Life after death: The bereavement midwife's role in later pregnancies

Abstract

The 'Clinicians in the Classroom' series of articles explored the value of expert clinicians sharing their expertise in the classroom setting (Power, 2016). One of the articles featured Tracy Rea (bereavement midwife), a regular contributor to the pre-registration midwifery programme at the University of Northampton, who invited Chris and Kate to a session to share their experiences of the loss of their son Stanley, and their subsequent pregnancy (Power and Rea, 2016). This article will follow Tracy back into the clinical area to look at her role in supporting bereaved families through subsequent pregnancies, and will include the reflections of a second-year student midwife (Sharon) who spent time with Tracy in her specialist antenatal clinic and peer support group, 'The Butterfly Group'.

Keywords

Bereavement midwife | Neonatal death | Student midwife | Pre-registration midwifery education | Reflection

Milton Keynes University Hospital offers a bespoke antenatal care pathway to women who have suffered a previous loss, by offering care led by their community midwife at their GP's surgery or being offered a referral to the bereavement midwife, Tracy Rea. A benefit of choosing to see Tracy is that women will have continuity of care, thereby avoiding the need to discuss their previous obstetric history with different healthcare professionals as the pregnancy progresses. By giving women this choice they are empowered to be active partners in their care. Equally, if women choose to be cared for by their community midwives, they are reassured that they can contact the bereavement midwife at any point in the pregnancy if they need additional advice or support.

Care by the bereavement midwife

The pathway followed by the bereavement midwife is that when women contact her, Tracy asks for their date of birth and first day of their last period and then takes a full history, including discussing the plan that was agreed with them when they lost their baby. It is important the consultant plan of care for the next pregnancy is noted, to ensure they are reviewed by the appropriate health professionals as early as possible in the pregnancy, depending upon the circumstances of their previous loss. A viability scan is then arranged with the Early Pregnancy Assessment Unit (EPAU). There they will note the history, arrange the 12-week dating scan and refer the woman to the appropriate care pathway. The booking appointment is completed by the bereavement midwife, who places a SANDS teardrop sticker on the maternity notes to ensure everyone involved in her ongoing care is aware of her obstetric history. From here, the women will be seen as regularly as they wish and have shared care between the bereavement midwife and consultant. If the previous loss was due to a fetal abnormality, following a 'normal' 20-week anomaly scan they will continue to be cared for by the bereavement midwife.

Specialist Antenatal Clinic

Schott and Henley (2014) suggest 'any pregnancy following the death of a baby is likely to be an emotional roller coaster of anticipation and heightened anxiety for both parents', and this is apparent in practice as most women want to be seen more often and for longer than the National Institute of Health and Care Excellence (NICE) antenatal pathway guideline suggests (NICE, 2017). Tracy's clinic is arranged in 30-minute time slots to allow sufficient time for women and their partners to express how they are feeling and how they are coping. Anecdotal evidence would suggest that the majority of time is spent dealing with anxieties as a result of their previous loss rather than the current pregnancy. The following case studies uses pseudonyms (NMC, 2015)

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to give an insight into how the involvement of the bereavement midwife in subsequent pregnancies is a positive initiative and 'prioritises people' (NMC, 2015).

Case study: Amber

I met Amber and Chris in the antenatal clinic as they had a consultant's appointment and wanted me to attend with them as they wanted a date for their elective caesarean section. The couple had experienced a previous neonatal death having had an emergency caesarean section under general anaesthesia. Amber appeared very anxious as she'd had an ultrasound scan the previous day and felt the sonographer had been abrupt and insensitive. The sonographer had said she was unable to get measurements of the fetal head as it was 'too big and in the wrong position'. This was an unfortunate choice of words, as in Amber's previous pregnancy there had been cephalopelvic disproportion (CPD), so this comment had triggered painful flashbacks for both Amber and Chris. They were then asked to sit outside for 15 minutes until the sonographer finally approached them to tell them there were no issues with the scan and they could leave. This experience had left the couple anxious and upset until I met them the next day at the consultant clinic.

While waiting in the clinic I was told the consultant was unavailable as she was conducting ultrasound scans all day in another part of the building. As I felt it was important for the family to be seen, as their advocate I approached the consultant on their behalf. I took the family to her and was surprised by Amber's heightened reactions to seeing the scanning machine, until she told me she actually thought we were ushering her into the scan room because the sonographer had found something wrong with her baby and she was going to receive bad news. The consultant reviewed the scan report and confirmed it was normal and she had no concerns. This case study not only demonstrates how important it is for healthcare professionals to use professional language and terminology at all times, as the sonographer's comments caused great anxiety to Amber, but also how valuable it was that I was able to be Amber and Chris's advocate to ensure they received timely and appropriate care.

Case study: Lianna

I met Lianna and John following the loss of their baby in 2016. The family had decided to terminate their pregnancy as the baby had the same genetic disorder as their youngest son, who had severe life-limiting disabilities (Niemann-Pick Disease). They also have two older unaffected children, one boy and one girl. Lianna and John were unaware of the genetic disorder until they were screened when their son was diagnosed. They wanted to expand their family but did not want to have another child with the same condition and so decided to have chorionic villus sampling (CVS) to rule out Niemann-Pick Disease. Lianna's son is now in end-of-life care and she is at 20 weeks' gestation. I anticipate her needing significant reassurance and support throughout her pregnancy, due to the complexity of her situation.

The Butterfly Group

Due to the anxiety of women with a previous loss, Tracy set up and now runs 'The Butterfly Group' with a community midwife colleague, to provide extra support for all women who have had a previous loss, either through miscarriage, termination for fetal abnormality, stillbirth or neonatal death. The group has been running for nearly three years and is an informal opportunity for women to meet others who have had similar experiences and provides them with a safe environment in which to talk about their feelings and experiences. The emphasis is on peer support, with women giving each other advice with Tracy and her colleague in attendance to ensure any advice given is appropriate and in line with current guidelines. Anecdotal evidence from the group suggests that women who have suffered a loss have similar worries, even if their losses are different. They form friendships that carry on after they have had their babies, and many tend to go to baby massage classes together, which are free to women who attend the group.

This bespoke model of care affords additional antenatal support for women and their families who have suffered a previous loss. In addition to the clear benefits for the women, this initiative provides student midwives with a rare opportunity to be part of a particularly sensitive area of midwifery practice. One such student is Sharon, and she is keen to share her experiences.

Reflections of a second-year student midwife: Sharon

I am a second-year midwifery student at the University of Northampton and I aspire to become a bereavement midwife on completion of my training. After my recent experience participating at specialist antenatal clinics with Tracy at my local Trust, my drive to join this specialist field in the future has been further validated.

During my recent placement on the Day Assessment Unit (DAU), I was privileged to be invited to attend Tracy's antenatal clinic, as she was aware of my enthusiasm to gain further knowledge and experience in this sensitive and important area of midwifery practice. This opportunity is not usually offered to student midwives until the final year of training, so of course I grasped it with both hands, feeling extremely lucky and excited to attend the clinic that afternoon.

To some, the role of the bereavement midwife is predominately for the immediate care at the time of disclosure to a woman and her family that their baby has

died, or in the postnatal period following a miscarriage, stillbirth or neonatal death; however, I had the opportunity to see that the role is comprised of so much more. I learned about the experiences of women and their families embarking on their next pregnancy, which can be an overwhelming and frightening experience as many have renewed grief for the baby they previously lost. Pregnancy is supposed to be a positive and exciting experience, but for some women this is overshadowed by feelings of guilt and anxiety, highlighting the importance of involving of the bereavement midwife in their care.

Prior to each appointment, Tracy gave me a brief outline of the woman's obstetric history and gained verbal consent from the women for me to be in attendance (NMC, 2015). The first couple arrived and the woman was visibly anxious, expressing feelings of psychological distress, which included regular sleep disturbance with recurring nightmares. Such symptoms demonstrated to me the deep imprints that bereavement leaves on women in everyday life that were previously unknown to me. I participated in the routine antenatal examination, which included auscultating the fetal heart, and I was taken aback by the overwhelming sense of pressure I felt to locate the fetal heart on the first attempt, since I was aware of the additional significance the reassurance would have for this couple.

It is impossible to describe the look that the woman gave me as we listened to the fetal heart, and this is a memory that will stay with me forever. Upon leaving, the woman and her husband both shook my hand and personally thanked me for caring for them. My feelings at that moment not only confirmed my passion for midwifery, but also reinforced my desire to become a bereavement midwife, as I now have first-hand experience of the positive impact of the bereavement midwife on subsequent pregnancies. When the clinic had come to an end, it was clear how much the women and their partners relied on the support and care they received from Tracy, and how much Tracy cared for them as she ensured she met the individual needs of each and every couple. I sensed a real connection between her and the women and their families. While professional in all respects, I had the sense of an almost familial relationship based on trust, compassion and honesty. I remember walking back to my placement feeling honoured to have been a part of the clinic and in awe of the relationship Tracy fosters with the women and families in her care.

I was also invited to attend the Butterfly Group the following week, which provides women and their families with an opportunity to meet and talk to others who have been through similar experiences, and show them they are not alone. It was clear to me that the Butterfly Group provides valuable support that allows reflections on the past to be exchanged and steps into the future to take place. I observed a feeling of togetherness from the five women who attended that day, each swapping stories and sharing their apprehensions, fears, and hopes.

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I believe bereavement midwives are vitally important to women who are planning a future pregnancy and upon confirmation of the next pregnancy. Having had the privilege of attending one of Tracy's clinics and the Butterfly Group, I witnessed the relationships between Tracy and the women in her caseload and I could see the lengths Tracy goes to when supporting, advising and reassuring women: she is truly 'with woman'.

Conclusion

It is clear that women who have suffered a bereavement and go on to have subsequent pregnancies have specific needs, and that the women in Tracy's Trust are fortunate to have access to a specialist care pathway. Not only do the women and their families benefit from this service but so do the student midwives who have clinical placements at the Trust. Working with Tracy provides them with an insight into the complexities of her role and how she gives outstanding care to women and families during their experience of 'life after death'. Tracy's role is an example of the diversity in the midwifery profession for student midwives upon qualification. As maternity services evolve to meet the ever-increasing and complex demands of women in the UK, these are exciting times for our midwives of the future. **BJM**

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