Anticipatory Grief

Shirley Potts
North Development Lead
Perinatal Mortality Surveillance Report at the Royal College of Obstetricians and Gynaecologists

Understanding babies’ deaths in the UK: 2014

Out of over 780,000 births in 2014...

- 5,623 registered deaths of babies before, during, or within the first 4 weeks of birth
- 4,633 deaths of babies born from 4 weeks of pregnancy
- 3,252 stillbirths
- 1,381 neonatal deaths
- 6 deaths for every 1,000 births

What do we know about why babies die?

Causes of stillbirth:

- 4% not reported
- 4% unknown causes
- 4% maternal health
- 5% complications before labour
- 6% complications during labour
- 6% congenital anomalies
- 46% unknown cause
- 22% placental problems

Causes of neonatal death:

- complications after birth 31%
- congenital anomalies 28%
- 13% born extremely early
- 7% infections
- 5% complications before labour
- 5% complications during labour
- 5% unknown causes
- 4% not reported
- 2% placental problems

How do rates vary across the UK?

Local mortality rates varied across the UK even after taking into account differences in poverty, ethnicity and the age of the mother.

They ranged from 4.9 to 7.1 per 1,000 births

When do babies die?

1 in 3 die at term, when the baby has reached 37 weeks’ gestation
1 in 4 die before 28 weeks’ gestation

What can we do to reduce the number of babies who die?

- Carry out local reviews of every death using a standardised process to identify local factors which may be responsible
- Establish aspirational UK targets for rates of stillbirth and neonatal deaths
- Offer a post-mortem to every family when their baby dies

© 2016 The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester
Crude extended perinatal mortality rates

- Rate suppressed due to small numbers
- Lower than the 'aspirational' target
- More than 10% lower than the UK average
- Up to 10% lower than the UK average
- Up to 10% higher than the UK average
- More than 10% higher than the UK average

The size of the symbol is proportionate to the number of births.
overview

- What is anticipatory grief?

- Theories pre and post-bereavement

- Talking about death to children

- Attending to meanings
“Are we nearly there yet?”

“Where does the end begin?”
Anticipatory Grief: The impact starts from diagnosis

Bereavement

“The overall experience of family members and friends in anticipating the death of a loved one, and in living through and adjusting to life beyond that death.”

Parkes, 2001
Fewer than half reported being at peace with themselves and their situation in life.

Parents of newly diagnosed children reported more severe anticipatory grief responses than those 6–12 months after diagnosis.

No statistical difference between mothers and fathers.

Rando acknowledges that the term *anticipatory grief* is a misnomer. She prefers *anticipatory mourning*. This is a critical distinction.

Fulton’s concern was that the term was easily misused.

“...assumption that the acknowledgement and processing of the grief prior to the loss would mitigate grief experienced after the death.”

*(in Doka: 2013)*
the dying child

the terminally ill child is reported to grieve loss of function and future, and to worry about being forgotten, experiencing pain, and leaving family members behind in sorrow.

Hinds et al (2005)
The Dual Process Model of Coping with Bereavement


Death Studies 23, 197-224
Potts, S. (2005)
*Everylife*
Salisbury, APS publishing
When a sibling is dying

- Appropriate time to explain to children and young people.....
- Openness and honesty fosters trust and security, and allays isolation, anxieties and fear. Secrecy promotes the opposite...
- ... and the child has no opportunity to share or express feelings of fear, anger, sadness.... or curiosity
- Children are often more aware of someone’s health status than adults realise
Information Sheets

- When a sibling is not expected to live: Supporting children
- Building resilience in bereaved children
- Children's understanding of death at different ages
- Explaining to young children that someone has died
- Explaining funerals to children
Child Bereavement UK supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement. Our vision is for all families to have the support they need to rebuild their lives.

Support & Information
0800 02 888 40

See how we can help
attend

- to be present at
- to go with as a concomitant or result; accompany
- to take care of; minister to.
- to look after; guard
- to listen to; give heed to
- to wait for; expect
- to apply oneself
- to pay attention; listen or watch alertly
- to be present
helping to ‘normalise’ grief responses

Physical
- Grief can be painful
- Palpitations, shortness of breath
- Flu-like feelings
- Lowered immunity
- Appetite and sleep changes
- Stress headaches/chest pains
- Exhaustion
Emotional

- Distress
- Relief
- Anger
- Longing
- Crying
- Laughing
- Isolated
- Misunderstood
Cognitive

- Lack of concentration
- Forgetfulness
- Fear of forgetting
- Unmotivated
- Resentful
- Seeking/needling information
Spiritual

- Challenge to faith (child-like faith?)
- Renewed faith
- Anger
- Peace
- ‘Continuing Bonds’
- Hope...... changes
.....a bereaved Mum speaks
References


Potts, S. (2005) *Everylife* APS. Swindon

https://www.npeu.ox.ac.uk/mbrrace-uk/reports

www.childbereavementuk.org