

Sharing the burden of miscarriage knowledge

A collaborative essay by Aimee Middlemiss and Susie Kilshaw

Pregnancy loss before viability is an experience faced by many women¹, and yet also something which many women will never face. In this collaborative essay, we argue that healthcare education and information sharing in the UK is too focused on the second position, to the detriment of those women who experience miscarriage. Research in social science has repeatedly noted the marginalisation of pregnancy loss experiences in society in general, and within healthcare (see, for example, Earle et al., 2008, Earle et al., 2012, Lovell, 1983, Kilshaw, 2020b, Layne, 2003, Oakley et al., 1984). Recently, pregnancy loss has become more openly discussed in the UK, through events such as Babyloss Awareness Week (<https://babyloss-awareness.org/>), the activities of the National Bereavement Care Pathway (<https://nbcpathway.org.uk/>), research into experiences of pre-viability pregnancy bereavement (Austin et al., 2021, Fuller and Kuberska, 2020, Kuberska, 2020) and personal accounts in the media, including those of celebrities.

However, there has been little public description of the physical experience of the event of miscarriage itself. A recent documentary fronted by Myleene Klass aimed to “start a conversation” around miscarriage, and yet had no discussion of the physical process of pregnancy loss. Indeed, whilst stories of pregnancy loss such as that of the Duchess of Sussex, are no longer unusual in the public domain, what remain untold are accounts of the physical event. Helen², one of our research participants, lost her daughter³ to miscarriage at home at 15 weeks’ gestation and described how she and her husband had no idea what to expect:

Any time miscarriage is dealt with, particularly, it's so...shrouded over. The actual event of what a miscarriage is. I accept you can't, no-one wants to see everything. But it's completely...There's the grief and devastation for the character in Eastenders, or Corrie, or whatever, of 'they've had a miscarriage,' and then that's it. They kind of lie on the sofa with a duvet and a cup of tea. [...] As it turned out, we were very, very ill-prepared for what was about to happen.

This essay draws on our research into the lived experiences of women such as Helen to call for increased knowledge of the physical events of miscarriage and other forms of pregnancy loss. Our collaboration involves bringing together our separate ethnographic research in medical anthropology and medical sociology. Susie’s research has looked broadly at experiences of miscarriage in the UK, including interviews with 40 women who had recently miscarried between 2014-2016 (Kilshaw, 2020a, Kilshaw and Borg, 2020) . Her current research looks at practices around the aftermath of miscarriage including remains disposal. As part of her ongoing ethnographic research in England, she is based at an Early Pregnancy Assessment Unit (EPAU), which sees women up to 16 weeks’ gestation, and the hospital gynaecology ward. Whilst her research includes miscarriages up to 24 weeks viability, the

¹ For an estimate, see Austin et al. 2021.

² Names of research participants have been anonymised where they asked for this, but some of Aimee’s participants such as Helen requested use of their own names.

³ We use the language chosen by participants in our research to discuss their pregnancy losses.

majority of the women she interacts with have experienced miscarriage in the first trimester. Aimee's research concerns later pregnancy loss, in the second trimester before 24-week viability, and includes foetal death, premature labour, and termination of pregnancy for foetal anomaly (TOPFA). She conducted ethnographic research in South West England which included interviews with women who had experienced 34 second trimester losses of wanted or accepted pregnancies between 2003 and 2019 (Middlemiss, 2021b). Both of us are also informed by our own multiple experiences of miscarriage.

In our research projects, we found that most women were underprepared for the possibility of miscarriage, how it might be managed in the NHS, and what to expect in terms of the physical process. This lack of advance knowledge was coupled with limited information from healthcare providers during the miscarriage itself, including underplaying of issues such as duration and pain, and limited detail on the possible range of experiences. Such lack of information has enduring consequences in individual women's lives. Distress and pain may be compounded by shock at how the event unfolds, and lack of detailed information may leave women unable to make fully informed decisions about their care. Many women are left trying to inform themselves about pregnancy loss as it happens, for example using stories recounted online. We argue that this is an unfair burden to place on individual women, particularly at a time of potential suffering.

We therefore propose a two-part solution to remedy this limited awareness, which we hope would reduce the shock of miscarriage and increase support and choice for those who do experience it. We call for more engagement by healthcare workers caring for women experiencing loss in sensitively providing detailed and specific information about the range of experiences of duration, pain, complications, and encounters with the remains of pregnancy or the foetal body. And we call for a comprehensive overhaul of universal health education in the secondary school curriculum about pregnancy loss, including miscarriage, abortion, and termination for foetal anomaly, to raise awareness for everyone of the range and detail of women's experiences at a time when few will be directly facing the possible distress of losing a pregnancy.

The gaps in the knowledge

Research conducted twenty years ago found women had minimal prior knowledge of the processes of miscarriage (Smith et al., 2006, Frost et al., 2007), and our work shows that little has changed since then. Conversations with women in our research revealed a widespread lack of foreknowledge about miscarriage. Women consistently reported that whilst they were vaguely aware of miscarriage statistics, they were unaware of the variation in type, process, duration and management options. For most women, their advance perception of miscarriage was of a sudden and brief loss of blood. This likely to be because of the common and persistent comparison of miscarriage with a menstrual period, an analogy which minimises its impact (Hey et al., 1989). In our research a major problem for women was a lack of forewarning from healthcare professionals about the possible duration of miscarriage or induced labour for foetal death, and a downplaying of the possibility of pain and the amount of blood which could be lost. As Nicole reported to Susie,

When they say 'you may experience pain and bleeding', that pain and bleeding may be worse than labour. My consultant then told me, later, 'You'd be really unfortunate if you had labour that bad.' And I was like, 'No one told me that. No one prepared me for that.' At the time, immediately afterwards, I said, 'If I'd known all of this, I'd have opted for surgery,' in the immediacy of it just having happened. Now I don't know, because I still think there's something quite important about having gone through it because the physical trauma, if that's what you want to call it, totally superseded the emotional grievance and grief and stuff.

Aimee's interlocutor, Tamsin, had laboured before, but was underprepared for the pain of her second trimester induction after her twins died during the pregnancy:

They said that it would be a milder version of giving birth. And that it wouldn't hurt as much as giving birth to a full term baby. And that was a complete no. It was worse! It was *more* painful. And I think that was because of the medication."

Our interviews also revealed limited knowledge about the possible variation in experiences. In later second trimester miscarriage, for example, the lack of availability of surgical resolution is broadly unknown to women. Complications known to be greater in the second trimester, such as retained placenta or blood loss were generally not discussed in advance of inductions. Women experiencing loss before the timeframe of stillbirth therefore do not anticipate having to undergo forms of labour and delivery, as Eva explained, talking about the foetal death of her son 18 weeks into the pregnancy:

I hadn't really realised that you'd have to go through sort of full labour. I just assumed that's what happened when you were, you know, 30 weeks pregnant or whatever. I just thought they could do a quick operation.

The consequences of this lack of foreknowledge were increased distress and emotional turmoil, and a difficulty engaging with healthcare decisions. Potential choices, such as requesting the surgical procedures which are limited by gestational timeframes, or requesting choice about the location and management of induced births, could be limited by lack of advance knowledge.

Lack of information was particularly acute when a pregnancy loss happened at home. This could occur spontaneously, perhaps in the period between diagnosis and appointment for further treatment, or as the result of medical management. Helen, who had the image in her head of a miscarrying woman wrapped up on the sofa, had been sent home after her daughter was discovered by ultrasound to have died *in utero*. Instead of the peaceful pregnancy ending she expected, the baby was born suddenly in the bedroom with a massive loss of blood. She called a midwife friend to help her:

I couldn't get up off the floor, absolutely out of it, and the blood was still coming, and [midwife friend] said, 'you need to call an ambulance, you're losing too much, I can estimate the amount of blood you're losing.' And I really didn't want to, but I just didn't know how to get down the stairs and into the car.
Why didn't you want to?

Because it isn't a medical emergency. I wasn't dying. [...] Everything is so normalised, to the point where you feel 'just get on with it, can't you just cope with a miscarriage?' So you kind of feel like you're the idiot who calls the ambulance, you know. If...I really wish in some ways they'd prepared us for how big it was. I wish they'd said, 'if you need an ambulance, you call it'."

Helen and her husband were also distressed by the unexpected emergence of the baby girl onto the floor of their bedroom when they had expected to encounter her in hospital. Lack of knowledge about what the foetal body or pregnancy materials might look like was a key anxiety for many women. During the final stages of Anna's miscarriage, which followed medical management at home, she described to Susie how she experienced something akin to labour, cramping, dramatic gush of blood:

As I went to wipe myself... there was a baby in my hand, and I just screamed to mum, 'There's a baby!' ... She said, "don't be so silly, there can't be," ... He/ she was tiny, about the size of my little finger.... Rather morbidly... he was kind of disintegrating by the minute. He looks like he was dissolving, like going into a more liquid shape....

Not wanting her mum to flush the baby down the toilet and uncertain about what they should do, Anna called the hospital who suggested looking at the Miscarriage Association website for ideas or bringing him in for the hospital to cremate. Similar to Anna, thirty-five-year-old Kim described being unprepared for the physical experience of miscarrying, the visceral aspect of the loss, uncertainty about whether or not to flush the tissues, and subsequent discussions around disposal following a miscarriage at 12 weeks in the hospital:

I went to the toilet and the baby fell out... I put my hand in the toilet and lifted it out, and the baby was about the size of a snack Mars Bar with the umbilical cord and placenta attached... The nurse came and took the foetus away, put it in a clinical box. Then she started asking questions about a funeral, and I was like, 'What the fuck?'

Like Kim, being unprepared for encounters with the foetal body and uncertainty about what one should do with it was a source of ongoing distress. Description of what women might see and their options for disposal could help them face the sudden births or miscarriages which were common in our research. Women in extremely premature labour were also underprepared for the possibility of a live birth towards the end of the second trimester and some regretted that the shock of this limited their response when birth happened.

In emergency situations it is difficult for health care providers to ensure that a woman has taken in the full meaning of the information they are giving. Furthermore, diagnoses of pregnancy loss and subsequent conversations are often during critical and intense moments, especially if the news is unexpected. Susie's ongoing ethnographic research includes observing health care providers at an EPAU and gynaecology ward. The nursing staff typically give clear and detailed descriptions of what a woman is likely to expect following the diagnosis of a missed or incomplete miscarriage. Yet her previous research reveals that women are commonly left unprepared and subsequently distressed by their miscarriage experience. This disjuncture may be explained by developments in miscarriage care since the interviews in 2015, but it is more likely due to variation in practices within

and across medical sites which Aimee's research noted. Some women, for example, will receive care for a pregnancy loss in Accident and Emergency (A&E), as was the case with Eve when her bleeding intensified. The clinician explained, "we think you are miscarrying" and booked her in for the next possible scan appointment the following day. Soon after Eve returned home, she actively miscarried:

I was really cross because they didn't warn me. They said it would be like a heavy period. No one said it would be like labour. I was shocked.

Despite the good intentions of healthcare providers, some underemphasise possibilities of pregnancy loss during initial assessments. Susie's ongoing research suggests that in their bid to reassure, some health care professionals may overemphasise how common bleeding is in pregnancy and, thus, minimise the threat of miscarriage, leaving women unprepared when a miscarriage subsequently occurs. Our research also showed some understate pain in advance of loss, perhaps in the hope that the woman they are addressing will be lucky, to reduce distress, or perhaps in order to ensure compliance with treatment. The impact of such practices puts additional pressure on staff at EPAUs and gynaecology wards to communicate the reality of pregnancy loss.

Informing society about how pregnancy loss happens

Our collaboration in this essay proposes a two-part solution to improve awareness of what to expect during a miscarriage. Firstly, for women directly facing pregnancy loss there needs to be realistic and clear communication from healthcare providers about the range of possible experiences including pain and duration. This information also needs to be more explicit about what women might see if they encounter the foetal body or remains of pregnancy, or if there is a live birth. We propose that patient information sheets for those presenting at gynaecology, Early Pregnancy Assessment Units, or Accident and Emergency should be more detailed and explicit in their discussion of the physical process of miscarriage, options for management, and what to expect when encountering pregnancy materials and the foetal body. Women facing imminent miscarriage should be encouraged to consider how they would like the process to occur and then given advice to enable this. Information sheets we have seen in our research often gloss over the physical process and women in our research found themselves still underprepared. We also propose improved training for healthcare professionals about pregnancy loss information giving, building on Susie's current work as a patient tutor in her local NHS trust. Furthermore, the focus on standardising healthcare responses to pregnancy bereavement in the National Bereavement Care Pathway needs to be matched with standardised healthcare protocols which prioritise the actual events of loss to minimise pain and distress for women experiencing miscarriage and other loss (Middlemiss, 2021a).

At the same time rather than targeting only those experiencing pregnancy loss, we propose clear and detailed education for everyone. There is a social difficulty in providing information about pregnancy loss during the traditional time in which detailed information is provided to women about pregnancy and birth, when they become pregnant. Pregnancy is culturally framed as a sensitive time when a woman should not be overly stressed, and when to speak about potential problems in pregnancy can be considered insensitive. Yet if

women are not prepared for the possibility of pregnancy loss and have no knowledge of the detail of how it happened, their potential to self-advocate and to make choices about their experience of loss is limited. And if partners also have limited knowledge about options or difficulties, they are also unable to support women's choices, as Helen and her husband found.

We therefore call for a comprehensive overhaul of the secondary school curriculum about miscarriage, abortion, and termination for foetal anomaly in Science and in Personal, Social, Health and Economic Education (PSHE). This would provide universal health education about the possibility of reproductive loss and how it can occur, with details of the processes and range of experience possible in pregnancy losses at various gestations. Bringing more detailed information into the secondary curriculum would ensure more widespread knowledge of pregnancy loss, including for boys and other people who will never personally experience the physical loss of a pregnancy, but who may in future offer support or healthcare to those who do. Earlier healthcare education about pregnancy loss also has the advantage of bringing forward the sharing of knowledge to a time in people's lives when they are less likely to be currently pregnant. Such education would provide advance knowledge, normalise pregnancy loss, and reduce the taboo that many women encounter. At present, women experiencing miscarriage bear the burden of the privatisation of pregnancy loss knowledge, in which some people are lucky enough never to need to know, and others know through shocking experience. Through health education, training, and foreknowledge, we would hope to reduce this burden for individual women in the future.

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