Multiple Grief in NICU

A presentation by
Ian Woodroffe

Psychological Therapist in NICU at Addenbrooke’s Hospital
Cambridge University Hospitals NHS Foundation Trust England
Accredited BACP Therapist, Supervisor and Trainer
Honouring the Parents

- At the start of this presentation I wish to honour all the parent’s who have shared there painful learning to inform us.
Learning Objectives

At the end of this presentation participants will have hopefully:

- Reflected on the Psychological World of NICU parents.
- Revisited learning on the body/mind relationship for physical and psychological well being.
- Considered multiple losses, affect and behaviour.
- Made a constructive link between grief theory and NICU practice.
- Have been introduced to the concept of the Journey Box, its rational and effectiveness.
A recognition that emotional well being is linked to physical well being.

‘Mind and body are inextricably linked, and their second-by-second inter-action exerts a profound influence upon health and illness, life and death. Attitudes, beliefs, and emotional states ranging from love and compassion to fear and anger can trigger chain reactions that affect blood chemistry, heart rate and the activity of every cell and organ system in the body—from the stomach and gastrointestinal tract to the immune system.

All of that is now indisputable fact’

*Kenneth R Pelletier, PhD MD Stanford Cancer for Research in Disease Prevention at the Stanford University School of Medicine*
Your assumptive world

You live with the assumption that your world is safe and secure.

If you did not live that way you would not have got out of bed this morning and you certainly would not travel on the freeways.

If your assumptive world is shattered then we can predict that you will have a psychological reaction to that experience. The result of that reaction will mean that your world will no longer be safe and secure and it may take a long time before it restores.
Assumptive world

If your world is shattered too violently then it is predictable that you will never recover to an extent that your world is restored.

What we do know is that a NICU incident demonstrates a shattering of the assumptive world of the parents.

Sometimes that shattering has occurred within a very short period of time.

So we need to be aware of the pre-pregnancy journey and the birth experience and put those into our understanding around shattered assumptive worlds and the effect on parents.
Loss, grief in the context of NICU

- We may wish to suggest that what we know in the adult world is also applicable to the preterm. Certainly the work of Brazelton et.al. would suggest this-noise levels etc. Contact with parents-transmission of mood and anxiety.

- ‘Parents and babies affect one another’s moods and physiology, such as when skin to skin care releases their oxytocins and slows their heartbeat and respiration in a relationship that is social and emotional as well as embodied’ (Goldson 1999; Mattiesen et al. 2001)
Responses to loss

- There are known behavioural and physical symptoms in responding to loss.

- Separation anxiety is well documented.

- ‘It is estimated that, in the UK alone, traumatic births may result in 10,000 women a year developing Post Traumatic Stress Disorder (PTSD).

- Also as many as 200,000 more women may feel traumatised by childbirth and develop some of the symptoms of PTSD.’ Birth trauma association.
Emotion effect behaviours

- The evidence would suggest that emotional upset may effect behaviours
- Eating, drinking and smoking
- And body functions- sickness, breathing, blood pressure, hair loss, periods stopping, skin conditions etc.
Multiple Grief in NICU

I make the assumption that we are all of one mind about the well evidenced fact that our physical and mental well being are inter-dependent and that the mind body link is a well established fact that underpins the work that we do.

I also start from the foundation of knowledge that we need to know about our ‘Assumptive World’ and the effect of a shattered assumptive world.
Losses at the start of the journey

- The pregnancy journey may contain many significant losses, all of which need to be processed.
Losses around premature birth

- There is evidence that many parents suffer from multiple losses after the birth of a premature baby and before the baby arrives on the unit:
  - Dreams of how the birth would be.
  - The rest of the pregnancy
  - Control
  - Confidence
Losses cont.

- Preparation/excitement and expectation
- Bonding and touch—possible separation through baby coming to the unit or in the transfer from another hospital and parents following.
- Attention as a pregnant mother
- Possibly the ability to feed
Describing the experience

• Terrifying
• Unreal
• Lonely
• Guilty
• Nightmare

• Hell on earth
• Devastating
• Scary
• Unattached
Feelings of the experience

- Anger
- Helplessness
- Guilt
- Resentment
- Fear
- Numbness
- Isolation
- Fragility

- Frustration
- Panic
- Despair
- Confusion
- Disorientation
- Exhaustion
- Worry
Feelings

- Excitement
- Hope
- Pride
- Thankfulness
Behaviours

- Withdrawal
- Tearful
- Angry with staff partner (God if faith system)
- Defensive
- Resigned numbness

- Needing Knowledge
- Needing control
- Demanding
- Thankful
- In awe
- Supportive of other parents
In addition to other life losses

- We are probably unaware of other losses that have happened to the parents that may be triggered by the current experience of loss.
Death of a twin
Multiple Grief experience

- Multiple Grief symptoms and possible grief overload
Grief Theory- William Worden

- To accept the reality of the loss
- To work through the pain of grief
- To adjust to an environment in which the deceased is missing
- To emotionally relocate the deceased and move on with life

J. William Worden     Grief Counselling and Grief Therapy     2001
Normal grief-feelings

Normal grief.

Feelings:

Sadness        Helplessness
Anger          Shock
Guilt          Yearning
Anxiety        Loneliness
Fatigue        Numbness

Relief
Dual process model

**Loss Orientated**
- Grief work
- Intrusion of grief
- Breaking bonds/ties
- Denial/avoidance of restoration changes

**Restoration Orientated**
- Attending to life changes
- Doing new things
- Distraction from grief
- Denial/avoidance of grief
- New roles/identity
- New relationship

*Stroebe and Schut 1995*
Continuing Bonds


- Continuing Bonds is about recognising that death might end life but does not end the relationship.

- Memorialising and remembering the person who has died and allowing the deceased person to influence our present lives are active and observable processes within the bereaved that are ongoing and revisited throughout their lives.
Continuing Bonds

- This is not about living in the past but rather about recognising how bonds formed in the past can influence our present and future.

- The resolution of grief is less about closure and more about accommodation of the loss into one’s life and the capacity to become fully future orientated.

- Bereavement support work should on this basis seek to assist the bereaved to express the reality of their inner world and to validate that reality as part of an acceptable progression through grief.
Grief theory to make sense in NICU

So how do we identify grief theory with NICU experiences?
Worden’s first task – Accepting the reality
Worden’s second task –

Stroebe Dual Process Model
Different behaviour responses of Mothers and Fathers. Loss/Restoration.

How do Fathers express their inner world? Some emerging evidence that it might be a year before feelings are allowed to surface.
The concept of the ‘Journey Box’

The container of ‘significant Objects’ to enable memory recall out of the mists of trauma.
If the baby dies then the box becomes a ‘Memory Box’ which aids the Continuing Bonds concept of grieving.
Journey Box

• Journey Box picture
If there was more time......

Post Death Support

Bonding Issues

Subsequent pregnancies

There is the whole issue about sibling expression of multiple grief.

There is the issue about other life losses whilst on NICU.
References

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- www.birthtraumaassociation.org.uk
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- Bowlby Attachment and Loss(1980) p100


Contact Details

• Ian Woodroffe
  • Email-ian@goldtraining.co.uk
  • www.goldtraining.co.uk
  • Tel/Fax +441223 813122

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