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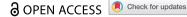
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## 'Now I'm a weird mother who doesn't care': Women's experiences of pregnancy remains disposal following miscarriage in England

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#### **ABSTRACT**

Pregnancy ends and its materials are framed differently depending on the social and historical context. Engaging with scholarship on the plasticity of meaning around pregnancy materials, this paper illustrates how the approach to pregnancy remains has changed in England since the 1980s, with remains progressively being treated as human remains with associated assumption of mourning. The paper revisits interview data collected between 2014-2016 with women who had recently miscarried, revealing diversity in approaches to miscarriage and pregnancy remains. The women's experiences preceded the issuance of guidance by the Human Tissue Authority (HTA) in 2015, which informed revising of clinical approaches to pregnancy remains disposal. The data is important in documenting practices around pregnancy remains and the way such approaches were formalised in activities of care. During the unfamiliar experience of miscarriage, the clinic was a key site of prescription and exploration, having a defining role in the meaning of pregnancy materials. Drawing on ethnographic research the paper provides examples of how women navigate these practices and possible frictions that emerge when approaches differ. The paper argues that clinical practices do not provide sufficient flexibility to respond to the diversity of women's approaches to their pregnancy material.

#### KEYWORDS

Pregnancy loss; miscarriage; disposal; bereavement; hospital practices; England

Maggie' discovered during her routine 20-week anomaly scan that the foetus she was carrying no longer had a heartbeat. Having not experienced any bleeding or cramping, Thirty-seven-year-old Maggie had experienced a missed miscarriage where the foetus' heartbeat stops, in this case two weeks earlier, with the scan revealing a 18-week gestation foetus.<sup>2</sup> Maggie underwent a procedure called 'medical management of miscarriage', which involves the administration of drugs (mifepristone and misoprostol) to expel the foetus from her body. Remaining in hospital for the procedure, Maggie was confronted with discussions about what would happen in the aftermath:



It was actually as I was giving birth...the specialist midwife said:... 'what we do is if you don't want to have a service or funeral... all of the babies are cremated'... And that just made me burst into tears because I felt like somebody else is arranging a service for my...fetus that I am not going to. So now I am like a weird mother that doesn't care: 'there was a service for your baby, and you didn't go?'

Discussions of funerals and cremations were unwanted and turned Maggie's 'fetus' into a 'baby' and Maggie into a 'bad mother'.

#### Introduction

Maggie was the first woman I interviewed in England as part of comparative anthropological research exploring the way in which approaches to and framing of pregnancy loss are impacted by the social context in which reproduction is embedded (Kilshaw, 2020a, 2020b, 2020c). Maggie's experience influenced the development of my current research, which focuses on what is left behind following a miscarriage and includes an investigation into how pregnancy remains are handled and disposed of in clinical and domestic settings. Miscarriage has been the subject of my research for 12 years and I draw on different projects to reflect on persistent themes (Kilshaw, 2020a; Middlemiss & Kilshaw, 2023). A researcher in the area of reproduction with a specialism in reproductive loss, recent work has extended Robson and Walter's concept of hierarchies of loss to include relational elements including ontological positions on what was lost (Middlemiss & Kilshaw, 2023); has investigated women's experiences of clinical disposal processes (Kilshaw, 2024) and pregnancy remains handling in both domestic and clinical settings. In light of this, this paper revisits interview data collected in England between 2014–2016 and analyses discussions about pregnancy remains. By using an anthropological approach, I seek to understand what practices reveal about the values afforded remains in different contexts and by different actors and the moments when these intersect. The paper contributes data in support of other scholar's work, which revealed that aligning pregnancy loss as bereavement structures caregiving in clinical settings (Fuller & Kuberska, 2020) and that clinical practices produce foetal personhood (Kuberska, 2020; Middlemiss, 2021, 2024). The paper shows how such an approach is problematic, as it overlooks the complexity of women's experiences and is not conducive to inclusive miscarriage care.

Pregnancy materials are framed differently depending on the social and historical context (Kilshaw, 2020a; Morgan, 2002) and are the source of the most profound ambiguity. The foetus is a shifting and flexible entity, which can be several things simultaneously, from a part of the woman's body to separate tissue, a bundle of cells, a site of diagnosis, a baby, or a child. A feminist academic literature has explored the cultural nature of the foetus, including Morgan and Michaels (1999), Kilshaw (2017b), Newman (1996), Taylor (2008), Roberts (2012) and Han et al. (2017). This paper contributes to scholarly work exploring the ontologies of the not alive foetal body including those who have published in this journal (Charrier & Clavandier, 2019; Fuller & Kuberska, 2020; Middlemiss, 2021; Smidova, 2019). Whilst engaging with understandings of the foetus, my work encompasses pregnancy remains more broadly and pays heed to the fact that they may or may not contain a foetal body. Whilst this paper and the research upon which it is based focuses miscarriage, I refer to 'pregnancy ends' to acknowledge the complexity and nuance of women's experiences. Incorporating spontaneous pregnancy endings and abortion, the term removes intentionality as the defining element (in the UK context, see for example Austin & McGuinness, 2019; Austin et al., 2021; Kuberska et al., 2020; Middlemiss, 2024) and associated assumptions around reactions to categories of loss. The term more accurately captures the diversity of pregnancy ends including ectopic and molar pregnancies as well as the multiplicity of reactions to such experiences, as revealed in the interviews. Such inclusivity is important, as women sometimes move between categories, as experienced by one participant who miscarried a day before her planned termination and many women encounter different types of pregnancy endings. A key finding of my research is that women's experiences and responses to pregnancy ends are diverse and culturally and socially contingent (Kilshaw 2020a, 2020b, 2020c; Kilshaw 2023; Kilshaw & Borg 2020; Middlemiss & Kilshaw 2023). No two women will have the same experience, and the same woman is likely to experience separate pregnancy ends very differently.

By exploring women's understanding of their pregnancy material and the hospital practices they encounter, the paper contributes to understandings of the ontologies of foetal beings in different ethnographic settings (Kaufman & Morgan, 2005; Kilshaw, 2017b; Lupton, 2013; Memmi, 2011; Middlemiss, 2024). Pregnancy materials may be viewed as waste, an anatomical specimen, or a human corpse with approaches to and regulation of their handling being historically, culturally, and geographically contingent (Morgan, 1999, 2002). Central to this is how this material classified; this may be in relation to value, such as the usefulness of aborted foetuses in medical research (Pfeffer & Kent, 2007). Charrier and Clavandier (2019) show how once considered waste, regulations in France changed to include post 15-week foetus in cemeteries hence changing classifications of these beings and their value. Also concerning the French context and post 15week foetuses, Memmi (2011) reveals how these beings are produced as persons by the prospect of funerals for them, with such practices to be found in Europe, North America, and Australia. In the UK context, Middlemiss (2021, 2024), reveals hospital practices and forms of governance to be inconsistent and contradictory; with disposal practices producing foetal personhood that may not be supported by other practices (see also Kuberska, 2020). Fuller and Kuberska (2020) reveal how discourses of bereavement and memorialisation practices mobilised by charities and others involved in pregnancy loss play a significant role in how it is represented and understood in England. The authors show how aligning pregnancy loss as bereavement structures clinical caregiving (Fuller & Kuberska, 2020): this paper supports these findings and reveals how this is welcomed by some women and rejected by others.

Uncertainty and ambivalence are common themes in narratives of miscarriage (Kilshaw, 2020a). Miscarriage was often unexpected with women describing being unprepared for the experience, this extended to the materials: what would they look like and what should one do with them? During this often-unfamiliar experience seeped in ambiguity women searched for normativity with the clinic a key site of prescription and exploration around the meaning of its materials. Clinical practices informed women's understandings, either through providing a model, buttressing emerging or preconceived framework, or creating friction when the approach was at odds with their own. It is therefore pertinent to understand meanings contained in hospital practices around pregnancy remains as well as exploring women's negotiations with them; the paper does so by drawing on ethnographic research.

The body of data is particularly important in documenting changes in practices around pregnancy remains and the way such approaches have become formalised in hospital documents and activities of care. The women's experiences occurred at a key moment: in the period immediately preceding the issuance of guidance by the Human Tissue Authority (HTA) in 2015 (HTA, 2015), which informed scrutiny and, at times, revising of local and national approaches to pregnancy remains disposal. The ESRC 'Death before Birth' (DBB) project explored the impact of the HTA quidance on local National Health Service (NHS) practices and found over half (44 of 81) of NHS Trusts<sup>3</sup> evaluated had changed their policy in light of the guidance (McGuinness & Kuberska, 2017) with more following in subsequent years. Whilst highlighting variation, the research found that most NHS Trusts framed pregnancy remains as something to be handled sensitively prior to 2015. By reporting on the development of disposal practices in England and showing how these changes increasingly framed miscarriage as significant loss and pregnancy tissue as sensitive material, the paper provides examples of women's experiences of these practices. I argue that women's needs were not being met by these practices: a pertinent finding given subsequent guidance (i.e. National Bereavement Care Pathway [NBCP], 2022) has gone further in positioning miscarriage as bereavement. Clinical practices around miscarriage and pregnancy remains disposal have been reactive, changing to be more sensitive. However, in developing patient-centred practices, hospital protocols may cause pain rather than alleviating it. Key to this is that approaches to, experiences of, and responses to pregnancy ends are diverse and clinical approaches do not provide adequate flexibility to allow for diversity. The paper argues (see also Kilshaw, 2023) that ensuring practices are women-centred, patient- led, and able to accommodate varying approaches to miscarriage is central to inclusive miscarriage care.

## **Background and historical context**

Local clinical approaches to pregnancy material are informed by national guidance, particularly that issued by the HTA, and regulated by UK law. While a clear set of legal rules surrounds the disposal of the body of a baby born dead after 24 weeks, the law governing the disposal of remains prior to this gestational age is less clear (Austin & McGuinness, 2019, p. 139). Historically, pregnancy tissue was routinely treated as clinical waste and incinerated with women not being involved in decisions around disposal. Resonating with the silence around pregnancy endings, there was little interest or public discussion about what happened to pregnancy materials. However, this began to change, as evidenced by a series of scandals and public furores in the 1990s and 2000s. Public concern about the practice of maceration and sluicing of foetal tissue following abortion led the Department of Health (DH) to issue a directive in 1991 to cease the practice and instead to 'store in a secure opaque container in a safe place' before being disposed via clinical waste pathway (Department of Health, 1991a in Myers et al., 2015). NHS Trusts were directed by DH to adopt 'sensitive disposal', a concept meant to mark respect for the foetus 'based upon its lost potential for development into a fully-formed human being' (Department of Health, 1991b in Myers et al., 2015).

Recognising a need for clear professional standards and responding to public perceptions of pregnancy loss, guidance was developed by the Royal College of Nursing [RCN] (2007)<sup>4</sup> and the Royal College of Obstetricians and Gynaecologists (RCOG, 2005), which informed local trust policies as part of pregnancy loss care. In addition, the Institute of Cemetery and Crematorium Management (ICCM) issued guidance for the funerary industry (2015), having been active in the subject of pregnancy remains disposal. The directive stipulated that foetal tissue be incinerated separately from clinical waste, but it also outlined that women should be offered 'ceremonial disposal' (burial or cremation arranged by the health care provider, or privately). The RCN and ICCM guidance suggested that whilst legal, the disposal of foetal tissue as clinical waste was 'completely unacceptable' (Myers et al., 2015). The clinical treatment of these materials demarcated them as distinctive from other human tissue; needing to be separated and handled differently. Pregnancy remains were progressively being framed as significant, meaningful material.

Changes in clinical approaches to the disposal of pregnancy remains have been influenced by a broader cultural shift since the 1980s. As attention began to be drawn to pregnancy loss, it became recognised as a significant life event. Several factors helped to erode the silence around pregnancy loss including the work of academics and charities. Feminist scholars, such as Linda Layne (i.e., 2003, 2006), have been instrumental in demonstrating that pregnancy ends were worthy of academic attention and contributed to public awareness. Charities, such as SANDS (founded in 1978) and the Miscarriage Association (founded in 1982), worked to raise the profile of pregnancy loss and advocate for those affected. Miscarriage was progressively framed as the loss of a baby with associations of bereavement. Similar transformations have been highlighted in a variety of contexts, such as in the US context where Reagan (2003) illustrated the move to normalise public mourning of miscarriage helped to legitimise and make visible the suffering of women whilst reinforcing conventional gender and family norms. Reagan's historical account has resonance in the English context where the experiences of mostly white, mostly middle-class women infused miscarriage with new meanings. Memmi (2011) showed how European hospitals transformed practices around pregnancy loss since the 1980s and 1990s with the focus on mourning with the foetal body and/or pregnancy remains central to bereavement practices and approaches.

A series of investigations, which highlighted a culture of the removal and retainment of human organs and tissue without consent amongst some hospitals, also played a role in a shift in clinical approaches to pregnancy remains. The media reporting of these incidents helped to create a public environment of sensitivity towards the handling, retention, and disposal of remains and pregnancy tissue. The Alder Hey organs scandal involved the unauthorised removal, retention, and disposal of human tissue between 1986-1996. The official report, the Redfern Report (2001), revealed that foetuses and stillborn babies were stored in 210 NHS facilities and that Alder Hey stored 1,500 miscarried, stillborn or aborted foetuses without consent. In response to the report's findings, Parliament established the HTA in 2005, as an independent regulator of organisations that remove, store, and use human tissue for research, medical treatment, postmortem examination, education and training, and display in public.

Pregnancy remains were again the centre of media attention in 2014 when the Channel 4 Dispatches programme 24 March 2014 reported on their routine incineration

without patient consent at some hospitals. In some cases, incineration was part of a waste to energy system, leading to headlines such as 'Thousands of unborn fetuses incinerated to heat UK hospitals' 24 March 2014. In response, the HTA were sought to develop quidance on the disposal of pregnancy remains, despite falling outside the scope of its regulatory remit due to such material being legally considered the woman's tissue. The HTA's guidance was followed by those of the RCN and ICCM (HTA, 2015; ICCM, 2015; Royal College of Nursing [RCN], 2015) to clarify and attempt to provide consistency on the management and disposal of pregnancy tissue. Subsequently, the National Bereavement Care Pathway was developed in 2017 and as is implied in its name, this guidance frames bereavement as the normative approach to miscarriage (NBCP, 2022).

#### **Methods**

The data was derived as part of a larger comparative project, which explored women's experiences of miscarriage in Qatar and England (2012-2017) (Kilshaw, 2017a, 2017b, 2020a, 2020c). The project included ethnographic research (Geertz, 1973) including interviews with 40 Qatari women in Qatar and 40 women in England who had miscarried in the previous six months. Drawing on the fieldwork conducted over 21 months in 2014–2016, this paper focuses on these latter interviews. Women were recruited by way of advertisements on online forums, via the Miscarriage Association website, and from one NHS Trust by means of a study poster. Ethical approvals were granted from UCL Research Ethics Committee, University College London, London, and the NHS Health Research Authority Research Ethics Committee<sup>5</sup> based on best practice around informed consent and participation.

Women were interviewed soon after their miscarriage and follow up interviews were conducted 3-6 months later. Interviews were in person in the participant's home or in a place of their choosing and lasted 45–90 minutes. Individual, semi-structured interviews were conducted as 'guided conversations' (Lofland & Lofland, 1984) and respondent were encouraged to give their own accounts and meanings in relation to the main research questions. Fieldnotes were recorded after each interview. Audio recordings were professionally transcribed verbatim. Transcripts were reviewed for accuracy and familiarity. Data were thematically analysed to inductively identify themes. Fieldnotes and interviews transcripts were analysed using thematic analysis approach, the method was iterative and based on a grounded theory approach (Strauss & Corbin, 1990). Practices around memorialisation and remembering as well as their absence were explored in interviews as was the physical experience of loss. Whilst not prompted to do so, some women's accounts included the handling, management, interaction with, and disposal of their pregnancy remains.

## **Hospital practices**

The research revealed diversity in how miscarriage was framed, experienced, and responded to by women and variation in miscarriage care including approaches to the pregnancy material (see also Kilshaw, 2024; McGuinness & Kuberska, 2017, Middlemiss, 2021, 2024). Women's recollections of discussions around pregnancy tissue were uncertain and vague despite interviews being conducted very soon after their miscarriage. This

may reflect that women were in a state of distress when such discussions took place, making the recollections hazy, or it may reflect that this was not a central element of their experience. When women referred to medical staff communicating practices of disposal, they were often unclear about the content and uncertain about the options offered. Emily, who later commissioned a tattoo to commemorate her miscarriage, was one of the few women who spontaneously mentioned the disposal of her baby following the surgical management of her miscarriage. She remembers the process vaguely:

[Y]ou sign a thing to say what you want to happen to the baby, and everything else, and that was the only thing I hesitated about. It kind of felt a bit weird not doing something, but Duncan was like, 'If you miscarried, [at home] Emily, it would just be nothing and it would just go down the toilet. So, what are you actually going to do with whatever it is? It's not going to be like a baby'. We just let the hospital ... we signed that, the one that most people do anyway. Do you remember what the choices were? They can keep it, or you can choose to bring it home, and they can help you with funeral arrangements, I can't really remember.

In Emily's case, as with others, by introducing choice, hospital practices created uncertainty. This was particularly so when women discovered that different settings provided different options for disposal or forms of memory making.

#### Resonating approaches to pregnancy materials

Zoe's miscarriage was diagnosed at her 12-week scan when it was revealed that her pregnancy had not developed beyond seven weeks. Zoe chose to flush her pregnancy tissue down the toilet, which is what most women in her position did (see Kilshaw, forthcoming). In her case, the physical process of miscarrying occurred in her home following medical management administered in the hospital. Zoe recalled that there was a discussion about what she could do with the material:

There was some discussion of whether we just flush it down the toilet, which is what I did.

Zoe vaguely remembered the suggestion of other options, but not a detailed discussion. As flushing the materials 'made the most sense' to her she did not explore other possibilities with clinical staff. For Zoe, the discussion at the hospital informed her actions and resonated with her understanding of her pregnancy tissue. Zoe and her partner did not consider her pregnancy to be containing a baby, anticipating the 12-week scan to be the point where they would perceive her pregnancy as comprising a being with personhood (see Middlemiss & Kilshaw, 2023). Zoe and her partner did not approach her miscarriage as a bereavement:

We did look around, like, 'Should we be doing something to mourn this loss?' but we just didn't feel that that was appropriate at this level.

For Zoe, hierarchies that link time and duration of pregnancy with magnitude of loss was in keeping with her own understanding. For others, such as Jennifer, their response was at odds with a society who deemed the loss of short pregnancies less worthy of grief (Middlemiss and Kilshaw, 2023). Jennifer experienced friction between her experience and others understanding of it, as those around her did not recognise the magnitude of her grief. However, her interactions with the hospital validated her bereavement:

The thought of passing the products of pregnancy and then having to flush that or dispose of it myself, literally horrifies me. The hospital does a cremation service every couple of months for all the miscarried and stillborn babies, if parents don't want to arrange that themselves. The service is next Thursday and Dave and I are attending ... there's a book of remembrance as well at the hospital, and you can have your child's name and your details, and a little message entered it. So, we've filled in the paperwork for that ... As a hospital, they're really good. They're clearly very on board with supporting parents.

Jennifer expressed pleasure at the hospital's practices and offer of ceremonial disposal of her pregnancy remains. Her bereavement was supported by the hospital whose practices respected the significance of her loss. The hospital was supportive and acknowledged them as 'parents'. Jennifer became a mother when she became pregnant, and she does not relinquish this role when her pregnancy ended:

You didn't just lose a pregnancy, you lost the one-year-old you imagined and the five-yearold on the first day of school and the grown up that you pictured in your mind, even in just those few short weeks .... Even though they might not have been public and it might not have been a child you met and held ... It was your child ... . 'I'm a mum too'. Just because I'm not pushing a buggy or going to the school gate, it doesn't mean that I wasn't a mum.

Such practices turn the foetus into a(n unborn) baby and in so doing turn women into a mother (S. Murphy, 2013). For Jennifer this was welcome as it supported her rendering of herself as a bereaved mother, the practices provided a means to enact her continuing identity as a mother. Austin and McGuinness (2019) note, however, that options for disposal imply explicit meaning to the status of the material and by so doing may convert the pregnant woman into a role or relationship that they do not welcome, as discussed in the next section. Such a transformation is particularly ambivalent as the role is typically not supported by subsequent policies (Middlemiss 2021; S. Murphy, 2013).

One of the hospital practices that Jennifer encountered was a book of remembrance. The act of commemoration prompted contributors to name their foetus, part of a process of producing personhood and kinship. Practices at other hospital similarly encouraged naming the foetus, as with Kim who was unsure how to proceed when hospital staff invited her to provide a name for her baby:

I don't want the baby to have no identity, so 'Baby Smith' was what he went as or what they went as.

For Kim and her partner naming was not something they had considered or planned to do, but once it was suggested by staff not doing so would have meant denying the baby's identity. The hospital practice suggested that the being does or should have personhood. Aimee Middlemiss (2024) illustrates how the giving of personal and kin names was the initial expression of positioning a foetal being as a baby with relational kinship. In the context of miscarriage with its ambivalence towards foetal personhood and legitimation of grieving, naming acts are political acts using 'the person-making power of naming' (L. L. Layne, 2006, p. 37).

Jennifer noted that at no point did the health professionals dismiss her grief as less worthy because of the duration of her 10-week-gestation pregnancy. She felt she was 'very lucky' to have been cared for in a setting, which had a procedure in place that respected and memorialised miscarriage. This was particularly pertinent to Jennifer, as she felt she did not know 'how to do it myself, or even if I should do it mvself':

I certainly found it very helpful that the hospital and ... the support they offered was them [saying], 'Yes, you have lost a baby, and that's really shitty and really sad'.

As Jennifer suggested, the hospital prompted her to understand her experience as a loss of a baby, something dreadful and sorrowful. Jennifer's and the hospital's framing of miscarriage reinforced one another. The hospital practices informed Jennifer's grief, providing a structure for her experience, which she felt was not acknowledged by those around her.

Malaika similarly found resonance with the hospital practices she encountered when she miscarried at 14 weeks:

I was in hospital for four or five days, and the sisters on the ward said, 'Do you want to see your baby?' . . . . They brought him with so much respect. They brought him in a little basket. He was on a beautiful, embroidered sheet with a little blanket on top. They brought him in a special cart. I was able to sit with him. I took a little picture. His body had changed a lot ... so I just took a picture of his little foot near my fingernail.

The nurses Malaika interacted with asked how she was, showed concern, and acknowledged her loss whereas others around her suggested:

Whatever's happened has happened for the best, [its] God's will. You'll have some more. When you get pregnant again, this will be behind you.

This was Malaika's third pregnancy and had followed IVF treatment in India. Malaika met her husband when she was 16 years old, and he was 17. The year after she had become pregnant, but her Indian Sikh parents did not approve of the relationship because he was Muslim. Her parents took her to India where they forced her to have an abortion. Malaika 'ran away' to avoid an arranged marriage, returning to the UK to marry her husband whereupon she converted to Islam. At 18-years-old she became pregnant and described the time following her daughter's birth as very difficult, mainly due to the isolation she felt amongst her husband's Iranian family who did not approve of her. In time, her husband's family became a source of love and support and the relationship with her parents improved.

Malaika described the family's approach as 'quite liberal' and 'not strict' in following the Islamic faith. When she miscarried she wanted to conduct the traditional 40<sup>th</sup> day after death ritual traditional to her family's practice of Islam. Her mother-in- law was hesitant saying, 'I've never heard of such a thing in Iran ... to do the 40th for a baby that hasn't even been born'. Malaika's position on her loss resonates with Alison Shaw's findings that Muslim women in the UK challenged traditional Islamic position that personhood is tied to ensoulment, experiencing miscarriage as a death that should be recognised with funeral rites (Shaw, 2014). Malaika noted that in Indian and Iranian culture women are not supposed to be open about pregnancy loss, however the hospital practices resonated with her approach to her miscarriage:

The patient affairs said, 'Look, we can deal with everything for you'. They were wonderful. They arranged a funeral ... We just turned up on the day .... I wasn't expecting it, the little casket was beautiful. Oh my God, I could not believe how beautiful, and how much respect they showed. They put him in the car, we walked behind the car, and then they took him out, they lowered him. There was so much respect.

The hospital practices followed common funeral customs in the UK where a funeral service, a ceremony honouring the person who has recently died, is followed by either burial or cremation of the body. Funeral processions, as described above by Malaika, led by a hearse carrying the body remain traditional.

The cases described in this section reflect women's diverse approaches to pregnancy endings and their pregnancy material. Varied hospital practices informed women's understanding of their miscarriage. The woman's approach and that of the hospital were harmonious, providing a positive experience of care. However, in other cases women found hospital practices not in keeping with their understanding of their miscarriage and its materials, as will be explored in the next section.

## **Discordant approaches**

Many of women who described encountering discussions about disposal reported negative experiences. This was typically due to the practices not reflecting their understanding of their pregnancy material. Ashley, who miscarried at 11 weeks, recalled:

I had a choice. I think I had a choice of I was allowed to see it, it could go to the crematorium ... 'I don't want to see it. Just get rid of it". [Did it surprise vou that vou were offered those choices?] I was completely shocked. 'Why would I want to see it? It doesn't even look like anything', and they were like, 'some women want to. Some women take them home and do something with them ... a burial at home or something'. I was like, 'no chance' ... it is nothing at that stage. [It is] just a blob. I didn't really think of it as anything because I hadn't even got to the heartbeat stage.

Ashley referred to pregnancies at her stage as containing 'just a growing blob', and suggested that after 12 weeks gestation a foetus 'is more of a baby'. Ashley had not had an ultrasound scan prior to miscarrying and had not seen the foetus nor heard a heartbeat. Like Zoe, she experienced an absence of plot points, particularly the 12week scan, which is central to developing foetal personhood (Middlemiss & Kilshaw, 2023) and did not frame her early miscarriage as the loss of a baby.

In some cases, it was not the duration of the pregnancy and the associated scan, but an absence of foetal development which was key to the woman's understanding of her pregnancy material. Beth described the diagnosis of her miscarriage and the subsequent discussions around what would happen with the 'remains':

In our case, it wasn't very relevant, because I had nothing there, but the nurse said, 'Here's a form about a funeral. Do you want a funeral? What do you want to do with the remains?' Hang on a minute, I've just been told that there's nothing there, and you're asking me: do I want to get it cremated? It's just a pregnancy sac. Why are you even giving me an option? Hang on, what the hell is going on here?

Beth's pregnancy had not developed and there was no embryo or foetus present, something known as an anembryonic pregnancy. Beth found discussion of a funeral inappropriate given the absence of a foetal body. Discussions around her pregnancy material reflected that in this clinical setting there was no differentiation between categories of pregnancy material, which was the case in most settings. This is, in part, due the ambiguity of this material at early gestational stages. Whilst there was a tendency to privilege all materials, some settings treated foetal/embryonic tissue differently from other pregnancy tissue. In some cases, this led to the latter being eligible for incineration whereas the former was not. The DBB project found that in sites where incineration was available, it was generally only permitted in certain circumstances, such as where there were no identifiable foetal remains or with very early losses (McGuinness & Kuberska, 2017).

In some settings, such as where Jenny's missed miscarriage was treated, foetal material was handled differently from other pregnancy tissue. Jenny remained in the hospital where her pregnancy materials were collected and inspected (see also F. Murphy & Philpin, 2010) in order to assess whether the entire pregnancy was expelled from her body. The hospital provided Jenny with a patient flyer, which outlined what would happen to the remains:

Before 13 weeks ... they have a big joint incineration in the hospital, and then after that it's sent, only the fetus, I think . . . they burn everything else. After 13 weeks and up to 24 weeks, they send the fetus to the crematorium and there's a service there. The paperwork said there would be two [religious figures], like a chaplain, present. . . . It wasn't suggested to us that there could be any other options, and, afterwards, we read, in various places, that, actually, you could ask and say, 'No, I want something else'. But I didn't know that at the time and that was just presented as the way it was done. So that's the way it was done.

In this setting, a differentiation of value was made around gestational age with early pregnancy material incinerated on site, whilst later gestational pregnancy remains up to 24 weeks were cremated. A further distinction was made whereby the post 13-week foetus is separated from other pregnancy material with the former cremated off site and the latter 'burned'/incinerated. Jenny noted that the information given to her by the hospital outlined there would be members of a religious order present, further lending weight to a specific reading of the pregnancy materials and their import.

Jenny's comments encapsulate unease about the handling of pregnancy remains, as well as giving insight into changing practices. Whilst consideration was given for sensitive disposal in this setting, women were informed rather than included as active participants in decision making and alternative options were not presented (see McGuinness & Kuberska, 2017). After her miscarriage, Jenny read other women's stories online learning that there were other possibilities for disposal and memorialisation, which caused her uncertainty and distress.

Jenny expressed displeasure that the hospital managed her pregnancy material as 'medical waste' and were 'just incinerated'. In fact, the hospital policy was likely 'sensitive disposal' in the form of communal incineration with other pregnancy remains. There was often confusion in hospital policy about the distinction between incineration practices: 'sensitive incineration' involved separating pregnancy material from clinical waste and disposing separately. Some hospital staff interviewed by the DBB research team expressed discomfort about discussing sensitive incineration as an option of disposal following pregnancy loss, instead calling it 'hospital cremation' (McGuinness & Kuberska, 2017). The authors suggest that this reflected problems with the use of unclear and unbiased communication. Jenny's miscarriage was managed by one of the hospital trusts identified in the 2014 Dispatches programme and subsequent reports, which revealed the hospital incinerated 'fetuses' of less than 13 weeks' gestation at their own 'waste to energy' plant, whilst telling mothers they would be 'cremated'.

In response to the Dispatches programme, the Cambridge University Hospitals NHS Foundation Trust spokesperson said: 'Trained health professionals discuss the options with the patients and families respectfully and sensitively, both verbally and in writing. The parents are given exactly the same choice on the disposal of foetal remains as for a stillborn child and their personal wishes are respected' (Withnall, 2014). This site, along with many NHS Trusts, revised their practices following the issuance of the HTA guidance (McGuinness & Kuberska, 2017) and women are now offered burial organised by the hospital. The relevant Patient information sheet (PIS) outlines: 'There are standard procedures in place for the sensitive disposal of foetal remains following miscarriage; interment (buried) in a local woodland burial site'. Women are directed to the Chaplaincy team for further information and given the contact details of the burial site. Thus, after 2015 incineration was no longer deemed appropriate at this site and the disposal method changed to burial. The quotation above highlights how management of pregnancy remains were aligned with those of stillborn baby.

Jenny's experience is an example of the changing and reactive nature of hospital practices, particularly post-2015, highlighting the fluidity and contingency of approaches. Jenny's experience also illustrates the central role that religion and hospital chaplaincies played and continue to play in the management of pregnancy remains. The information given to Jenny in 2014 outlined there would be a member of the chaplaincy team present during cremation. Post 2015 the chaplaincy continued to have a role in the management of pregnancy remains, being the point of contact for information about the burial site. There was consistency in placing pregnancy remains disposal in the realm of the chaplaincy, which lends itself to a specific reading of the pregnancy materials and their import. The link between religion and hospital disposal was a point of friction for many women, which is the subject of forthcoming work.

## Maggie's story, continued

Maggie, the woman I introduced at the beginning of this article, felt herself to be labelled a 'weird mother' when she did not want a funeral for her foetus. The nurse and the information given to Maggie during her time in hospital produced meaning about her miscarriage (see Reagan, 2003). The suggestion of a funeral service by the midwife conflicted with Maggie's framing of her pregnancy and its material. Maggie reflected on why she had become distressed when the nurse spoke to her about the possibility of a funeral service:

It was just the idea that somebody's going to have a service about something that's to do with me and not them. But now I had this decision that I didn't want whether or not I wanted to be present because I wouldn't have thought about having any sort of funeral. It just felt really over the top and weird.

A funeral was not something Maggie would have considered and the need to engage in such discussions was not something she welcomed. Maggie's language reflected her framing of her pregnancy and the foetus as primarily a part of her and not as a baby with personhood. Understanding her foetus as part of her rather than a separate being coincides with the British law on foetuses but is contradicted by the clinical practices she encountered. A critique of foetal subjectivity has emerged in feminist theoretical perspectives but has not been documented by empirical social science. This position has emerged in my current research with interviews revealing some women resist hospital disposal practices due to seeing their miscarriage materials as part of them rather than a separate entity (Kilshaw, forthcoming). Maggie described the approach as 'over the top and weird'; practices invested her pregnancy remains with value and meaning that she did not share. The process of normalisation prescribes a funeral is the proper, moral, correct thing to do in such circumstance (Kuberska, 2020), imbuing meaning in the material transforming it into a baby. Such practices produced opportunities for frictions for those that do not wish to engage in such person making. At the very least it creates more uncertainty for those who do not innately share such a framing. Several women described discussions around funerals and disposal as a point when they questioned their approach, leaving them wondering whether this was what they were 'supposed' to do.

Maggie was the mother of four children, ranging in age from nine to fifteen-years-old. She had not considered having more children until she met her new partner following her divorce. Having experienced pregnancy and childbirth in England in the first years of the millennium and then again in 2014, Maggie provided insight into the shift in societal and medical approaches to pregnancy. Maggie expressed bemusement that foetus had become an object of affection early in pregnancy with 'bonding' in utero through scans becoming the norm. In previous pregnancies, scans were a medical activity whereas in her more recent experience, ultrasound consultations were directed more at the woman as an active participant or consumer. Julie Roberts (2012) has illustrated how the scanning process is seen as a means to connect with the foetus and develop a relationship with it. Maggie suggested the medical approach to her pregnancy had been informed by this change:

They really sentimentalised it. I found it more upsetting than if they'd been more clinical ... 'this person's going to come in and talk to you about the funeral', and ... I was like, 'Funeral?' [From] foetal abnormality scan [to] funeral.

Maggie and others resisted hospital practices around disposal as oppressive (see Reagan, 2003 for other examples). The implicit associations in sensitive disposal practices are that a pregnancy contains a baby from the moment a woman becomes pregnant.

Maggie's reflections and reproductive experiences illustrate the shift in approaches to pregnancy and pregnancy loss since the 1980s, which has been well-documented in the scholarly literature. Miranda Waggoner (2017) revealed how in the United States a healthy pregnancy is now defined well before pregnancy begins: the zero trimester. The emergence of this pre-pregnancy care developed over the past 20 years with public health messages encouraging women of reproductive age to anticipate motherhood and prepare their bodies for healthy reproduction even when pregnancy is not on the horizon. Parenting has extended its reach backwards in time (Dow, 2013, p. 38;): one only has to look at moral and public discourse around alcohol and food choices during pregnancy (Lee, 2007; Lowe & Lee, 2010; Miller, 1997) to reveal the penetration of intensive mothering (Hays, 1996) to the pre-birth and even pre-conception stage. Hospital practices around pregnancy remains can be seen as in keeping with changing approaches to pregnancy, which emphasise foetal personhood and the creation of a mother very early



in pregnancy if not prior to it. An extension of this is an understanding of women experiencing miscarriage as a bereaved mother and pregnancy remains as human remains.

#### **Conclusions**

In England pregnancy remains are legally considered the woman's tissue (HTA, 2015), but due to the perceived sensitive nature of the material and in reaction to a series of scandals, several relevant bodies issued quidance on the disposal of pregnancy remains (HTA, 2015; RCN, 2007; RGOG, 2005), which inform local NHS practice. Clinical practices normalise understandings of miscarriage and its remains. Since the 1980s pregnancy loss has progressively been framed as a form of bereavement, which leads to a need to address what happens to the 'body' (Memmi, 2011). The woman's experiences described here occurred prior to local NHS Trust policy revisions in light of the 2015 HTA Guidance. Since then, the guidance was reviewed in 2021 and no updates were made; and a number of other organisations issued guidance, including The National Bereavement Care Pathway (NBCP) for Pregnancy and Baby Loss, which was launched in 2017 and updated in 2022. The NBCP takes a position on the implicit personhood of foetal beings. The guidance illustrates a continuing, and strengthening, tendency to construct miscarriage as the loss of a baby, who leaves behind a mother whose appropriate reaction is one of bereavement. A central aspect to this discourse is framing pregnancy remains as human remains that require ceremonial disposal. Whilst located in a biomedical context such an approach counters biomedical -legal discourse which categorises them as non-living, non-beings (Middlemiss, 2024).

Approaches to and understandings of pregnancy, pregnancy ends, and pregnancy materials are culturally and historically contingent, they are also fluid. Thus, it is pertinent to provide detailed information about women's experiences and their perceptions of their pregnancy material to ascertain whether guidance and practices align. Furthermore, are such practices flexible enough to meet diverse approaches to pregnancy endings and its materials? As shown here, there is diversity in how women approach their pregnancy endings and pregnancy remains/material. Approaches vary between women and may vary for the same women for different pregnancies or even during the same pregnancy. Perceptions may range from an inconvenience or a relief to extreme distress and feelings of bereavement; the materials may be perceived as waste, matter, a bundle of cells, or the body of a baby or child. Clinical settings establish norms for women's behaviour and emotion (Reagan, 2003) and, thus, evaluating whether their practices meet women's needs is key. Hospital practices inform, support, buttress, but also potentially diverge from women's framing of their pregnancy end and pregnancy material. In the former this leads to a positive experience of care; in the latter it may exacerbate or cause feelings of uncertainty and/or distress (Kilshaw, 2024). This is why I chose to look more closely at the remains and remnants of miscarriage including the management, handling, and disposal of pregnancy material in clinical and domestic settings for my current research.

Elsewhere I have suggested ways that hospital practices around pregnancy remains disposal could allow for more flexibility by offering a collaborative and tiered system of information sharing (Kilshaw, 2024). I have suggested consenting for pregnancy remains disposal procedures should provide an opt-out, so women are not to be



forced to re-frame their miscarriage and pregnancy material in ways that are unwelcome or upsetting to them (Kilshaw, 2024). Certainly those who wish to engage in person making and frame their pregnancy end as bereavement should be supported in doing so and offered a bereavement care pathway. However, those who do not should not be forced to frame their pregnancy end in a way that challenges their experience of and agency about their body, their pregnancy, and their pregnancy material (Kilshaw, 2024). Understanding diversity in the way women approach their pregnancy materials will help ensure practices are women-centred, patient-led, and are able to accommodate varying approaches and reactions to miscarriage and its materials.

#### **Notes**

- 1. Participants have been pseudonymised throughout the text.
- 2. A note on language. Throughout the paper I use the term (i.e 'foetus' or 'baby') that the participant in question used.
- 3. The NHS is divided into regional areas. An NHS trust is an organisational unity within the NHS services of England and Wales that serve either a geographical area or specialised function.
- 4. The RCN guidance 'Sensitive disposal of all foetal remains' was first published in 2007, updated in 2015 and then reviewed and updated by the RCN Women's Health Forum in 2018.
- 5. For reasons of anonymity and so as not to disclose the NHS Trust in question the specific Research Ethics Committee has not been named and approval reference has not been included but was provided to the editors.

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## **Data availability statement**

Due to ethical concerns, participants did not consent to the sharing of their data, and as such the data supporting this publication are not publicly available.

#### **Ethics statement**

All relevant ethics approvals were sought and gained.

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