Chapter 32

Dealing with the Melancholy Void: Responding to Parents Who Experience Pregnancy Loss and Perinatal Death

Hedy Cleaver and Wendy Rose

Introduction

> I go about my domestic duties in mourning, sighing over the melancholy void that death has made . . . There sits her empty cradle . . . I shall never see her sleeping there again.[1]

This was one woman's reaction to the death of her baby in the first half of the nineteenth century. Her grief and despair are timeless. However, the understanding and compassion shown to miscarriage and perinatal death is now very different.

Although such loss does not respect age, previous fertility or wealth, women living in poverty are at most risk.[2] The impact on the mental health of parents depends on a number of variables, including prior mental health, relationship between partners, culture, gender identity, medical and social support and religion. This chapter explores how the support provided to those experiencing loss reflects many of the seismic societal changes taking place on a broader canvas from the 1960s onwards.

Contribution of Legislation in Marking Change

Legislation in the last fifty years has marked both advances in medical science and changing attitudes towards pregnancy, parenting and the loss of a baby. It continues to do so. Stillborn babies had no legal existence prior to 1927 in England and 1939 in Scotland. 'The stillborn were thus treated as if they had never existed, and registered as neither a birth nor a death.'[3] The Stillbirth (Definition) Act 1992 extended the definition of stillborn from lost after the twenty-eighth week of pregnancy to lost after the twenty-fourth week. Those born earlier are not registered and there is no legal requirement for burial or cremation. Attitudes, however, continue to change. 'In recent years, with greater understanding of the significance of the death of a baby at any stage of pregnancy, more babies born before 24 weeks have been formally buried or cremated.'[4]

Medical terminology and its wider use have evolved; abortion originally described pregnancy loss without clarifying whether it was spontaneous or induced. Change began with the Abortion Act 1967, allowing women greater legal access to abortion services and the Guidance on the Act was updated in 2014.[5] Women who experienced a spontaneous miscarriage were thus able to talk to their doctor without fear of being criminalised and those seeking terminations could be referred to expert and safe clinical services. It was not until the 1980s with the development of ultrasound, enabling the foetus to be seen, that doctors consciously began using the term miscarriage to refer to early pregnancy loss.[6]

https://doi.org/10.1017/9781911623793.034 Published online by Cambridge University Press

Prevalence of Pregnancy and Perinatal Loss

The rate of conception in England and Wales has, over the past half century, shown considerable variation. In 1969 conception was estimated to be 832,700 for women of all ages, falling to 686,400 in 1977 and by 2010 had risen to 909,200. Since then there has been a steady decrease. Scares over the safety of the contraceptive pill between 1976 and 1996 may have contributed to increases in conceptions due to the use of less reliable contraceptive methods.[7]

Not all conceptions lead to a live birth. It is estimated that today one in four pregnancies in England and Wales ends in miscarriage.[8]

A foetus may be lost because of an ectopic pregnancy. The recorded incidence increased between 1966 and 1996, 'probably due to a sexually transmitted agent' and has remained stable since.[9] It currently accounts for around one in every ninety pregnancies in the UK.[10] Some women decide to terminate their pregnancy. The recorded abortion rate increased from 6 per 1,000 resident women in England and Wales in 1970 to 20.8 per 1,000 in 2010. Of these, 1 per cent were performed in 2010 because of a substantial risk of foetal abnormalities.[11] The rate of perinatal mortality in the UK has been declining, falling from 11.8 deaths per 1,000 total births in 1981 to 7.5 deaths in 2011.[12]

There is now greater interest in monitoring and understanding pregnancy and perinatal loss. MBRRACE-UK undertakes regular perinatal surveillance reports to identify trends in stillbirth, neonatal and perinatal mortality rates.[13] The reports have informed the NHS Long Term Plan covering maternity and neonatal services, aimed at reducing stillbirth, neonatal mortality and serious brain injury.[14]

Attitudes to Motherhood and Fertility

It might be expected that widely held views on the imperative of motherhood would have undergone major changes over the last fifty years, thanks to family planning, the development of medical fertility techniques and greater economic independence.

Post-war advertisers targeted women as mothers and homemakers, mirroring the prevalent view in society. Women were expected to bear children and, in the mid-twentieth century, 'doctors who believed that female infertility was a psychosomatic condition recommended adoption as a "cure"'.[15] Even now, the prioritising of motherhood continues. The results of a recent UK survey are surprising. 'Around four in five British women say being a mother is "more important" than having a career, while only 6% put having a career first'.[16]

Although women are expected to become mothers, there has been a major change in the public response to pregnancy. In the 1960s and 1970s, it was often seen as a rather embarrassing condition and any evidence was disguised. Today the stigma and shame are disappearing, pregnant women can remain in the workforce, they are featured and celebrated in the media and clothes are designed to emphasise the baby bump. Fertility is also no longer seen as the prerogative of young women: 'Fertility in the over-forty age group has trebled since the 1980s, and there are now more women giving birth in their forties than in their teens.'[17]

Views on single parenthood have gradually been overturned. In the 1960s and 1970s, secrecy and shame surrounded unmarried motherhood,[18] attitudes perhaps reinforced by John Bowlby's influential work on attachment, which stressed the two-parent family and the stay-at-home mother as the bedrock of social stability. Change started in the 1970s with the wider availability of oral contraception and continued in 1984 with the licensing

https://doi.org/10.1017/9781911623793.034 Published online by Cambridge University Press

of the 'morning-after pill'. This meant that to have a baby as a single woman became largely a matter of choice. Language has also changed; terms such as 'bastard', 'illegitimacy' and 'living in sin' are now rarely used except by the fiercely religious. Yet policy progress has been slow and remains dogged by political and media rhetoric of 'the feckless poor' and 'problem families'.[19]

Attitudes towards same-sex partnerships and members of the LGBT community have shifted radically; the number of people who think same-sex relationships are 'not wrong at all' has gone from 17 per cent in 1983 to 65 per cent in 2018.[20] The many changes in the law around same-sex relationships since 1967, when sex between two men over the age of twenty-one in England was decriminalised, have kept pace with public opinion. Views on the LGBT community continue to shift, including their equal rights to parenthood (see also Chapter 34). A discussion on the impact of pregnancy and baby loss must take a broader perspective on parenthood than would have been assumed fifty years ago.

Fear and Hope in Pregnancy and Perinatal Loss

Pregnancy evokes a variety of emotions: for some, it will produce feelings of joy, excitement and hope for the future; for others, anxiety, dread and guilt; but for many the emotions will be mixed. Women's reactions will be predicated on whether pregnancy was wanted and planned and the underlying mental health of the parent – issues that will subsequently shape their reaction to losing the pregnancy or baby.

Until relatively recently, many women still feared childbirth, knowing a mother or baby who had died in the process. Today most women trust that technology will minimise risk and they will have a problem-free pregnancy and give birth to a perfect child. Once the pregnancy is established, many women start to plan their future with the yet unborn child and a bond is formed stimulated by foetal activity.

In the mid-twentieth century, the pervasiveness of eugenic beliefs and fear of an 'abnormal' child led to couples being advised to feel fortunate if they experienced a miscarriage because the foetus would have been malformed. Although parents' unhappiness was recognised, grief was not emphasised; what was stressed was the possibility of future success. 'Doctors and science writers exuded confidence in medicine's abilities to give all women babies . . . Follow directions and there is no reason you should not have a fine, full-term baby'.[21] To achieve medicine's promise of a healthy baby, a woman might have been required to submit to repeated examinations, long stays in bed, abstaining from all physical activities and ingesting pharmaceuticals.

The medical advancements of the 1960s strengthened the belief that women who miscarried would give birth to a healthy child if they followed their doctor's advice. Yet this is not always the case; 1–2 per cent of women have three miscarriages in a row, classified as recurrent miscarriage.[22] Half of these result from chromosomal anomalies where the embryos would not survive; others are due to a wide variety of issues such as anatomical defects, infections and haematological disorders.[23] Nonetheless, three-quarters of women who experience recurrent miscarriage go on to have a successful pregnancy, and there is no evidence that 'lifestyle adaptation' increases the likelihood of success.[24]

Impact of Loss on Women's Mental Health

In the mid-twentieth century, miscarriage was a private affair that was rarely spoken of. Attitudes are changing due to the campaigns of vocal groups such as the Miscarriage

https://doi.org/10.1017/9781911623793.034 Published online by Cambridge University Press

Association and Mumsnet with its Miscarriage Care Campaign. Baby loss is now treated with greater sensitivity and parents are offered choices, including funerals and other types of ceremonies, for a foetus that would previously have been quickly removed for disposal.

Although miscarriage is now more openly discussed, it could be argued that only certain voices are heard. Miscarriage is expected to evoke grief and trauma. Yet for women who were distressed rather than delighted at becoming pregnant, a miscarriage may be seen as good news. Other would-be parents, particularly those who have experienced recurrent miscarriage, may suffer intense grief that will not be resolved for years. When a much-wanted pregnancy is lost, women tend to be at risk of depression, anxiety, post-traumatic stress disorder, guilt and self-blame.[25]

> I was shocked. I had no idea that a miscarriage could happen so quietly, without bleeding or pain. Instead of going home clutching pictures of our baby, we left the hospital with instructions on how to shed its dead body.[26]

Research for the Stillbirth and Neonatal Death Society (Sands) found women who had experienced intrauterine death or stillbirth shared similarly profound emotions. The parents expressed a sense of 'overwhelming loss of what might have been. This was felt not only in relation to the baby as a physical presence, but also the loss of joy, of celebration, of parenthood and, in some cases, of their sense of self'.[27] Redshaw and colleagues' study of the impact of neonatal death and stillbirth showed similar results, practically a third of women reported symptoms of anxiety and a quarter reported depression.[28] These findings were substantiated by a meta-analysis of the negative psychosocial impact of stillbirth.[29]

There is general agreement that terminating a pregnancy is associated with increased risks of mental health problems,[30] with some groups of women at greater risk of negative outcomes.[31] When the termination is for reasons of foetal abnormality, it can have a profound impact on both parents because of the existence of choice and the potential for self-blame.[32]

For same-sex partners, losing a pregnancy or baby may be amplified because of the complex processes involved in becoming pregnant and the emotional and material investment. They may also face heterosexism and prejudice from health professionals. 'Some health professionals seemed unable to understand my partner's distress at losing her child ... I don't think they understood what it meant for my partner, that she was a parent and she had lost her baby too.'[33] Lesbian partnerships experience loss in similar ways to heterosexual women, but the impact on mental health appears to last for longer.[34]

Perhaps most devastating is when a baby is lost due to failures in clinical practice, systems or culture. There have been several investigations into preventable perinatal deaths at maternity units over the past few years.[35]

Silent Partners in Grief

Masculinity has been characterised by emotional detachment, silence and rationality. Traditionally, men have been excluded from all aspects of pregnancy and childbirth. Popular media portrayed their role as the 'anxious father' allaying his fears in the company of friends (often in the pub) while waiting to toast the arrival of a healthy baby. Changes began in the 1970s with more women giving birth in hospital and the belief that they should be allowed to choose whether to have their partner with them. By 2010, would-be fathers were expected to accompany their partner for the ultrasound, take an active role in antenatal

https://doi.org/10.1017/9781911623793.034 Published online by Cambridge University Press

classes and be present at the birth. Public recognition of fathers' more active parental role was marked finally by the introduction of paternity leave of up to two weeks in 2003.

Recent research has focused on men's experiences of baby loss. Qualitative studies reinforced by meta-studies have identified key themes.[36] This body of work suggests men react in similar ways to women, experiencing guilt and blame, regret, fear and grief as well as shame, stigma and post-traumatic stress disorder.[37] 'I will never forget what I saw. I can't. It's burned into my mind forever'.[38]

Many men felt grief and a deep sense of loss not only for their baby but also for their lost dreams of fatherhood. Because the woman experienced the event biologically, men felt less entitled to feel or to communicate their emotions. Many assumed the traditional role of protector, putting aside their own emotions to support their grieving partner; others buried their grief by taking on practical tasks. They 'expected themselves, and were expected by others, to be unaffected by the loss: yet, they recounted feelings, uncertainties, and desire for support beyond anything they would have anticipated'.[39]

Parenting after Miscarriage or Baby Loss

Awareness that the experience of losing a pregnancy or baby can affect parents' relationships with existing or future children is being acknowledged. Losing a pregnancy is associated with an increased likelihood of women experiencing sadness, low mood and excessive worry during any subsequent pregnancy, emotions that subside once the baby is born.[40] However, the arrival of a healthy baby may cause conflicting emotions as parents struggle to bond with their new baby while still grieving for the baby lost. A widely held misconception is that pregnancy and baby loss are far more prevalent for first-time mothers. The evidence suggests otherwise; just under half of neonatal deaths and 41 per cent of stillbirths occur following a previous successful delivery.[41]

The Missing Sibling

Following a miscarriage or stillbirth, a proportion of women will experience mental health problems that affect their capacity to care about themselves and their existing children. Men may deal with their grief by an increased use of alcohol or drugs, a coping strategy that makes them less available to their children.[42] Children will be directly affected by the loss and their reactions may be complicated as jealousy may have vied with excited expectation.

> When a baby is stillborn, it is a tragic event not only for the parents but also for older siblings who are waiting for their little sister or brother.[43]

A Swedish study identified several themes that helped parents and children deal with such loss. These include making the stillborn baby and the loss a reality for the sibling: providing honest, age-appropriate information, creating memories, recognising and acknowledging the child's grief and being able to show how they feel themselves.[44] When parents are unable to provide the support and understanding children need, children will self-interpret the loss of their sibling and the risk of pathological reactions can be high.[45]

Research suggests that, by supporting parents through the grieving process and facilitating the sharing of the loss within families, the emotional well-being of children can be better protected.[46] The debate has now moved into the political arena in the UK. The impact

https://doi.org/10.1017/9781911623793.034 Published online by Cambridge University Press

on children was acknowledged and fundraising for counselling applauded in the government's debate on baby loss in 2017.[47]

Professional Practice in Response to Baby Loss

Fifty years ago, all evidence of miscarriages and stillborn babies was immediately removed from the labour ward and parents had no opportunity to see or hold their baby.

> When they rushed my baby out of the room, I assumed I'd given birth to a monster, something that was too awful to look at. That thought haunted me for many years. Now I realise that he probably looked perfect, just as if he was asleep.[48]

It was generally believed at the time, both within the medical professional and wider society, 'that parents could, and should, forget their babies, and that it was best to carry on as though nothing had happened. Expressions of grief were discouraged.'[49]

While stillborn babies have been registered since 1927, even as late as the 1960s and 1970s many parents were not provided with a death certificate and few knew what happened to their baby's body. The 1970s heralded a gradual change in attitudes and practices, changes led by the work of Sands and other similar organisations. As a result, since the mid-1980s parents of a stillborn baby are consulted about funeral arrangements.[50]

The remains from a miscarriage continue to be classified as 'medical waste' and the Human Tissue Act 2004 made no distinction between the disposal of pregnancy remains and that of other tissue from a living person. Attitudes are beginning to change. The Guidance provided by the Human Tissue Authority in 2015, although acknowledging that parental consent is not required for the disposal of pregnancy remains, stresses that hearing the wishes of the parents 'are of paramount importance and should be respected and acted upon'.[51]

The NHS review identified the different responses of parents who suffer pregnancy loss, 'some wanted to remember their baby whatever the gestation and should have the opportunity to do so'.[52] The review found that 'compassion and attitude of the staff have a lasting impact on the experience' but that high workloads and competing priorities could hamper this important work.[53] The review also identified the relevance of the environment:

> due to shortage of beds I was moved to the maternity department where I was put in a side room and forgotten about. All through the night I lay awake and crying to myself as the new born, very new born baby next door cried all through the night as if it was in my own room.[54]

Health professionals are more aware of the impact of losing a baby and parents are offered opportunities to see and hold the baby, to take photos and collect keepsakes. Research on the impact of making memories is nuanced. For example, Crawley and colleagues found no direct relationship between maternal mental health and memory making, but the sharing of memories with partners, families and friends, along with the time since the baby died and professional support, were factors associated with improved mental health.[55] Watson's autobiography provides an illustration of the difference support can make to grieving parents. Recorded on a thank-you card in a neonatal intensive care unit was the following message:

> To Maddie, the bereavement midwife. You helped us through the worst time of our life. We will treasure the memories you let us make during Annabelle's short time. Thank you is not enough. But there are no words.[56]

https://doi.org/10.1017/9781911623793.034 Published online by Cambridge University Press

Developments in Perinatal Mental Health and Community Services

How individuals experience losing a pregnancy or baby is personal and it would be wrong to assume that one type of response would suit everyone.[57] The type of support available can depend on the stage of pregnancy. Busy health professionals who deal with early pregnancy loss on a regular basis may normalise the event and fail to recognise its possible profound psychological impact. Women are routinely discharged quickly from hospital and often return home in a state of shock: many mothers and fathers may leave with undetected and unresolved psychological symptoms.[58]

Our understanding of the process of grieving over the last fifty years has influenced the development of preventive and community mental health services. Some parents will not need or want professional or community support while for others it will be a lifeline. For a few women, a stillbirth will have long-lasting effects. A better understanding of the experience and access to psychosocial support may benefit some women and their families to deal with the impact.[59] Gaps in the provision of maternal mental health services have been identified,[60] as has the lack of accessible support services for men that acknowledge and validate their experience of grief.[61]

As in the nineteenth century with child welfare services, charitable organisations have played an instrumental part since the 1970s in changing the landscape through campaigning; working with health professionals; raising funds for research; promoting good practice; providing information and advice; and, above all, supporting grieving parents and their families. Their role underpins the advances made in the last fifty years, and they are often founded by bereaved parents, devastated by their own loss and the lack of understanding of its significance and impact on their lives. Each with their own distinctive missions, these organisations have shown drive and resilience and continue to be strongly active. Bliss, Sands, Miscarriage Association, Tommy's, Lily Mae Foundation and Mariposa Trust are among many organisations providing new models of bereavement care and support. They engage with the NHS to bring about much-needed specialist and expert resources to help parents in their contact with the NHS and at home in the community.

Parliamentary engagement in the issues and NHS England's action plan are more recent advances. The All Party Parliamentary Group on Baby Loss made a commitment to providing high-quality bereavement care through their initiative *Safer Maternity Care*.[62] The Parental Bereavement (Leave and Pay) Act 2018 provides for the first time in the UK's history a legal right for bereaved parents to have leave from work, bereavement pay and employment protection. NHS England is engaged in improving women's access to perinatal mental health support through the establishment of new services and targeted funding.[63]

Conclusion

Advances in medical science and major changes to the law have influenced and reflected wider society's changing attitudes to pregnancy and parenthood. Consequently, single parents draw less condemnation and same-sex partnerships are legal. Attitudes towards miscarriage and perinatal death have benefited from these changes. What was previously a very private affair is talked about more openly, revealing the profound and long-term impact such loss can have on the mental health of would-be parents and existing children. This has resulted in health professionals

https://doi.org/10.1017/9781911623793.034 Published online by Cambridge University Press

managing miscarriage and stillbirth with greater compassion, enabling parents to have the opportunity to hold their baby and create memories. Fifty years ago, parents were sent home from hospital to cope with their grief alone; charities and voluntary groups, working in conjunction with health professionals, now fill the gap and provide information and a range of support. Although much has been accomplished, there is certainly scope for further advances.

Key Summary Points

- Any discussion on the impact of pregnancy and baby loss must take a broader perspective on parenthood than would have been assumed fifty years ago.
- Loss of a baby can affect any woman, irrespective of age, previous fertility or wealth, although those living in poverty are most at risk.
- Grief and despair for women at the loss of a baby were historically seen as a private affair. The need for health services to offer sensitivity and choice in coping with loss is now better recognised.
- The consequences of loss are far-reaching for all family members, including existing children. Some may not cope, which can have a profound effect on their mental health and well-being, if not addressed.
- Community mental health and voluntary organisations offer greater compassion and support to grieving families but the need for easily accessible and responsive local services remains.

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https://doi.org/10.1017/9781911623793.034 Published online by Cambridge University Press