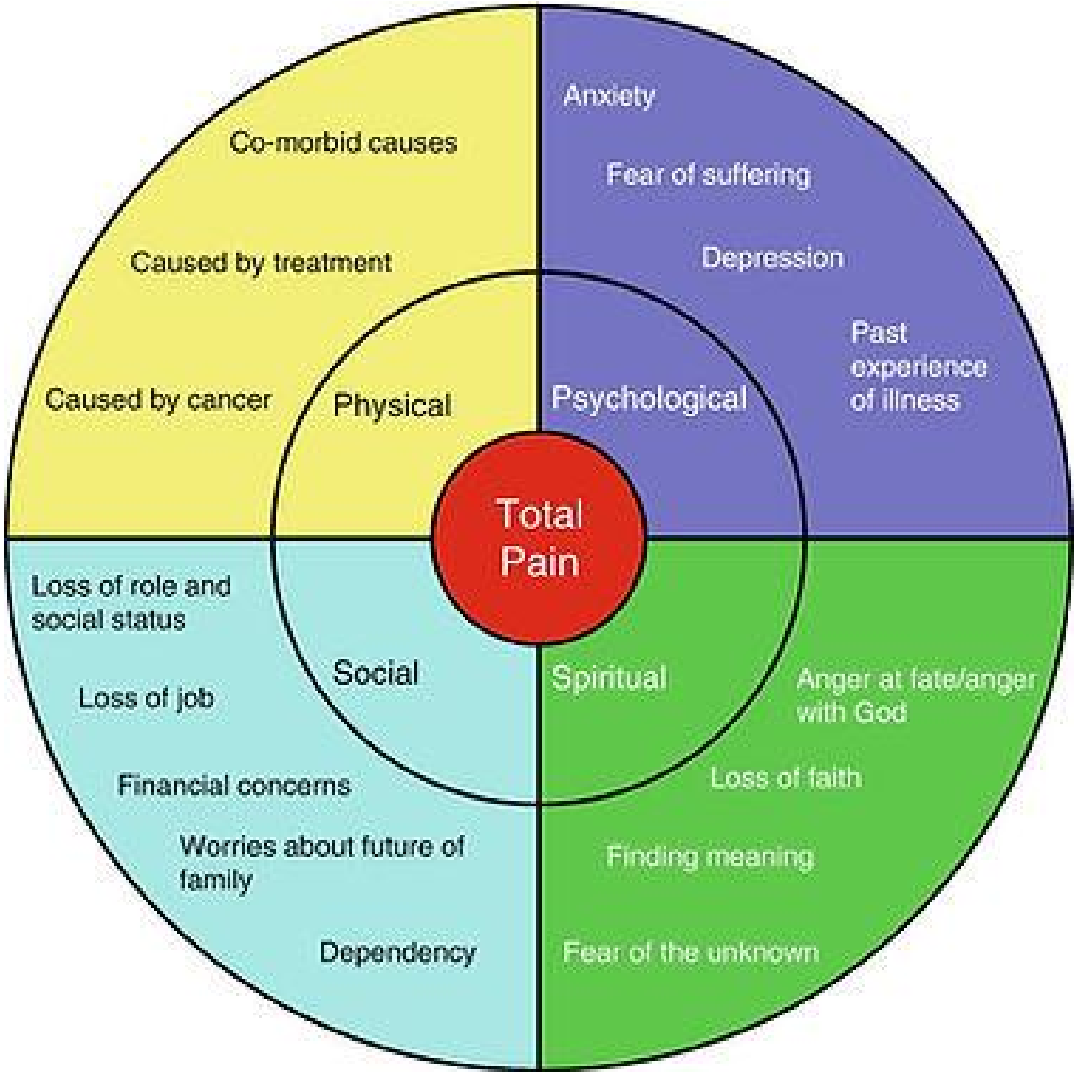
Systematic Review

Components of Perinatal Palliative Care: An Integrative Review

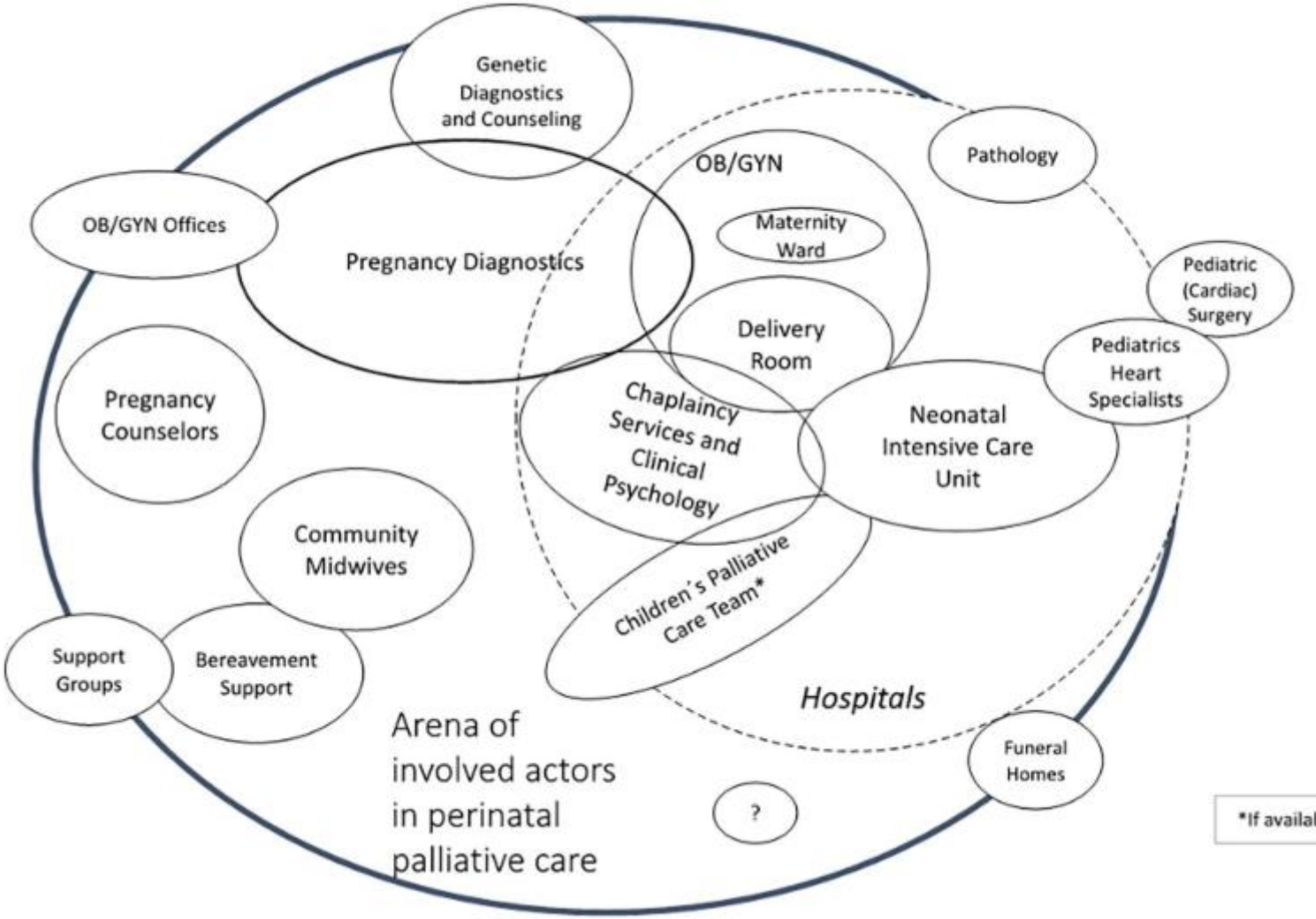
Laure Dombrecht [1,*], Kenneth Chambaere [1], Kim Beernaert [1], Ellen Roets [2], Mona De Vilder De Keyser [3], Gaëlle De Smet [3], Kristien Roelens [2,†] and Filip Cools [4,†]

5W

- Whole person
- Whole Family
- Whole process
- Whole team
- Whole community



Multidisciplinary team



Wiesner K, Hein K, Borasio GD, Führer M. "Collateral beauty." Experiences and needs of professionals caring for parents continuing pregnancy after a life-limiting prenatal diagnosis: A grounded theory study. *Palliative Medicine*. 2024;38(6):679-688. doi:10.1177/02692163241255509

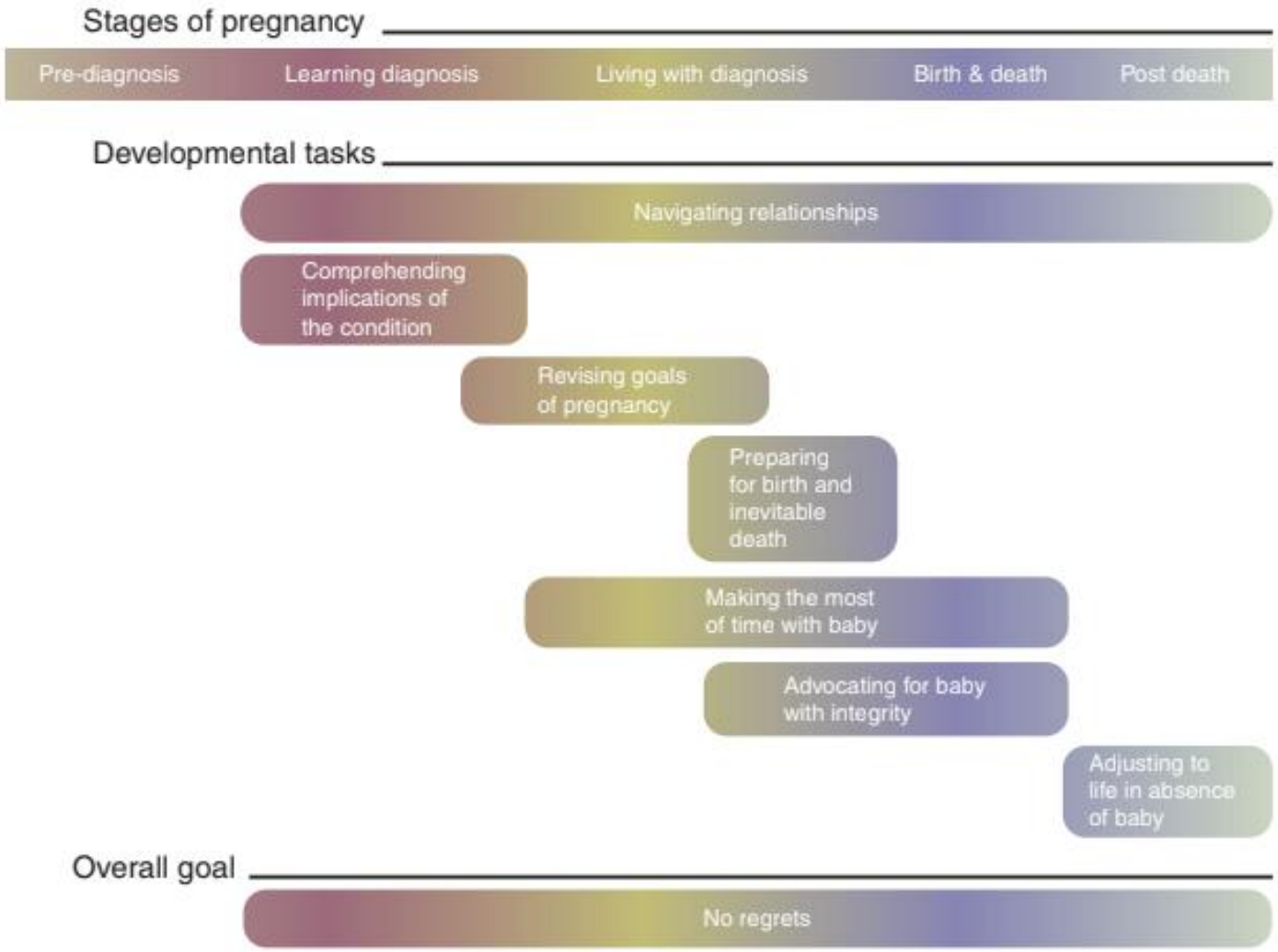
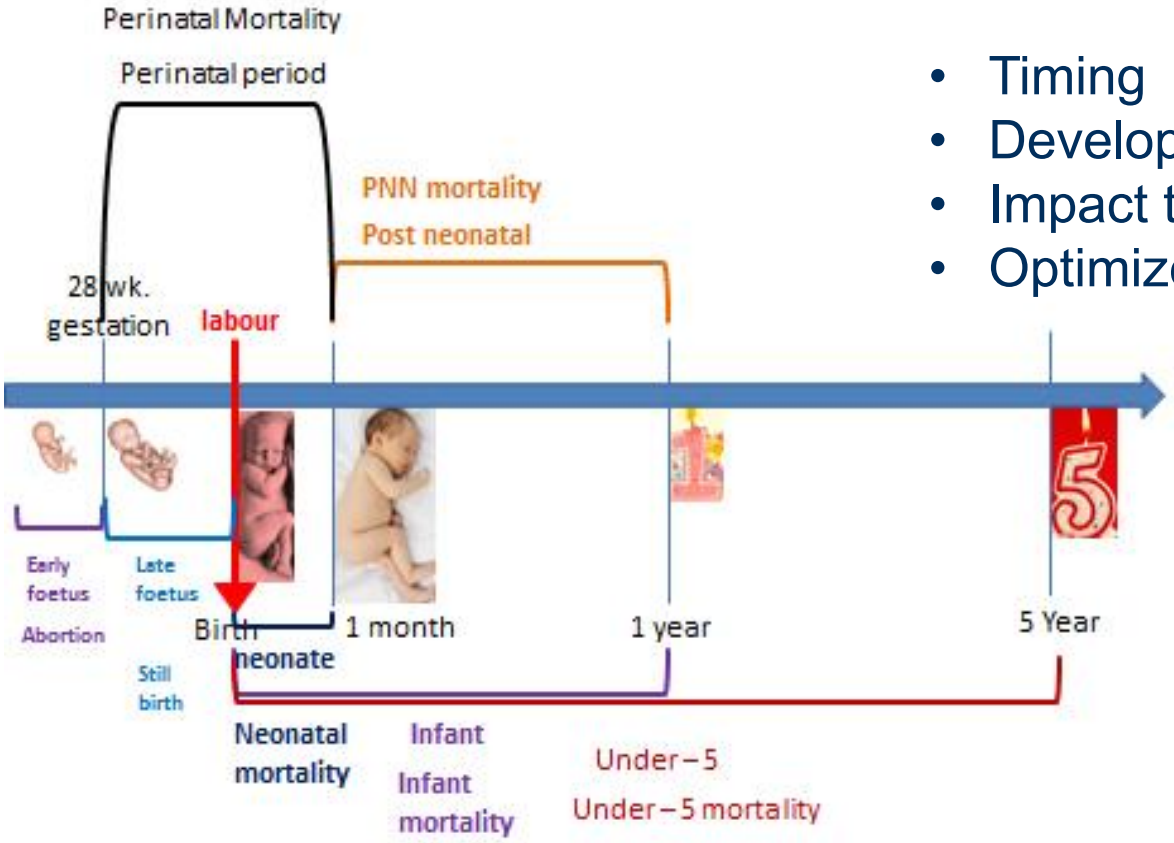


Fig. 2.3 Revised tasks of pregnancy with lethal fetal diagnosis [27]. (Reprinted from Côté-Arsenault and Denney-Koelsch [27], © 2016, with permission from Elsevier)

How does it differ from Paediatrics life limiting illnesses?



- Timing
- Developmental needs
- Impact to parents and family
- Optimize quality of life

Perinatal palliative care
Possible care components

Practical organization of a perinatal palliative care team
PPC team members
Training of staff members
Provide a place and/or circumstances for palliative care
Collaboration with hospice or home care services
Activation of the PPC team
Regular audit of the PPC approach
PPC protocol in place
Fundraising of the program
Organization of communication between the PPC team members/actors
Community awareness and involvement

Care components of the perinatal palliative care program
Child-directed care - Care of the child preceding death - Care of the child after death - Post-mortem medical procedures
Family-directed care - Family-centered care - Promote bonding and parenting - Family-centered psychosocial support - Practical support - Maternal care
Healthcare-provider directed care - Support for healthcare providers - Debriefings after death - Relieve PPC members of other tasks when caring for an infant in their final moments
Advance care planning - Care plan during the life of the fetus/child - Death plan - Regular revisions of the plan
Components regarding the decision-making process - Which information is shared? - Manner of sharing information - Shared decision-making - Conflict resolution
Care for externals - Care for other families at the ward

Citation: Dombrecht, L.; Chambaere, K.; Beernaert, K.; Roets, E.; De Vilder De Keyser, M.; De Smet, G.; Roelens, K.; Cools, F. Components of Perinatal Palliative Care: An Integrative Review. *Children* **2023**, *10*, 482. https://doi.org/10.3390/children10030482

Perinatal versus Neonatal

- Formal perinatal consultation for diagnosis
- Birth Plan (shared decision)
- Access to neonatal and paediatric palliative care
- Support through antenatal, intra-partum and postnatal/bereavement
- Prepare families for all the possibilities before and after delivery

ACOG Opinion. Obst Gynae 2019

- Eligibility for palliative care
- Family care
- Communication and documentation
- Flexible parallel care planning
- Pre-birth care
- Transition to supportive care
- End of life care
- Post end of life care

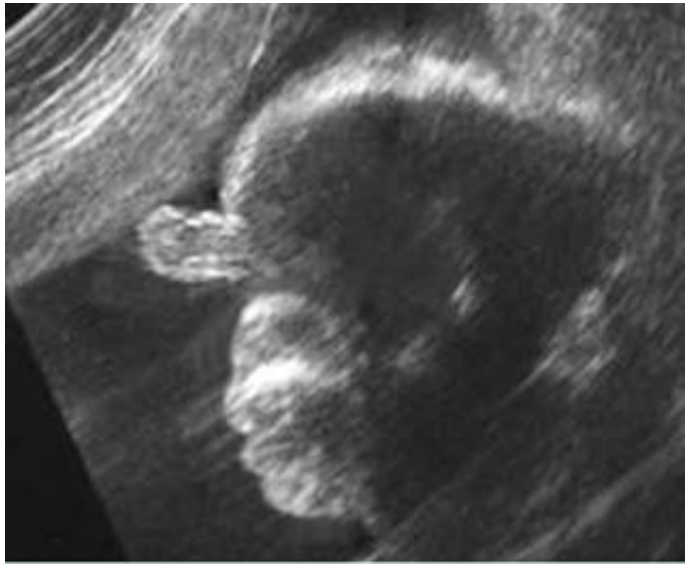
Neonatal Palliative Care Guideline. University of Southampton

Establish eligibility

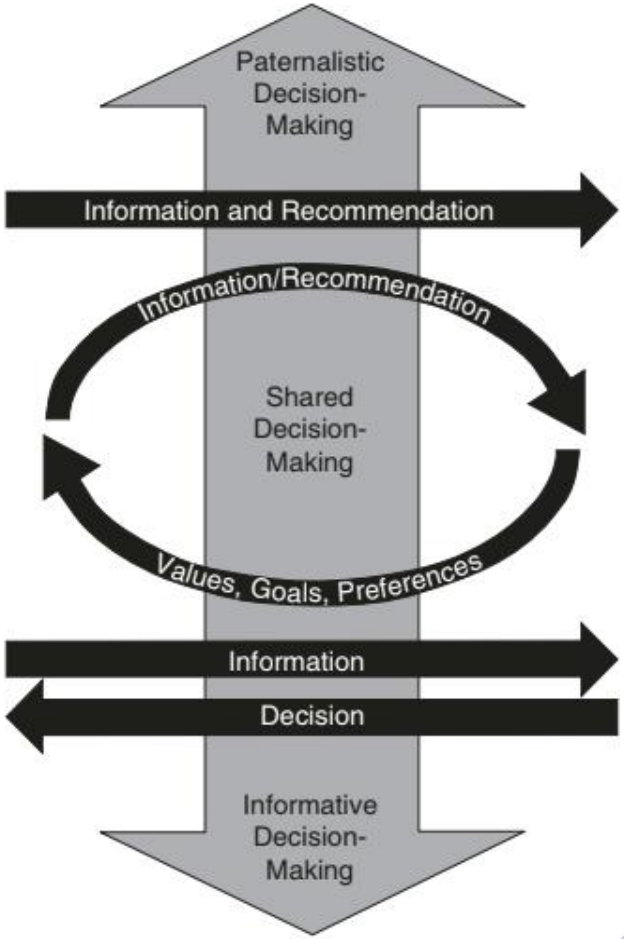
Which babies?

Severe reduction in the future quality and quantity of their life, that life sustaining treatment would not be in their best interest.

A. Antenatal diagnosis of severe congenital abnormality.
B. Extreme prematurity.
C. Post natal illness or complications. The prognosis should be agreed by at least two senior clinicians.



Communication --> Shared decision making



Documentation

- If alive?
- Advance care plan

Family

- Psychological
- Spiritual
- Social

Flexible Parallel Planning

- care planning is continuously reviewed in the best interests

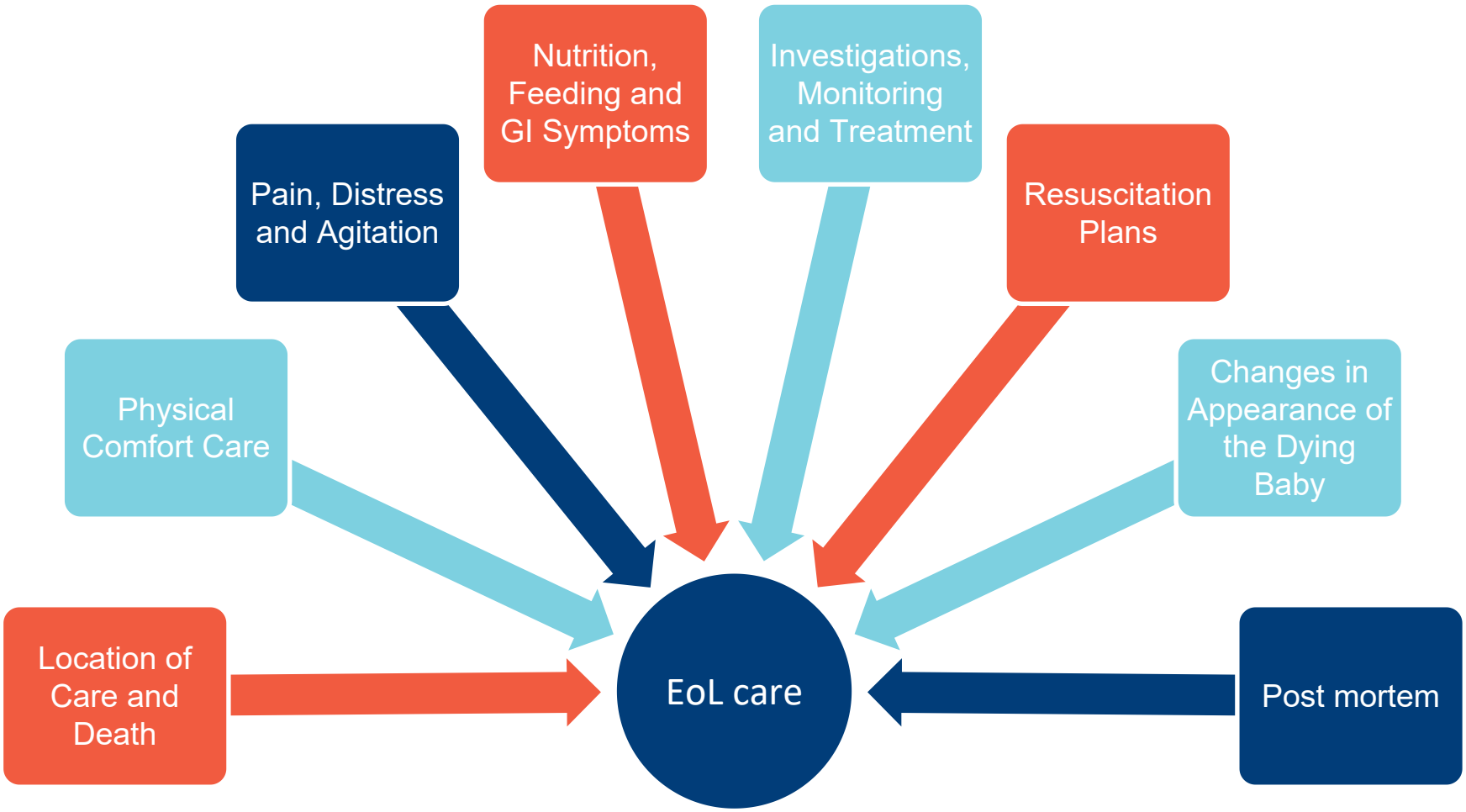
Pre-birth Care

- palliative care plan for the baby with the family
- approach and limitations to resuscitation at birth
- location of ongoing care

Transition to supportive care

- rapid assessment
- specific tests

End of life Care



Post End of Life Care

- Certification and Registering of Death
- Funerals
- Bereavement

Challenges

Medical indications

Principles of beneficence and nonmaleficence

- How is the problem classified: acute/chronic, reversible/irreversible, emergent/nonemergent
- What is the goal of treatment?
- What is the probability of different outcomes
- based on the proposed treatments?

Parent or guardian preferences

Principle of respect for 'parental' authority

- Is the surrogate capable and legally responsible for making decisions for the patient?
- What are the family's medical values? How do they make complex decisions?

Quality of life

Principles of beneficence, nonmaleficence, best-interests

- What are the short term burdens of therapy? Can these burdens be lessened?
- What is the expected long-term outcomes for the patient? Would parents consider a likely outcome an acceptable quality of life?
- Are there any biases or experiences that may influence clinicians, parents or guardians?
- Should a comfort-directed plan be presented as an alternative to disease-directed therapy?

Contextual features

Principles of justice and fairness

- Are there religious or cultural implications to a decision regarding therapy?
- How will a treatment decision impact other family members?
- Is a decision by a family due to financial concerns?
- Are there scarce medical resources which will be unfairly allocated by a decision?
- Are there professional, inter-professional, research, metric-reporting or business conflicts of interest?

Treating an intervention level 1 patient: futile or brave?

Solomons N, MSc, Department of Dietetics, University of the Western Cape
Nortje N, DPhil, Department of Psychology, University of the Free State
Correspondence to: Nico Nortje, e-mail: Nortjen1@ufs.ac.za

Challenges

- Late referral - manage by single team
- Disagreement in care – what is 'best' at that time?
- Ceiling of care?
- Short time to know the patients and families
- Nutrition & feeding
- prognostication
- Investigation & monitoring
- post-mortem
- resus preferences - termination
- memory making...

Appendix A

Pathway 1: Recognition of Poor Prognosis

BEREAVEMENT SUPPORT

Consultation/Parental Concern

Antenatal Scans

Scans

Assessment of Baby

Newborn Examination

Birth

Critical Event

Diagnosis of Poor Outcome

Transfer to NICU Not Appropriate

Place/People
Information
Interpreters
Emotional Support

Breaking Bad News

'ACT' First Standard
Every family should receive the disclosure of their baby's prognosis in a face-to-face discussion, in private and should be treated with respect, honesty and sensitivity. Information should be provided for the family using language they can understand.

FAMILY ROOM
Go to 'Withdrawal of Treatment' Pathway

Involve Parents in Withdrawal of Treatment Options and Plan for Transfer

HOME
Go to 'Transfer to Home for End of Life Care' Pathway

REPATRIATION to Local Unit

Hospice

Move to 'Withdrawal of Care' Pathway

'ACT' Second Standard
Every baby and family should have an agreed transfer plan involving family of carers, hospitals, community and hospice services (if appropriate). The family should be provided with the resources they need.

Pathway 2: Withdrawal of Active Treatment

BEREAVEMENT SUPPORT

PALLIATIVE CARE

'Recognition of Poor Prognosis' Pathway Completed

'ACT' Third Standard
Every family should receive an assessment of their needs as soon as possible after the life limiting/life threatening diagnosis has been made. They should have their needs reviewed at regular intervals.

Discuss with the family their needs and wishes

Commence advanced care plan

Discuss resuscitation status

Spiritual

Physical

Emotional

If appropriate, discussion around the need/desirability of Post Mortem Examination/ organ donation

Plan the care for the baby with the family

'ACT' Fourth Standard
Every family should have a care plan agreed with them to coordinate care and support their needs. A key worker should be identified and agreed with the family.

Family
- Emotional
- Physical
- Financial
- Informed Choice
- Interpreters
- Spiritual Needs
- P/N Care of Mother
- Bereavement Care

Environment
- Place of care
- Time
- Privacy
- Support
- Create memories
- Ceremonies
- Family & friends

Baby
- Physical care needs
- Symptom and pain control
- Spiritual needs

'Advanced Care Plan'

Transfer to Home/Hospice

'End of Life Care' (Pathway 4)

Adapted from: UHS 'Neonatal Palliative (Supportive and End of Life) Care Guideline' 2011 and ACT 'a neonatal Pathway for babies with Palliative Care

Pathway 3: Transfer to Home/Hospice for End of Life Care

BEREAVEMENT SUPPORT

'ACT' Standard
Every baby and family should have an agreed transfer plan involving the family, carers, hospital, community and hospice service if appropriate. The family should be provided with the resources they require before leaving hospital.

Completed Pathways 1 & 2 *'Recognition of Poor Prognosis' & 'Withdrawal of Treatment'*

'ACT' Standard
Every family should have an agreed multi-agency care plan for the delivery of coordinated care and support to meet their individual needs. A key worker to assist with this should be identified and agreed with the family.

Planning for Home/Hospice

Family
- Team Meeting
- Care choices
- Support in caring
- Training
- Sibling well being
- Family functioning
- Postnatal care of mother
- Equipment
- Plan for resuscitation (ACP)
- Emergency contact numbers for support team
- Emotional support
- Interpreters
- Financial/Benefits
- Meet with the team who will be caring for them in the community if possible

Baby
- Symptom control
- Equipment
- Baby Care needs
- Medication

Environment
- Family
- Liaison b/n health care professionals (i.e. GP, HV, CCN, NNU, Outreach Sister)
- Social Services
- Midwifery Team, Home visit by multiple agency team
- Funeral directors

Advanced Care Plan

- Identification of lead consultant
- 24 Hour contingency plans documented & liaised
- Drug dosages, how these are obtained and by whom
- Documented and agreed ACP
- Support for family
- Contact details
- Transport arrangements
- Parallel planning: Feeding, O2, nasogastric tube, suction, monitoring

Access to:
- Training
- Psychological support
- Spiritual needs
- Pharmacy needs
- Equipment supplies
- Access to team
- Weekend & night time plan
- Advice for after death

- Baby Care needs
- Nursing supplies
- Therapies

'End of Life Care' (Pathway 4)

PALLIATIVE CARE

Adapted from: UHS *'Neonatal Palliative (Supportive and End of Life) Care Guideline'* 2011 and ACT *'a neonatal Pathway for babies with Palliative Care*

Pathway 4: End of Life Care

BEREAVEMENT SUPPORT

Completed Pathways 2 & 3 *'Withdrawal of Treatment' & 'Transfer to Home/Hospice for End of Life Care'*

'ACT' Fifth Standard
Every family should be helped to prepare an end of life plan for their baby and should be provided with care and support to achieve this.

Family
- Communication
- Time
- What to expect when baby is dying, colour, breathing, etc.
- Informed choices about spending time with their baby
- Contact details of professionals
- Liaise with the referring unit if applicable
- Spiritual and emotional support
- Practical arrangements (including registration of birth/death & transport)
- Cultural and Religious needs
- Funeral planning
- P/N Care for mother
- Care of the extended family
- Creating memories (involve the family in this)

Baby
- Symptom control
- Pain Control
- Dignity
- Time with family
- Spiritual needs

Environment
- Place of death
- Transfer arrangements
- Ambience
- Place after death
- Nursing and medical documentation
- Multidisciplinary communication throughout (GP, Health Visitor, Mortuary, Chaplaincy, Porters, Funeral Directors, Wards, etc)
- Use of cold room at local hospice
- Transport

Continued Bereavement Support (after death)

At Home
- Practical advice on how to contact the Funeral Director
- Length of time to keep baby at home
- Community Teams (GP, HV, MW, CCN)
- Support Groups

Funeral
- Burial or cremation
- Private or Hospital
- Ensure correct documentation completed

If required, gain Post Mortem /organ donation consent at appropriate time in an appropriate place.

Follow Up Support
- Continued emotional support
- Refer as appropriate, i.e. counselling or support groups
- Practical advice
- Information for extended family & siblings
- Follow up arrangements, appointments with consultant

PALLIATIVE CARE

Adapted from: UHS *'Neonatal Palliative (Supportive and End of Life) Care Guideline'* 2011 and ACT *'a neonatal Pathway for babies with Palliative Care*

History

36 y old - polyhydramnios & IUGR twin
USS – DCDA with microcephaly, holoprosencephaly, proboscis feature
Suspicion of Patau twin
Consanguineous parents
Maternal hx - abortion 4 times & 1 term with Patau syndrome (cyclops)
Mother presented with pre-eclampsia at 35 week

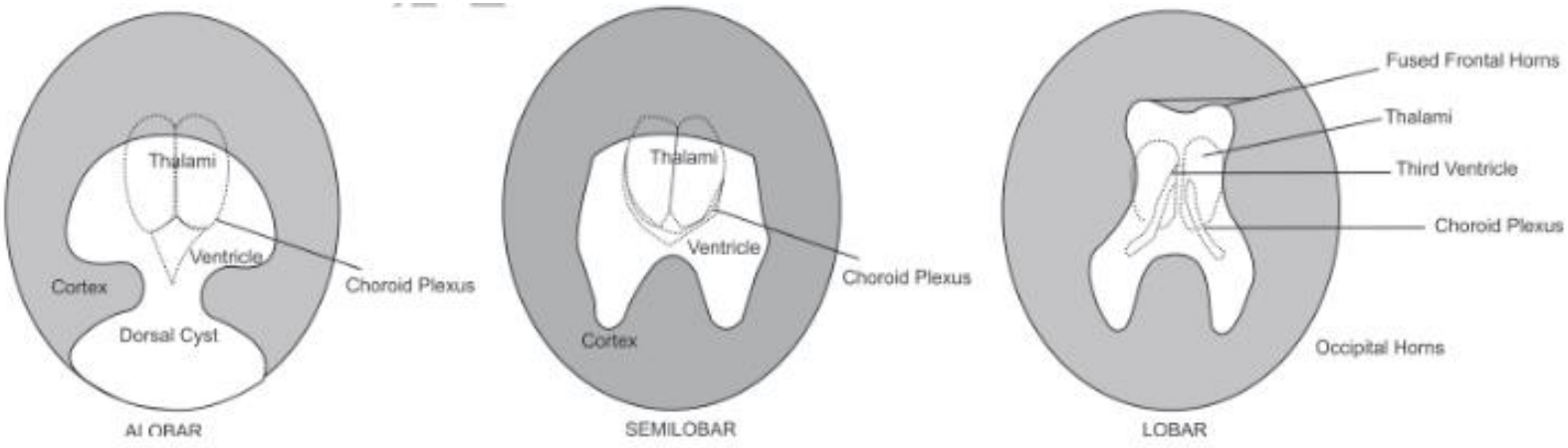


Fig 1: Types of holoprosencephaly

Meeting with obstetrician

Guarded prognosis , poor survival

Referred to PPC

Information about Patau syndrome

Birth planning --> LSCS due to one twin in transverse lie

Place of care ---> Hospital

Resus - Unlikely to pursue if gross congenital abnormality

Allow natural process

During delivery

LSCS

No resus initiated

Allow father to come in

Offer genetic test for recurrent Patau

Discuss on burial process & rituals

Follow up in clinic for bereavement

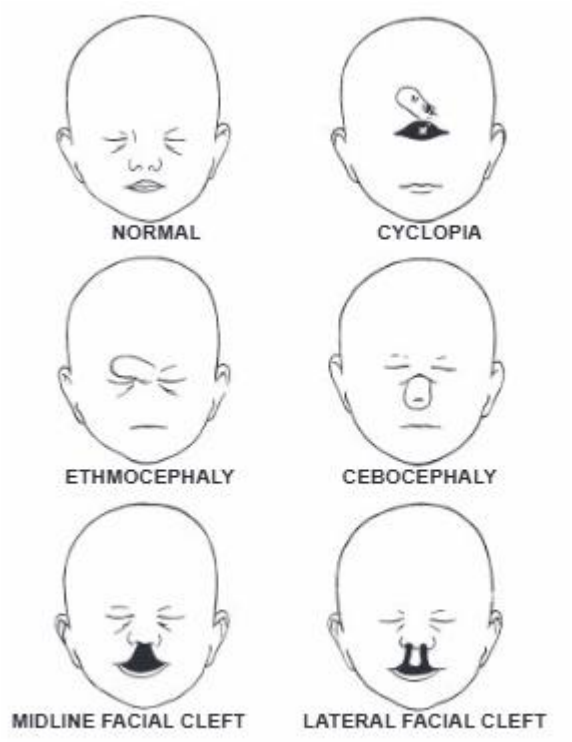


Fig 3: Different malformations seen with holoprosencephaly

Cases at a single centre

- Patau syndrome
- Edward syndrome
- Encephalocele
- Dilated cardiomyopathy
- Hartsfield syndrome [Holoprosencephaly with limb deformity]
- Arthrogryposis with renal dysfunction and cholestasis syndrome
- Hypoplastic left heart syndrome
- Goldenhaar syndrome with semi lobar holoprosencephaly
- Infantile leukaemia ...

Mostly neonatal!
Mostly syndromic and congenital anomalies...

5. Conclusion

- Principles – holistic, family centred
- Multidisciplinary team involvement
- Help for informed decision making

fahisham@gmail.com

Thank you