Maternity voices: bereavement care 40 years on

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Bereavement care 40 years on.

A Stillbirth is a baby delivered with no signs of life known to have died after 24 completed weeks of pregnancy. There were 5,623 registered deaths of babies in 2014 who died after 24 weeks and within 4 weeks of birth (Embrrace 2016) Experiences of bereavement can have profound emotional, psychiatric, and social effects on parents, relatives and friends (Heazell et al 2016, RCOG 2010, Cacciatre 2013). It may also have far reaching consequences on the woman's subsequent parenting skills (Warland et al 2011) and on a subsequent child (Hughes et al 2001).

This article is based on a case study by a 3rd year student midwife, who, in the course of writing up an assignment on stillbirth for a BSc Hons degree opened up discussion with her own mother who experienced a stillbirth 40 years previously. The discussion demonstrates how changes in bereavement care over 4 decades affected one woman, her partner, and her family. Good practice following stillbirth and subsequent bereavement care will be discussed following SANDS guidelines (Stillbirth and Neonatal Death Society (2016) which makes recommendations for good practice.

Carrie's story

I always thought that my mum and I had a close mother and daughter relationship but while working on my final assignment for my midwifery degree I discovered a whole new depth to my mum that she had kept hidden for 44 years. I believe her sharing this "secret" with me has created a mutual understanding and an even stronger bond between us.

In the early 1970's my mother had her first baby, a stillborn female infant. I grew up in a shroud of secrecy and whispers and heard snippets of conversations about "the first baby" but we never talked about my sister. While researching studies for my assignment, I decided to talk to my mother about her experience of the care she received while suffering a stillbirth. It was a difficult conversation to initiate but I asked questions and listened to my mum's answers! She talked and talked! It was as if she had finally been given the permission to talk about the first baby. She still refers to her as 'the first baby' because she cannot bring herself to say her name, to accept that

she had a baby that had died. I realized that this may be the first time my mum may have felt able to talk about her baby and to express her grief.

My mum had a normal pregnancy and like most pregnant women she was excited about the imminent arrival and she decorated the nursery and bought little outfits and blankets, all neutral colours of course as they didn't have ultrasound scans to determine the sex of the baby. My mum went into spontaneous labour. She was not supported emotionally or physically throughout her labour and awoke from her anaesthetic to be told by a nurse that her baby had died. There was no choice of seeing or holding the baby or taking photos or pictures or collecting keep sakes, nothing! It was only in the mid-1980s that the death of a baby at the time of birth began to be recognised as a major bereavement. Until then, a baby who was born dead at any age was swiftly removed from the labour ward. The parents were given no opportunity to see or hold their baby. Since then practices have changed and studies have found that giving women the opportunity to see and hold their baby may help them in the process of grieving (O'Leary and Warland 2013, Radestad 2009). The Nice guidance (2014) and SANDS (2016). recommend that a woman should be given the chance to bond with the infant and say goodbye if she wishes to. Each woman will feel differently and parents' feelings about this may depend on how health professionals offer this choice to women. Erlandsson et al (2012) found that if the health professional assumed the parents wanted to see their baby this felt more natural and comfortable.

My mum had no bereavement care, no acknowledgement by the caregivers of the death of her baby. Her consultant told her she was "better off" not seeing the baby. Those two little words made my mum think, for all these years that her baby was deformed or disfigured in some way. All this meant that my mum and dad grieved in silence feeling unable to talk about what had happened or how they were feeling. My parents must have felt completely isolated, shocked and worried that their feelings and sadness were unacceptable and abnormal.

After the death of her baby, family friends would ignore my mum if they bumped into her in town and if they did have to speak to her, no one mentioned the loss of her baby. One afternoon she bumped into a lady who had been pregnant at the same time

as my mum and the lady had her baby cuddled in the pram. My mother came face to face with her and she couldn't hold back the tears, they rolled down her cheeks. The lady crossed the road and ignored my mum, pretended she hadn't seen her.

I discovered that my father arranged for the burial but they never discussed any aspect of it so my mother had no idea where or if her baby was buried. My parents just didn't talk about it! They went home from the hospital and had to pack up all the baby things. How difficult it must have been for them and they still didn't talk about it. My mum had my brother a year later. When she was pregnant with me she felt the same movements and cravings that she had had with the first baby. I was born in a doctor's house in the outskirts of Lahore, Pakistan and my mum believed I was going to die. There is research to suggest that women experience some anxiety relating to stillbirth during subsequent pregnancies, so good support systems are important not just in the weeks after the loss, but also when planning for future pregnancies (Campbell- Jackson *et al* 2014, SANDS 2016).

My mum has now found the baby's burial place. She is in an unmarked grave with 11 other babies where we will lay some flowers and possibly a plaque. My mother has spent the last 44 years carrying around her secret grief like a burden and now she seems a little bit lighter. The memories of that day, things that were said, things that were done, or not done are still upsetting for my parents, decades later, but they are comforted knowing of the changes now in practice.

Initially as a student midwife I had no sense of the bereavement of a mother when her baby dies. As I have cared for and spent time with women who have suffered a loss I understand a little bit more every time. One of the biggest things I have learned as a student midwife is that I am not afraid to talk about and acknowledge the death of a baby and finally how proud of my mum I am for completing her journey and commemorating my sister's death.

Discussion

Nowadays, health professionals are far more aware of the impact of the death of a baby on the woman and her family. The SANDS (2016) and RCOG (2010)

guidelines stress the importance of good physical and emotional care for women who have a stillbirth to help identify and minimize psychological and physical ill effects.

Parents are offered opportunities to see and hold their baby, to name him or her, to collect keepsakes, and to make their own decisions about funeral arrangements and memorials. Since 1992, babies who are stillborn after 24 completed weeks of pregnancy have to be registered which means more parents have a certificate to provide official recognition of their baby's existence. Increasingly, people in wider society also recognize that the death of a baby before or around the time of birth is a major bereavement and has life-long consequences.

SANDS (2016) highlight the need to acknowledge the grief of partners or other family members who may be severely affected with depression or anxiety (Lee 2012, and that parental relationships have a higher risk of dissolving after still birth (Gold et al 2010). Counselling should be offered to all women and their partners and they should be advised about support groups.

This case study has highlighted the long- term effects on a woman and her family following a stillbirth and that there is healing in being able to acknowledge and express feelings and experiences, even if this is many years after the event. The unique quality of the relationship created by the midwife and experienced by the parents at the time of a stillbirth will continue to influence a woman for many years to come.

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