

Perinatal Loss & Working with Complex Bereavement


Dr Sarah Finnis
Consultant Clinical Psychologist
Obstetrics and Gynaecology
Hillingdon Hospital

Plan

- * What is perinatal loss?
- * Who could be seen in the MMHS and when?
- * What is the psychological impact of loss?
- * What can we do to help –formulation and intervention?
- * Case study

What is perinatal loss?

- * Miscarriage (loss before 24 weeks)
- * Ectopic pregnancy
- * Termination of Pregnancy (TOP/ MTOP)
- * Fetal reduction
- * Stillbirth (loss after 24 weeks)
- * Neonatal death (3.7 per 1000)
- * Sudden or unexpected death in infancy
- * Baby removed due to care proceedings



One in four women experience a miscarriage in their life-time

9 babies are stillborn every day in the UK



Bereavement care quality standards

- * A parent-led **bereavement care plan** is in place for all families, providing continuity between settings and into any subsequent pregnancies.
- * **Bereavement care training** is provided to all staff who come into contact with bereaved parents, and staff are supported by their Trust to access this training.
- * All bereaved parents are informed about and, if requested, **referred for emotional support and for specialist mental health support** when needed.
- * There is a **bereavement lead** in every healthcare setting where a pregnancy or baby loss may occur.
- * **Bereavement rooms** are available and accessible in all hospitals.
- * The preferences of all bereaved families are sought and all bereaved parents are offered **informed choices about decisions relating to their care and the care of their babies**.
- * All bereaved parents are **offered opportunities to make memories**.
- * A system is in place to clearly signal to all health care professionals and staff that a parent has experienced a bereavement to enable **continuity of care**.
- * Healthcare staff are provided with, and can access, **support and resources to deliver high quality bereavement care**.

Bereavement care in hospital - Memory making

Hand and footprints

Seeing and/or holding their baby or baby's remains –in a suitable container if needed

Photographs of the baby or remains

Certificate of birth or loss

Other memorials

A memory box –or items for a box if one is not available

A copy of the scan image, if still in the notes or not already taken

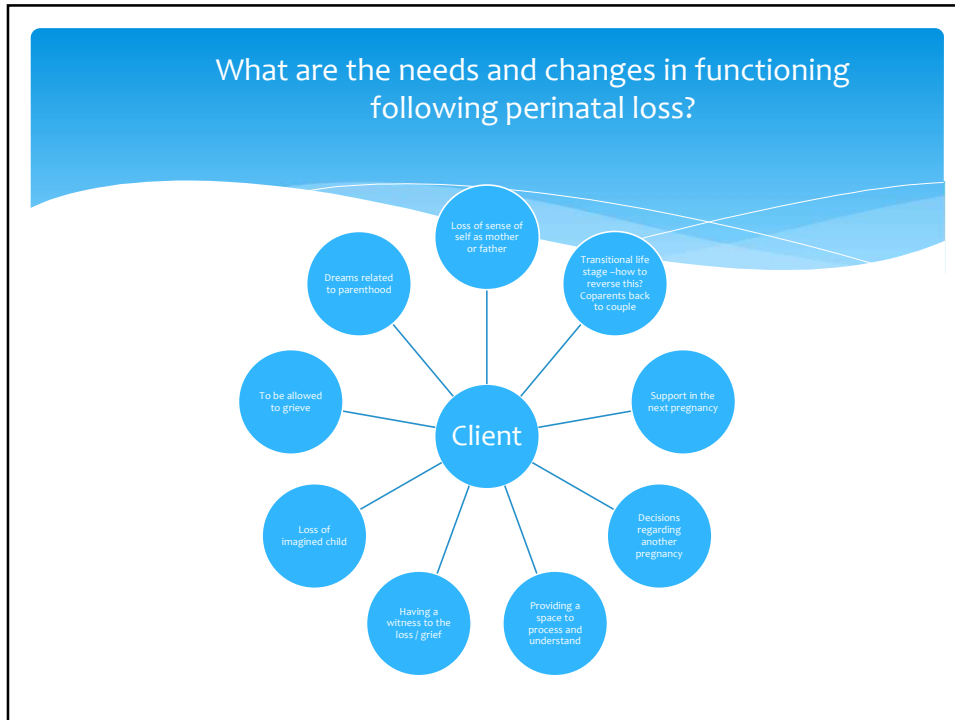
Taking the baby or remains out of the hospital environment

Thinking the unthinkable

- * “Speaking of perinatal grief is hard. The grieving process alone is isolating and draining but along with it goes this silence... this idea that it should be kept in the dark. I get it –it’s uncomfortable. No-one wants to think about it... what it would be like if it happened to them. No-one wants to make someone feel worse (ps. Not possible), so there is little general knowledge on how to help someone –or even yourself through it”

Common psychological responses.





Complex Perinatal Loss and Bereavement – Questions Questions Questions.....

- * Searching:-Why did my pregnancy end in a loss:
- * What could have been done to prevent it?
- * Could it happen again?
- * How long should I wait until I try again?
- * Should I go to the same hospital?
- * Should I use the same baby things?
- * What will I do if I don't feel my baby move?
- * Will I ever be able to love another baby as much as I love the one I lost.
- *and so many more questions.

- * Grief

- * The 'normal' grieving process = 'Stages of Grief' (denial, anger, bargaining, depression, acceptance). Kubler-Ross

- * Grief work now often uses the acronym:

- * **T**= To accept the reality of the loss.

- * **E**= Experience the pain of the loss.

- * **A**= Adjust to the new environment without the lost object.

- * **R**= Reinvest in the new reality.



What is the emotional impact of pregnancy loss on men?



What is the mental health impact following loss?

- * After loss
- * PTSD -38% at 3 months/ 18% at 9 months
- * Anxiety -20% at 3 months
- * Depression -5% at 3 months

- * In next pregnancy
- * Anxiety (d = 0.69)
- * Depression (d = 0.22)
- * Stress (d = -0.002)

Hunter, A., Tussis, L., & MacBeth, A. (2017). The presence of anxiety, depression and stress in women and their partners during pregnancies following perinatal loss: A meta-analysis. *Journal of Affective Disorders*, 223, 153-164.

Farren, J., Jalbrant, M., Ameye, L., Joash, K., Mitchell-Jones, N., Tapp, S., ... & Bourne, T. (2016). Post-traumatic stress, anxiety and depression following miscarriage or ectopic pregnancy: a prospective cohort study. *BMJ open*, 6(11), e011864.

Complicated Grief Disorder

- * **Complicated Grief Disorder** -'Persistent Complex Bereavement Disorder' DSM 5 -Further study.
- * Distinguished from Depression and PTSD
- * More commonly found following disasters, violence and loss of a child/baby

Complicated Grief Disorder.

- * characterised by:-
- * Indefinitely yearning/longing for the deceased
- * Preoccupation with the circumstances of the deceased's death
- * Intense sorrow and/or distress that does not improve over time.
- * Difficulty trusting others
- * Depression
- * Detachment and/or isolation
- * Difficulty pursuing interests or activities
- * A desire to join the deceased
- * Persistent feelings of loneliness or emptiness
- * Impairment in social, occupational or other areas of life.
- * Over a prolonged period

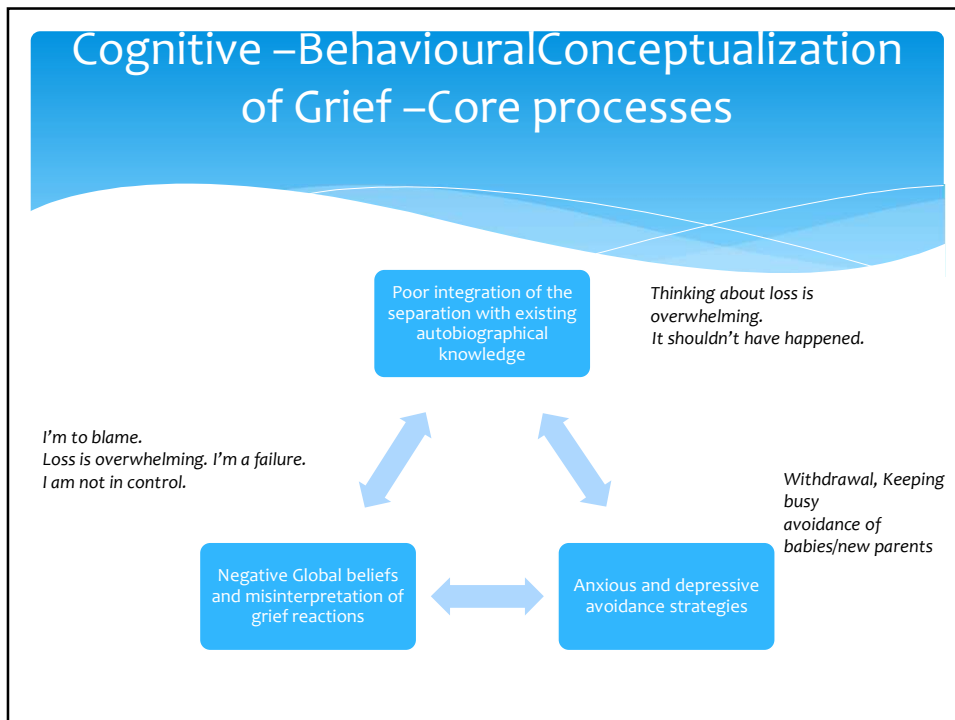
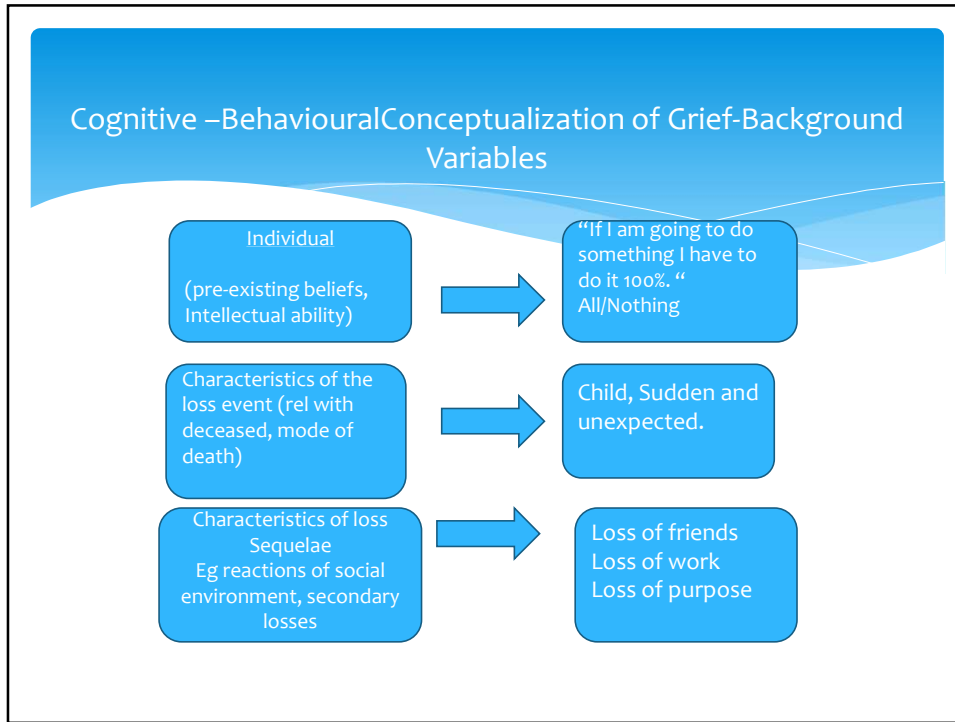
Complicated Grief Disorder.

Separation distress

- * Yearning, searching, preoccupation with memories of the deceased and loneliness

Traumatic Distress

- * Avoid reminders of the loss, feelings of purposelessness about the future, numbing, feeling stunned, dazed or shocked, difficulties acknowledging the death, feeling that life is empty, difficulties imagining a fulfilling life without the deceased, feeling that a part of oneself died, shattered world views, anger over the loss.



Cognitive –Behavioural Conceptualization of Grief –Clinical Outcomes

- * **Persistent Complicated Grief**
 - * Separation distress
 - * *Eg, yearning, searching, pre-occupation, loneliness*
 - * Traumatic distress
 - * *Eg, disbelief, feeling that life is meaningless, Numbness, feeling stunned or shocked.*

Interventions

- * The loss needs to be conceptually processed and integrated into autobiographical memory.
- * unhelpful beliefs and interpretations need to be identified and adjusted.
- * Anxious and depressive avoidance and other coping strategies (hyper-vigilance to baby triggers) need to be replaced by more helpful strategies that facilitate adjustment.

Interventions

- * Psychoeducation and normalising of grief reaction.
 - * Task –to learn to live with event (as part of life story) so that not overwhelmed with painful emotions.
 - * Loss has disrupted old certainties.
- * Facilitating integration.
 - * Making it real –ie memory boxes, names, photos, rituals.
 - * Exposure –‘the narrative’ –conception, loss, rituals. Hot spots.
- * Changing unhelpful beliefs and misinterpretation of grief reactions.
 - * Cognitions about events leading up to the event.
 - * Ie: If I do everything the right way, I can prevent bad things happening.
 - * I will break down and cry uncontrollably

Interventions

- * Reducing anxious and depressive avoidance.
- * Adapting CBT skills
 - Response prevention.
 - Thought suppressions
 - Behavioural activation
 - Facilitating healthy adaptation.
- * Integrating Compassion Focused Therapy.

Complex Perinatal Loss and Bereavement – Preparation for a another baby

- * Awareness of when experienced loss in relation to current pregnancy.
- * Coping with anniversaries as well as current pregnancy – heightened emotions.
- * Sex of baby lost/sex of current baby
- * Focus on earlier sessions in managing anxiety, low mood.
- * Guilt
- * Belief –just need to have a healthy baby and all will be ok.

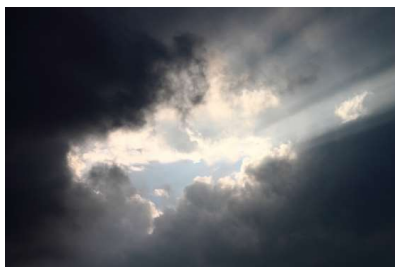
Complex Perinatal Loss and Bereavement – Preparation for a another baby

- * Belief –just need to have a healthy baby and all will be ok.
- * Difficulty of thinking of self as mother/father/parents.
- * Permission giving:-
 - * Need to introduce reality of having a baby, common experiences, ie sleepless nights, post birth fug of early weeks and months. Having a longed for baby does not necessarily lessen impact of these –ok to feel mixed emotions.

Antenatal Psychology Care-plan – after previous loss

- * Possible triggers for trauma.
- * Mix emotions when have baby.
- * Privacy

“Without the compassionate care and support of you all we don’t think we could have coped with such a devastating loss and hope for the future. I could not be here with my baby if I had to go on my journey alone.”



Useful signposting list

- **Action on Pre-Eclampsia (APEC)**
- Helps and supports women and their families who are affected by or worried about preeclampsia and aims to raise public and professional awareness of pre-eclampsia. www.action-on-pre-eclampsia.org.uk
- **Antenatal Results and Choices (ARC)**
- Offers non-directive individualised information and support for parents making decisions around antenatal testing, including when a baby has a significant anomaly. www.arc-uk.org
- **Baby Mailing Preference Service (MPS) online**
- Free site where parents can register online to stop or help reduce baby-related mailings. www.mpsonline.org.uk/bmpsp
- **Bereavement Advice Centre**
- Offers information and advice for people with practical concerns after the death of someone close to them.
- www.bereavementadvice.org
- Bereavement Care Network
- Online network for bereavement care professionals who offer or are interested in care for parents when a baby dies.
- bereavement-network.rcm.org.uk
- **Bliss**
- Offers support for families of premature or sick babies, including bereaved families. www.bliss.org.uk
- **British Pregnancy Advisory Service (BPAS)**
- Offers advice and treatment for termination of pregnancy in the UK. www.bpas.org
- **Child Bereavement UK (CBUK)**
- Provides support for families when a baby or child has died or is dying and offers support for children faced with bereavement. Offers training for professionals. www.childbereavementuk.org/
- **The Compassionate Friends**
- An organisation of bereaved parents, siblings and grandparents that offer support to others after the death of a child or children. www.tcf.org.uk
- **Cruse Bereavement Care**
- Offers support to bereaved people and training for professionals. www.cruse.org.uk
- **Ectopic Pregnancy Trust**
- Provides support and information for people who have had or been affected by an ectopic pregnancy. www.ectopic.org.uk
- **JobcentrePlus – Bereavement Services Helpline**
- Provides information about benefits claims. Telephone: 0345 608 8601 www.gov.uk/contact-jobcentre-plus
- **Lullaby Trust**
- Offers support and advice for parents whose baby dies suddenly and advice on safer sleep. www.lullabytrust.org.uk
- **Miscarriage Association**
- Offers support and information for individuals affected by pregnancy loss and for health care professionals.
- www.miscarriageassociation.org.uk
- **Multiple Births Foundation (MBF)**
- Provides support and information for multiple birth families (including bereavement support) and information for professionals. www.multiplebirths.org.uk
- **Rainbow Trust Children's Charity**
- Offers support to families in England with life-limiting and life-threatening conditions. <https://rainbowtrust.org.uk>
- **Relate**
- Offers relationship support to help people strengthen their relationships. www.relate.org.uk
- **Remember My Baby Remembrance Photography**
- UK-based charity who have professional photographers who voluntarily provide their photography services to parents whose baby dies before, during or shortly after birth. www.remembermybaby.org.uk
- **Sands, the stillbirth and neonatal death charity**
- Provides support and information for anyone affected by the death of a baby, before or after birth. National helpline, local parent-led support, literature and online support. Works to improve care when a baby dies and promotes research to reduce the loss of babies' lives. www.uk-sands.org
- **TambaBereavement Support Group**
- Offers support for families who have lost one or more children from a multiple birth during pregnancy, birth or at any time afterwards. www.tamba.org.uk/bereavement