Baby Loss: The Melancholy Void

Hedy Cleaver and Wendy Rose

Lancaster University: 9 February 2022

Families coping with baby loss



With kind permission of the artist Harry Venning

Changing legislation, language and outcomes

- The landmark Abortion Act of 1967 had a major impact on the health of pregnant women
- Abortion originally referred to all forms of pregnancy loss both spontaneous and induced
- With the development of ultrasound in the 1980s doctors began to use the term miscarriage to refer to early pregnancy loss

Changing attitudes to fertility and motherhood

- Women are expected to have children
- Pregnancy celebrated and fertility is no longer the prerogative of young women
- Single parenthood is now more acceptable
- Terms such as 'bastard', 'illegitimacy' and 'living in sin' are now rarely used
- Views on same-sex partnerships have shifted radically, they now have equal rights to parenthood

Losing a baby

- What do we mean by baby loss?
- Likelihood of losing a baby:
 - One in 4 women experience a miscarriage
 - One in 90 pregnancies is ectopic
 - In 2019 stillbirth rate in England was 3.8 stillbirths per 1,000 births
 - Neonatal death rate in England in 2019, was 2.7 deaths per 1,000 live births
- Over the past decade neonatal death rates have generally fallen by 30% and still births by 25%
- Rate of miscarriage also on the decline

Baby loss – who is affected?

- Miscarriage, still birth and neonatal death can happen to any woman, no-one is exempt
- Rate doubles for babies of Black or Asian ethnicity
- Women living in poverty remain at far greater risk
- Other risk factors include: age, obesity, imprisonment, and mothers born outside the UK
- Preventable baby deaths, the result of failures in clinical practice, systems and culture, and shortage of resources

Baby loss and women's mental health

- Pregnancy evokes a variety of emotions: joy, excitement and hope for the future – anxiety, dread and guilt
- Losing a pregnancy or baby may be associated with profound emotions – increasing risk of depression, anxiety, post-traumatic stress disorder, guilt and self-blame
- Mid-20th century miscarriage a private affair now treated with greater sensitivity and a better understanding of grief

Silent partners in grief

- Traditionally men were excluded from all aspects of pregnancy and birth
- Today partners are expected to be there for ultrasound, play an active role in antenatal classes, and be present at birth
- Partners experience many of the emotions felt by mothers, but have little support after baby loss

Grieving parents

- Widely held misconception that baby loss is more prevalent in first-time mothers
- Growing knowledge that losing a pregnancy or baby can affect parents' relationship with existing or future children
- Arrival of new healthy baby may result in conflicting emotions – impact on bonding
- Unresolved grief may affect capacity to look after existing children

Grieving siblings

- Most parents involve children in the anticipation of a new baby
- "Non arrival" of the baby can have a profound effect of siblings
- Siblings experience two losses: the expected sibling and their parents as they were before the bereavement
- Children's reactions complicated: shock, helplessness, grief mixed with a sense of reprieve; many blame themselves
- Support for family enables better outcomes

Professionals' response to baby loss fifty years ago

- In 1960s all evidence of a baby removed immediately
 - ➤no death certificates
 - Few parents knew what happened to their baby's body
 - remains from miscarriage classified as 'medical waste'
 - > parents encouraged to put the loss behind them
- 1970s attitudes start to change

Expectations of professionals now

- In 2015 Human Tissue Authority provided Guidance on disposal of "pregnancy remains"
- Health professionals more aware of impact of baby loss
- Parents now offered opportunities to:
 - see and hold baby
 - > take photos, collect keepsakes
- Supporting parents may be hampered by:
 - ➢ high workloads and lack of staff in NHS
 - ➤ competing priorities
 - \succ shortage of beds

Community support

- No guaranteed routine follow-up after discharge from hospital
- Parents' psychological well-being following baby loss is often not assessed or treated
- Needs of parents with existing children are also underestimated and consequently receive less emotional support
- Many parents continue to struggle to cope without appropriate support being available

A tailored response

- Coping with baby loss is unique to the individual – people handle grief and loss differently
- Help and support must be tailored to the specific circumstances and needs of individual family members

Supporting colleagues at work

- Work colleagues will have different wishes and needs – must be treated as individuals
- Timing the return to work is a key issue
- Talking about the lost baby
- Grief is not quickly overcome and a parent may struggle to concentrate at work – they may need support to take time out when this happens

In Conclusion

- We have looked at baby loss through a prism of social change, medical progress and legal reforms
- The consequences of baby loss are far reaching for all family members, including children
- Some may not cope and hidden grief continues, with profound effects on families' mental health and wellbeing
- Many are in work and will need support to adjust
- Although public and political understanding of loss is developing, timely and appropriate services lag behind

References

- M. Albakri et al (2019) 'Relationships and gender identity'. In: Curtice, J., Clery, E., Perry, J., Phillips, M. and Rahim, N., eds. *British Social Attitudes: The 36th Report*, London: The National Centre for Social Research, pp.114-141
- H. Cleaver & W. Rose (2021) Dealing with the Melancholy void: Responding to Parents Who Experience Pregnancy Loss and Perinatal Death. In Ikkos, G. & Bouras N., eds. *Mind, State and Society*, Cambridge University Press, pp.315-325.
- H. Cleaver et al (2018) 'Parenting while grieving: The impact of baby loss, Journal of Public Mental Health, 17: 168-75
- E. Clossick (2016) 'The impact of perinatal loss on parents and the family', *Journal of Family Health*, 26(3):11-15
- E. Draper et al (2021) *MBRRACE-UK Perinatal Mortality Surveillance Report,* MBRRACE-UK, University of Leicester
- J. Farren et al, 2020, 'Post-traumatic stress, anxiety and depression following miscarriage and ectopic pregnancy: a multi-center, prospective, cohort study', *American Journal of Obstetrics and Gynecology*, 222(4):367.e1-367.e22

References

- W. Jordan (2014) 'Most women put motherhood ahead of career', International, Lifestyle, Politics & current affairs
- C. Lee and P. Slade (1996) 'Miscarriage as a traumatic event: a review of the literature and the implications for intervention', *Journal of Psychosomatic Research*, 40(3):235-44
- NHS (2014) A review of support available for loss in early and late pregnancy, available at:<u>https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Available-Support-for-Pregnancy-Loss.pdf</u>
- E. Peel (201R. Linnakaari et al (2019) 'Trends in the incidence, rate and treatment of miscarriage-nationwide register-study in Finland 1998-2016', *Human Reproduction*, 1:34(11): 2120-2128
- B.S. McCreight (2004) 'A grief ignored: narratives of pregnancy loss from a male perspective', *Sociology of Health & Illness*, 26(3): 326-350
- 0) 'Pregnancy Loss in Lesbian and Bisexual Women: An Online Survey of Experiences', *Human Reproduction*, 25(3): 721-727

References

- S. Quenby et al (2021) 'Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss', *The Lancet*, 397(10285):1658-1667
- L.J. Reagan (2003) 'From Hazard to Blessing to Tragedy: Representations of Miscarriage in Twentieth-Century America', *Feminist Studies* 2003; 29(2): 357–378. *JSTOR*, <u>www.jstor.org/stable/3178514</u>
- M. Redshaw et al (2014) *Listening to parents after stillbirth or the death of their baby after birth*, Policy Research Unit in Maternal Health and Care, Oxford
- Sands (2019) Out of sight out of mind, available at: <u>https://sands.org.uk/sites/default/files/Out%20Of%20Sight%2C%20Out%</u> <u>20Of%20Mind%20Report%202019%FINAL.pdf</u>
- Tommys (2018) Going back to work after neonatal death, available at: <u>www.tommys.org</u> > baby-loss-support > going-back-to-work
- C. Watson (2018) *The Language of Kindness: A Nurse's Story*, London, Chatto & Windus