

Death before birth: Understanding, informing and supporting choices made by people who have experienced miscarriage, termination and still birth

Fuller, Danielle; McGuinness, Sheelagh; Littlemore, Jeannette; Kuberska, Karolina; Turner, Sarah; Austin, Louise; Burgess, Meera

License:

None: All rights reserved

Document Version

Publisher's PDF, also known as Version of record

Citation for published version (Harvard):

Fuller, D, McGuinness, S, Littlemore, J, Kuberska, K, Turner, S, Austin, L & Burgess, M 2018, *Death before birth: Understanding, informing and supporting choices made by people who have experienced miscarriage, termination and still birth: Preliminary project findings for meeting with representatives of the Department of Health and Social Care*. <<https://testprojectwebsiteblog.files.wordpress.com/2019/03/summary-of-project-findings-report-for-dhsc.pdf>>

[Link to publication on Research at Birmingham portal](#)

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.



death before birth

Understanding, informing and supporting
the choices made by people who have
experienced miscarriage, termination,
and stillbirth

**Preliminary project findings for meeting
with representatives of the Department of
Health and Social Care**

Friday August 24th, 2018

Professor Danielle Fuller
Dr Sheelagh McGuinness
Professor Jeannette Littlemore
Dr Karolina Kuberska
Dr Sarah Turner
Louise Austin
Meera Burgess



UNIVERSITY OF
BIRMINGHAM



University of
BRISTOL

This page introduces the 'Death before Birth' (DBB) research project to provide context to this report. Further details of the project can be found at deathbeforebirthproject.org.

Project team

- University of Birmingham: Prof Jeannette Littlemore (Principal Investigator); Dr Karolina Kuberska; Dr Sarah Turner; Meera Burgess
- University of Alberta: Prof Danielle Fuller
- University of Bristol: Dr Sheelagh McGuinness

Research Assistance

- University of Birmingham: Alex Dixon
- University of Bristol: Mrs Louise Austin

Overall project aim

To examine the law surrounding the disposal of the remains of pregnancy and the ways in which it is interpreted, and to examine the narratives of women and those who support them, focusing on metaphor as a commonly-used resource for expressing the inexpressible.

Project objectives

The research undertaken for this report meets the following DBB project objectives:

- **Objective 1:** Determine the socio-medical and legal contexts within which decisions about the disposal of the remains of pregnancy following miscarriage, termination, and stillbirth are made.
(Objective to be met by performing a content analysis of trust and partner organisations' protocols)
- **Objective 2:** Investigate how professionals supporting women who have experienced pregnancy loss interpret 'Guidance on the disposal of pregnancy remains following pregnancy loss or termination' (Human Tissue Authority, 2015) and how this Guidance impacts on their work.
(Objective to be met through the use of semi-structured interviews)
- **Objective 3:** Gather a dataset of language used by people who have experienced miscarriage, termination or stillbirth and by representatives from our partner organisations.
(Objective to be met by conducting semi-structured interviews and focus group meetings)
- **Objective 4:** Critically assess the way in which understanding of the new HTA guidelines and perceptions of the law have shaped the decisions made and the practices undertaken by those listed in O3 when dealing with the remains of pregnancy
(Objective to be met through the analysis of the interview and focus group narratives using N-Vivo)
- **Objective 5:** Identify key features of the language used by the bereaved and by representatives from our partner organisations when talking about dealing with pregnancy loss, with a particular focus on metaphor
(Objective to be met through the analysis of interview and focus group data using corpus linguistic techniques, the Pragglejaz Metaphor Identification Procedure (Pragglejaz Group, 2007) and Cameron et al's (2009) Discourse Dynamics Approach to metaphor)

Table of Contents

1. Introduction and Context	3
2. The Use of Metaphor to Understand and Communicate about Pregnancy Loss	4
(a) Methodology	4
(b) Findings.....	4
3. Experience of ‘Giving Birth’ and ‘Labour’	8
(a) Pain	8
(b) Provision of information	8
(c) Location of care	9
(d) Standard of care.....	10
(e) Individual experience and preferences.....	10
4. Registration and Certification	13
(a) Choice	13
(b) Significance.....	14
(c) Name of Certificate	15
(d) Knowledge and understanding of law	16
5. Further Issues	17
(a) Experience of registration.....	17
(b) Parental Leave.....	18
6. Miscellaneous	20
(a) Role of Coroners	20
(b) Disposal of Pregnancy Remains	20
Appendix: Most common metaphors in dataset	21

1. Introduction and Context

This document provides an overview of preliminary findings from our research project which, is a socio-legal, linguistic study of how people in England who have experienced miscarriage, termination, and stillbirth reach decisions concerning the disposal of the remains of pregnancy, how their perceptions of the law impact on their decision-making, and how they communicate their experiences and choices to those who are there to support them.

The project engages with an important and large-scale social issue: it is estimated that approximately 1 in 5 known pregnancies end in miscarriage, 1 in every 200 births is a stillbirth, and 2,000 terminations for reasons of fetal anomaly are performed in the UK each year. Yet many of those affected experience uncertainty, ambiguity and silence in the face of pregnancy loss. Often unexpected and unexplained, pregnancy loss engenders complex emotions that are difficult to articulate, even to those in supportive roles.

Our study seeks to replace the social and legal uncertainty surrounding miscarriage, termination, and stillbirth by engaging stakeholders with a view to producing evidence-led policy and practice. This document contains preliminary findings that have emerged from qualitative analysis of:

- Semi-structured interviews with:
 - Bereavement care providers in hospitals within NHS England (8 bereavement midwives, 2 gynaecology nurses, 1 bereavement nurse, and 1 mortuary care manager);
 - Professionals in the funerary industry (5 funeral directors, 8 bereavement service managers, and 2 officers at national funeral care institutions);
 - Individuals who work for charities that support bereaved individuals (n=16);
 - Women who experienced stillbirth (n=9), miscarriage (n=11); and termination following a diagnosis of fetal anomaly (n=11);
 - Partners (n=4) and friends (n=1) of these women.
- 4 Focus Groups with a total of 10 participants:
 - Women who experienced stillbirth (n=7);
 - Women who experienced miscarriage (n=1);
 - Partners of women who experienced stillbirth (n=2).

Our work with bereaved parents identifies the use of metaphor as a tool to understand, communicate and make sense of such difficult feelings. Studying the metaphors that the bereaved parents use when talking about this emotionally-complex, potentially isolating experience and the decision-making processes that accompanied it has provided a powerful way of gaining insights into their thinking processes and of opening up additional lines of communication with support agencies.

English law is not straightforward when it comes to treatment of miscarriage, termination, and stillbirth. Our research examines questions ranging from the status of fetal material to an examination of how law can legitimatise or stigmatise certain sorts of pregnancy loss and bereavement. Through a detailed analysis of interviews with a range of stakeholders and bereaved individuals we uncover the way in which law shapes experiences of pregnancy loss and bereavement.

Working with our partner organisations – the Miscarriage Association, Stillbirth and Neonatal Death Charity (SANDS), Antenatal Results and Choices (ARC) – we are identifying the best ways of using our findings to inform training for supporters, to provide an evidence base for formal guidance produced by the Royal Colleges (e.g. RCN, RCOG), and to contribute to public awareness about pregnancy loss.

2. The Use of Metaphor to Understand and Communicate about Pregnancy Loss

Summary: Implications for communication surrounding pregnancy loss

- It is important for those who care for people who have experienced pregnancy loss to be sensitive to, and tolerant of, metaphorical responses to the situation which at first sight may seem 'irrational' but which are, in fact, powerful ways of dealing with and coming to terms with the situation.
- People should listen to the language that is being used and respond to this language in non-judgemental ways, taking the lead from the bereaved.
- People should avoid language that minimises the loss.
- It is important to validate that a future life has been lost.
- People need to be given time to make decisions following pregnancy loss.

(a) Methodology

- We conducted interviews with 31 women who had experienced miscarriage, termination, or stillbirth, a minimum of six months before the interview and 20 people who support the bereaved persons either through their work with charities or in their role as partners or friends.
- Participants were recruited through the Stillbirth and Neonatal Death Charity (Sands), the Miscarriage Association (MA) and Antenatal Results and Choices (ARC) and although we were able to recruit women who had experienced pregnancy loss, there was a lower response from their partners.
- We recognise that because we recruited our participants through support organisations, our sample is skewed towards those who felt the need for the support that these charities offer. Their experiences may not be shared by everyone who goes through pregnancy loss, as people's grief responses differ in nature and in strength.
- The interviews were semi-structured and 60-90 minutes in length.
- During these interviews we explored participants' experiences of pregnancy loss, focusing on their emotional reactions, what they did with their baby in terms of funerary arrangements, and how they reached their decisions.
- We identified a number of metaphorical themes which were common in our dataset to talk about a number of topics and from this we were able to consider the implications of these metaphors and the insights that they might provide into the ways in which the individuals are experiencing their loss.

(b) Findings

Through our analysis of interviews conducted with bereaved families and support agencies, we have found that the experience of pregnancy loss appears to shape the ways in which people view the world through metaphor. Our main findings are as follows:

- People describe their grief in very physical terms:

- You think you've got everything together and then you sort of *have the rug ... pulled out from under [you]*
 - [those feelings] can really *eat at you*
 - The miscarriage *broke me*. And not much in my life has broken me before. I just kind of ... get on with things and it broke me.
- People experience emptiness on both a physical and a metaphorical level:
 - It's not like losing a parent or – I've lost grandparents and even friends that have died but *it's NOT like that because it's part of you and he's a part of me. It's like I lost myself for a long, long time* and then you have to try and rebuild yourself and your confidence and everything
 - I feel *part of me is missing*
 - We're all sort of left like with *this emptiness inside of us* which is very physical as well as emotional.
 - People experience a distancing and separation from their own body:
 - *I knew my body could do what it had to do*
 - Mine ... stopped growing at six weeks but I was twelve to thirteen weeks pregnant cos *my body hadn't realised that nothing was happening*
 - It'd been several weeks already and that *my body hadn't caught on* that I'd probably need to have some kind of induction
 - *The body's obviously very good at keeping hold of babies that it shouldn't do*, because it did that four times.
 - For some, this distancing allows the body to be given agency and it is then blamed for what has happened:
 - My primary feeling, the first feeling was that *my body had failed me totally*
 - There is a whole range of emotions from *feeling really angry with my body* and myself not knowing that it was happening and for *my body for letting me down*.
 - Participants sometimes see their minds and brains (or parts of their minds and brains) as being separate from their main identities. In some cases this is a conscious decision on the part of the bereaved, perhaps as a coping mechanism, and in others it is an uncontrollable consequence of the bereavement, with these two points lying at opposite ends of a gradual scale:

More retrospective
agency



I completely separated myself from the pregnancy, it was almost – it was just a scientific process that was happening, that was how I dealt with it really

So if I go [to the memorial garden] and think about them and cry maybe I can go home and cry a bit less because I can *siphon off my crying into that part*

The - thoughts get all jumbled and you get claustrophobic and it all just keeps going round and round so *you need I need somewhere else to try and put it*

I think *the sensible part of my head KNEW* (that it wasn't going to happen)

I think you just put up a barrier of being normal to protect yourself but your brain isn't really functioning the same way. *Your brain is just getting you through the motions...* disconnect from what's happening in your life emotionally to get you through the day

I was a mess. So I did really pull it together for [the labour] but *even now I think I wasn't really there*

Less retrospective
agency

- In some cases, people experience a different reality as a result of the pregnancy loss:
 - It's a bit like being *thrown down a path that you didn't expect to go on*. A bit like Sliding Doors? ... that suddenly something's happened to you ... you're going that way and you keep looking but and eventually you can't see that path anymore and *that's your new path*. So you carry on your life but you're in a new world. It's sometimes I compare it *like a parallel world*. Like I can see what our life would've been but this is where we are now. I never expected it but we're creating our own... I think the crux of it is that it will change everything about your life forever.
- This is understood by people who are there to support the bereaved, as these two examples by SANDS support workers demonstrate:
 - When you're grieving *you can sort of enter sort of a grief world* where y- you start to push people away
 - This is what I describe to parents, *if the world is going round that's the world you know* and then when you have a baby that's died *you get off*; you know *the world is still going around* and then as time goes on, you know, *you might go round a couple of times and then get off again and get on again*, do you know what I mean? And then gradually you'll get back on but you have to do it at your own pace *so it's kind of dipping in and out you know*.
- People sometimes attempt to reconcile the death of the baby with an alternative 'reality' in which the lost babies are still alive, by talking as if, on one level, the baby were still conscious:
 - I wanted to bury him with other babies *to keep him company*
 - I went back the following day actually on my own cos I wanted to see him again and I wanted to give him the soft toy and the photo of us because those are the things that he was going to go to the post-mortem with. *Didn't want him to be on his own when he went*.
- This idea of 'reconciliation' is a significant feature of recovery and this can take time. Its importance is recognised and encouraged by healthcare workers, as shown by this extract from an interview with two hospital workers who work with bereaved parents:
 - A: Before the funeral, it's your time to do the things that you wanted to do, so I understand that many dreams you had aren't achievable, but if there are some, our job is to help you dream the dream basically, and lots of them are to do with dad,

but we've had dad who always wanted beer, and he said *I want a can of beer, dad and lad*, we've facilitated that

- B: Yeah he wanted a can of beer with his da- his son and sadly his son was stillborn, *so we let him have some beer in the family room with his baby.*
- Recovery involves an acceptance of the fact that things have changed irreversibly:
 - I went and spoke to the doctor and they just said it'd be something I just got over, basically. They didn't provide any kind of support or anything. They just said, 'give it time, give it time'... you know, I don't think I'll- well, you don't 'get over it', do you. *I don't think I'll ever get over it.* You know, I think you just learn to, urm - *it just lives alongside you and changes you. But I don't mind that. I kind of think I ought to be changed.*
- An essential part of the recovery process involves a validation of the baby's existence:
 - (The family had shown a picture of the coffin at the thanksgiving service) Everyone came out saying it was the coffin that got them. Cos that was shown the coffin was that big... and they realise actually what we had - it was almost a little eye-opener into what we'd gone through, and not for our sake but just to realise we want him to be a person. [...] and that he's- *he was alive* and that *there he was* and *he has a place.*

These ideas were expressed by people who had experienced pregnancy loss at all gestational stages and there were no noticeable differences between the language used by people who had experienced miscarriage, stillbirth, or termination for reasons of fetal anomaly.

3. Experience of 'Giving Birth' and 'Labour'

Summary: Women's experiences of 'giving birth, 'labour', pregnancy and baby loss vary widely.

- Variation is produced by a range of factors:
 - a. pain;
 - b. level of information given;
 - c. location of care;
 - d. satisfaction with medical attention received; and
 - e. individual history and personality traits that may impact one's ability to deal with an experience of pregnancy or baby loss.
- Often women are not fully informed about what they may experience during miscarriage, stillbirth, or termination for fetal anomaly.
- There is no correlation between the type of birthing experience and pregnancy loss a woman undergoes and the desire for formal recognition of baby loss via registration or certification.

(a) Pain

The pain of labour is often downplayed by clinical and medical staff across all birthing situations. Giving birth is often painful regardless of gestation and mode of delivery. Several women who we interviewed spoke about how unprepared they were for the physical pain they would suffer. Lack of information and staff talking about pain in understated language contributed to their 'naivety' about the physiological reality they would experience giving birth.

For example, Alice had a termination at 13 weeks because of a diagnosis of fetal anomaly and opted for induction over a surgical procedure believing that the former would be less painful. However,

It was the most horrific experience. I didn't appreciate how painful it was going to be: I ended up completely off my trolley on any drugs that they could give me. [...] I understand [now], because they induce labour, it sometimes can be more painful than natural labour, because you're inducing it.

Karen, a volunteer for the Miscarriage Association who also runs a face-to-face support group, told us that many women who miscarry are told by medical staff that it will be 'like a period pain':

I get quite a few calls about that: 'how much blood should I be losing?', 'these pains that I'm having, is that normal?', 'I've been getting these pains' and I'll be saying to them, 'well, the pains you are getting are labour pains because your body has got to go into labour for the cervix to open and for the baby to go away.' So the pains that you are experiencing can be really quite severe and they didn't realise they were gonna have these pains. They're told it's like a period pain [...] – it's nothing like a period pain.

(b) Provision of information

Some women experiencing early miscarriages are not aware of what is going to happen to them physically; frequently they are not offered comprehensive information upon confirmed diagnosis, and they may be offered euphemistically-phrased information.

Clarabeau's first pregnancy ended with a miscarriage. She described the vague advice she received after the diagnosis:

The Early Pregnancy Unit nurse said: 'I don't really want you to have a natural miscarriage now because I think it would be quite horrendous because the baby's not as [it should have] been, you could be poorly'. That's all she said. So I said, 'Well, what-, how does that happen? What do you do to stop it?' She said: 'We can't.' She said: 'You lose naturally – when you start losing naturally – you need to come in immediately' and I think it was basically a wing and a prayer that nothing happened.

Sometimes information is offered through leaflets that focus on medical aspects of care, as Clarabeau also told us:

She just basically gave me a leaflet that said what a D&C [dilatation & curettage] was. So, don't eat after 7 a.m., when you come in, don't wear nail varnish.

(c) Location of care

The location in which a woman experiencing pregnancy loss is cared for is likely to determine the options and resources available to her, such as continuity of appropriate bereavement care, pain relief, private room, and provision of relevant information.

Gynaecology wards tend to have a higher patient-to-nurse ratio than maternity wards, fewer staff trained in bereavement care and fewer options for pain relief for women undergoing miscarriages or terminations even though most pregnancy losses are diagnosed in these settings. Julie, a bereavement midwife at a large London hospital, explained:

In the gynae wards there's still substandard care in many ways, one of it being that the facilities are not really ideal. They're on open wards, sometimes, we've just had a single room designated to [women], kind of a bereavement little room inside the gynae ward. The staff don't have enough training, they feel very insecure about delivering babies that are you know on the bigger side, and the pain control is inadequate.

Furthermore, it is not always clear where the woman experiencing pregnancy loss should be – or would rather be – cared for. Specifically, second trimester miscarriages and terminations can occur either in gynaecology or labour wards, depending on hospital guidelines. Maria, a gynaecology ward sister at a large teaching hospital in central England described the complex set of factors at play when choosing an appropriate place of care for women losing pregnancies in the second trimester:

Sometimes it's not appropriate for patients to be cared for on delivery suite, and vice versa. [...] Mid-trimester – sort of early-mid trimester is a bit of a grey area, you know? The mums, some of them don't want to be on delivery suite, they don't want to be in that environment, because they know it doesn't have a happy ending. [...] I think it's wholeheartedly acceptable for women not to be nursed on delivery suite, however, I'm not entirely sure that gynae ward is appropriate either. I think they should have kind of multifactoral caregivers. They should have obstetricians and gynaecologists and nurses AND midwives involved in their care. And it should be away from what we'd describe as a traditional delivery suite.

Many labour wards include especially designated bereavement suites, offering parents privacy and comfort in pregnancy loss. Many of these rooms have been equipped using funding from perinatal death charities.

Some women undergoing surgical terminations of pregnancies following a diagnosis of fetal anomaly must seek medical attention in abortion clinics outside of NHS hospitals. They sometimes describe these experiences as 'being on a conveyor belt', emphasising unavailability of appropriate

bereavement care. Alice's first pregnancy diagnosed with fetal anomaly was terminated by inducing labour but required surgical intervention for the retained placenta. When her next pregnancy was diagnosed with another anomaly, Alice insisted on surgical termination but the local hospital did not provide this service and she was advised to go to an abortion clinic.

I was knocked out, they did what they needed to do, and as soon as I came round I was basically chucked into a waiting room then with other people. And it was... the nurses were very apologetic, that the facilities were rubbish. But then again there was nothing done to assist and it was, yeah it was a conveyor belt. It was horrible and it was rubbish. It was really rubbish.

(d) Standard of care

We need to expand our understanding of 'giving birth' and 'labouring' because it also describes the realities of different types of pregnancy and baby loss experiences. Women do not always expect to have to give birth and to have to labour when they make a decision to terminate a pregnancy due to fetal anomaly or if their baby dies in utero.

It is not just the physical pain of giving birth for which many women are underprepared. A number of women who we interviewed did not know or were not told much about the physical process of induced miscarriage or were shocked to discover that they would have to undergo labour with a stillborn baby. As Sue explained:

My first reaction was just, well, it was just having no idea of what was gonna happen next really because obviously I was 35 weeks pregnant so... I was expecting to have a baby 2 weeks later. I dunno, you know, it had to come out. I didn't really think I'd have to give birth to the baby. It just seemed absolutely barbaric to me at the time to make me do that and I asked if I could have a c-section and they said no.

Like many women, Michelle was not sure what her miscarriage at 14 weeks would involve. She was unprepared for the contractions, bleeding and birth of a 'whole' baby at home. She told us how, before she went home,

We were shown to a separate room and a nurse came in and again she was very good, she was very sensitive and calm and said all the right things but when I asked her what would happen next she seemed a bit shocked that I'd asked? And a bit uncomfortable with the fact that I needed to know how I was gonna get our baby out? And she basically just sort of said, well, because the miscarriage was in progress just to go home and wait.

(e) Individual experience and preferences

How a pregnancy ends does not determine people's choices about memory-making or their opinions about access to registration. Women's experiences of delivery may involve a range of medical interventions: pregnancy loss is not always accompanied by labour.

Some women might choose surgical management of miscarriage or surgical termination of a pregnancy following a diagnosis of fetal anomaly; in other circumstances a caesarean section might be the appropriate mode of delivery.

Opting for a surgical management of a missed miscarriage might be motivated by the desire to control the timing of the loss, for instance due to childcare duties, or knowledge of possible complications of expectant management of miscarriage. Mary told us:

At that point I think I was 16 or 17 weeks pregnant and of course NHS Trust don't perform surgical terminations; only, you know, basically, you go in and and give birth. But I didn't want potentially my last experience of giving birth being this traumatic. [...] We didn't want to put our daughter through that because she didn't know I was pregnant. And I just didn't want to be away from her for a period that I couldn't define so I needed some control over the the the situation and I was really sort of just pushing back against this whole idea of having to go into hospital and give birth.

While caesarean sections following a diagnosis of intrauterine death are relatively rare, they are often requested by parents. Whether or not this request is granted, the circumstances of an emergency caesarean delivery may play an important role in how the experience of stillbirth or miscarriage is remembered. Cathy, whose request to have a caesarean section was denied, recounts:

I did not feel able to go through a normal birth and the head of midwifery was called in. At one point I had the head of midwifery, the consultant anaesthetist, the consultant doctor, the bereavement midwife, and one of the normal midwives, five people all standing round the end of my bed telling me that I couldn't have a caesarean, that I had to go through the natural birth and it was for my own good. And then as they they were leaving the bereavement midwife went up to my husband and said to him: 'If you continue to support your wife's decision about having a caesarean, you will be visiting her in the intensive care unit.'

Conclusion

There is no correlation between the type of birthing experience and pregnancy loss a woman undergoes and the desire for formal recognition of baby loss via registration or certification.

During our research we heard a range of opinions from women who had experienced pregnancy loss about the registration of births pre-24 weeks' gestation. Some were content with an informal certificate of loss that they had been offered by the hospital; others wished for the opportunity to formally register their baby's birth or death. For others, having a certificate or participating in formal registration processes were not actions they wished to take as part of their memory-making practices. How women and their families feel about this issue does not depend on whether a pregnancy ended prior to 12 weeks or much later.

For Juliette, who had a late miscarriage at 20 weeks shortly after a diagnosis of fetal anomaly, access to formal registration is more important than the memory box and certificate offered by hospital staff:

I don't really buy into the whole angel baby thing though, to me it's mawkish; it doesn't fit with my value system. So I didn't like all the angel stuff. [...] When they offered us a certificate I just thought 'no', you know, what's that gonna do? I don't think that's gonna help us. I would have liked to have a birth certificate, you know, for it to be properly registered in terms of systems not, you know, not a fake certificate.

Steph used her knowledge of the law to determine when she would birth her baby who had been diagnosed with a fetal anomaly at 21 weeks. For her, registration was an important aspect of memory-making and end-of-life practices:

I'd researched the law at that time which is when I read about how they treated remains before 24 weeks and after. So I made a conscious decision based on that: I would wait till after 24 weeks for that reason cos I wanted a birth certificate for my daughter. I wanted her to have a proper burial and not be considered just remains.

It is crucial to note that some people do not view certification as the most important way of acknowledging 'a life' or their loss. As Katie, who had a termination at 23 weeks after a diagnosis of fetal anomaly, told us:

And it wouldn't change who he was or how I felt about him or what had happened. None of that would be different if I had a certificate for it. It wouldn't legitimise my experience or make it more real or make it less real or anything.

In sum, most women in our research study would have liked the option of an informal certificate of loss or of life, but not all of them would choose it if it was offered.

4. Registration and Certification

Summary: As noted in the previous sections we encountered a range of views about the importance of registration and certification.

- There is variation in practice about whether certificates for pre-24-week losses are offered.
- Certificates, both formal and informal, performed an important function in being a tangible acknowledgement of participants' experiences.
- Voluntary certification of pre-24-week losses could be an extremely valuable option for some parents. However, not everyone would want to take it up.
- Most participants who experienced stillbirth would rather have separate birth and death certificates.

(a) Choice

In our interviews many views were expressed about provision of certificates of loss and about registration of stillbirth. In the interviews these two processes are often discussed using the same language of 'certificates'.

The discussion below underlines the variation in practice around *informal* certification with some hospitals offering a certificate for pre-24-week miscarriage, others not. This situation of variability expands when we consider the different types of clinics where terminations occur or the different places (within the hospital or outside of the hospital) where people may have a miscarriage.

Where 'certification' was discussed our interviewees said that:

- They had received a certificate;
- They would have liked to receive one; or
- It is a choice that should be offered to all bereaved individuals.

This highlights the importance of having the choice to be provided with a certificate which marks the loss. Harriette, who experienced a miscarriage in the first trimester, summarises this view as follows:

[A]lthough I have my own feelings on that everyone's very different and they're entitled to their own opinion and again I don't want to tread on anyone's toes but, yeah, there was none of that. There was no there was no CHOICE of that either.

None of our participants said that they would have minded being offered a certificate, however, not everyone would have wanted one. Several reasons were provided for why an individual may not want a certificate.

Clare, who had a termination for reasons of fetal anomaly, stated:

I think it would have been ... horrible to have a certificate. Especially as we didn't have a name.

Other participants highlighted the difference between 'official' stillbirth certificates and other informal certificates of loss provided by the hospital.

Juliette, who had a miscarriage at 20 weeks, shortly after a diagnosis of fetal anomaly, stated:

When they offered us a certificate I just thought 'no', you know, what's that gonna do? I don't think that's gonna help us. I would have liked to have a birth certificate, you know, for it to be properly registered in terms of systems not, you know, not a fake certificate.

Whereas Isabel, who had a termination after a diagnosis of fetal anomaly, felt more positively:

[I]t was just it was nice really ... because I know a lot of people can get quite funny about, you know ... not ... the birth not being officially registered and I think that was the hospital's way of saying the birth does matter.

It is important to note that even those who would not themselves want a certificate emphasised that the choice to have such a certificate was important, a view summarised by Alice, who had a termination following a diagnosis for fetal anomaly:

[T]hat's just me, though. I know lots of people who kind of want things acknowledged and, you know, rely heavily on memorandums and stuff like that so certainly having it available for other people ... But, erm, [it was] just not of interest to me.

(b) Significance

As mentioned above, a key theme that emerges is the way in which the option of being provided with a certificate constitutes a tangible acknowledgement of women's experience. Our interviewees described this in terms of acknowledgement of their:

- Child existing
- Being a parent
- Bereavement/ grief

For example, Clarabeau, who experienced a miscarriage stated:

[I] would've liked the baby to have been recognised.

Similarly Alice, who would not herself want such a certificate, said:

I think a lot of it kind of comes down to wanting, you know, your loss kind of recognised or validating that I was pregnant.

The majority of our focus group participants, most of whom had experienced a stillbirth, felt very strongly about the importance of the certificate as evidenced in the following statement:

[I]t's like a birth certificate in a way that's proof that she was here in some form. ... That is proof that she was here that she's a, I don't know, a number but she's a part of our world ... in some way.

Similarly Jodi, who supported her friend through a stillbirth, said:

I think now, as a mum, I would I recognise that you wanna come away from the hospital with something. Some proof of him. Because he did... Yes, he didn't didn't come into the world alive but he did have a life.

Most of our participants felt that certification processes were an important part of the bereavement care process. However, for some this was not the case as is evident in the following statement from Katie, who had a termination following a diagnosis of fetal anomaly:

I mean, no, what's the point of that? ... What's the purpose of that? To register that he existed? I know that he existed ... I don't need telling, I don't need a certificate for that.

And it wouldn't change who he was or how I felt about him or what had happened. None of that would be different if I had a certificate for it wouldn't legitimise my experience or make it more real or make it less real or anything so.

Similarly, a participant in one of our focus groups who had experienced a stillbirth stated:

[I]n terms of the piece of paper he was in my heart. I didn't need to... I think when I read the certificate, it just upset me, to be honest, but yeah, for my husband it was more of a practical thing.

Other sorts of acknowledgement or proof that their child existed were also highlighted. Carly, who experienced a miscarriage, when asked if having or being offered a certificate was important to her, answered:

No, I don't think so. We had the pictures from the scan which I kinda wanted. I don't really know what I'd do with it – fold it away in a drawer or somewhere. I felt like I wanted to kinda mark that this had happened and that ... there was a little person growing and I'm not sure ...if a certificate or medical certificate would have changed that – but having pictures, I kinda appreciate at that time.

As such, any system of certification be it formal, or informal, should be situated within a broader context of acknowledging loss within bereavement care.

(c) Name of Certificate

A key theme to emerge in the discussion with individuals who had experienced a stillbirth was dissatisfaction with being provided with a stillbirth certificate rather than a birth or death certificate. Most participants felt that registration and certification performed an important function in terms of acknowledging their experience. There is, however, a tension between this position and the fact that many participants who had experienced a stillbirth felt that being given a stillbirth certificate rather than a birth certificate devalued their experience and/or their child's existence.

A participant in one of our focus groups summarises this view as follows:

The actual piece of paper itself, the fact that it's written at the top stillbirth, death, is horrible. I would've preferred it to be a birth certificate and then someone else fill in the fact that he died cause, you know, at hospital he died so they have to fill in paperwork anyway. ... I'd've preferred that so because even though the form means to me: yes, he was registered and he was ours and he was our baby I would've preferred if it'd just been a birth certificate.

Another focus group participant emphasised how a stillbirth certificate did not reflect his wife's experience:

[F]or me the hardest thing was it's a certificate of stillbirth ... rather than a certificate of birth because that's almost almost like saying this is different, it is a bit of a slap. ... [A]nd I felt that [NAME] deserved it because she'd had to give birth to him, you know, she doesn't give stillbirth to him she gives birth to him.

As is evident from this statement, receipt of a stillbirth certificate rather than a birth certificate was understood to devalue the experience of giving birth. Another focus group participant felt it implied their child was less important than a born alive child:

I wish I didn't have to register as a stillbirth. I wish she was recognised. I mean, she lived for 40 weeks and 5 days inside me and everyone could see that she was alive because you know and feel it so I don't see what's the difference with that? Of course I can see, you know, maybe a clause that tells them that she didn't breathe air you know but not in any way different from a baby dying from 1-day-old, you know? I just think somehow it makes my experience, my baby, less worthy of being a human being than another though, you know, that had a chance to experience life outside of the womb.

(d) Knowledge and understanding of law

Generally, many of our participants were unclear about the legal meanings and processes which attached to stillbirth and miscarriage. The following statement from one of our focus group participants whose baby was stillborn touches on many areas where confusion was evident:

[W]e had to go to the registry office for that but nobody kind of explained that when you go to the registry office, they don't make any special allowances for the fact that you're registering a dead baby. So we went on a day and we waited in a line and there were babies, live babies being registered everywhere. It was just really really clinical, very cold meeting ... and there'd been a lot of misunderstandings as well so I was told that I could claim some sort of benefit like child trust fund or child benefit or something and then phoned up about that and then was told that because he hadn't taken a breath he wasn't allowed we weren't allowed that money and it was the same with the registration. We were told that we had to go and register his birth but when we went because he'd died during labour we ended up with a certificate of stillbirth not birth and a death certificates and it was like a matter of minutes ... He was probably born with a heartbeat but they couldn't get him breathing. They they weren't sure that he definitely had a heartbeat the last moment before he was born. Um ... yeah, the registration was horrible.

Our findings evidenced lack of understanding of what benefits individuals who had experienced miscarriage and stillbirth were entitled to.

Conclusion

Many participants appreciate the offer/option of certification but some would decline it. It is just *one* means of recognising a baby or a life. And, as we know from our research overall and from our stakeholders, women do want different things.

For some in our sample, an informal certificate of birth or life is not necessary, for others, it is not sufficient (they want formal certification and/or registration). One-size-fits-all is not appropriate as an approach but if all hospitals offered the option that would increase choice/enable agency/a choice to be made.

Our findings suggest that consideration should be given to whether bereaved individuals could be given a birth and death certificate. If this is not possible then it is worth considering whether an alternative name could be given to their form.

5. Further Issues

Summary:

- Consideration should be given to whether registration processes could be improved for bereaved individuals to better accommodate their needs; specifically, could registrations take place at the hospital or at a time when live births are not being registered?
- Training should be given to registrars and appropriate systems put in place to ensure that bereaved parents experience appropriate responses when they register the stillbirth.
- New Zealand has recently introduced legislation to ensure that individuals who experience miscarriage are offered time away from work. Our findings suggest that a similar policy would be welcome in England.

(a) Experience of registration

In accordance with English Law all stillbirths must be registered. There was variation in how our participants experienced this with many reflecting on the process in a negative way.

Deborah's son was stillborn. Her negative memories of the experience of going to register the stillbirth touch on many of the key themes that emerge:

[O]h yeah, we had to go to [NAME] register office to register him. I dunno when we did that. That was horrible because that was still ... I wished we could've done that in the hospital or... Because we had to go sit with the people with their new babies. Waiting to register births. That wasn't very nice. I can't remember being too bothered about it but it's a bit of a ball-ache to have to go do it, you know?

[I]t would've been nice if they could've just we could've done that somewhere else. Yeah, I mean, you probably... do you have to do it at a register office unless it's an authorised place like a wedding? ... [I]t would be nice if they did it on a day that they didn't register baby's births or something like that?

It just wasn't very nice cause, especially, it wasn't very long after he was born so, you know, I was still in maternity clothes or still feeling a bit bleh, that's not very fair. To feel bleh and not have a baby and then looking at people with their newborns, sort of waddling in after having babies, just: sod you!.

As detailed in this account some participants thought that registration could be better facilitated either by taking place:

- At the hospital
 - see above.
- Through an online process:
 - *It's just not nice to go through the process of having to get it and going to the registry. I kind of wonder if – and this is one of the wider points is – we're living in an online world and things now. Why do you have to go and register – why do you have to go down to the registry office to kind of do these things. (Matt, son was stillborn)*
- Or on a day when live births are not being registered:

- *I think a special clinic or a special time you know just half a day a month where registrars are available to register stillbirth babies? So you don't have to sit in the waiting room with live babies? It would be helpful.* (Focus Group Participant who experienced stillbirth)
- *[Y]ou know, it won't take that much for them to make to give a very special day for still... you know ... for families that have stillborn babies. Or even, you know, babies that died, you know, as you know as really young. So there's less contact with living babies when we register, definitely.* (Focus Group Participant who experienced stillbirth)

Our findings suggest that consideration should be given to whether registration processes could be improved for bereaved individuals to better accommodate the needs of bereaved individuals.

Our findings also evidence of variation in the standard of care provided by registrars.

Kim, who had a termination following a diagnosis of fetal anomaly, describes efforts to minimise the impact that being around parents and babies might have:

[T]he registry office we called them up and said we were coming down and they made arrangements so that we didn't have to sit in the baby room with all the other people registering their babies. So they took, kept us to one side and although as you're doing registration they're kind of in pods, so you can see other people but they were aware enough not to kind of have us in the in the general waiting room, so... But again, that was again, it's tougher than we ... it's a tough thing to have to do.

Others had a less positive experience. Selena's twins were stillborn at 25 weeks. She recalls:

Pregnancy, giving birth and then even after I gave birth it supposed to go cause it's a stillbirth, it's not a late miscarriage. So up to twenty-four weeks it's miscarriage and after twenty-four four weeks it's already stillbirth. I needed to go and register <tearfully> the death of my children so we did go and I, well, was supposed to call register office and make and appointment and go and register them. <tearfully> So we did call, we said why we want to go there and for what and we came to register office and lady came with big smile and asked: <imitating>hello, good morning you came to register birth of your children</imitating> <tearfully>and I just ... I just sat down and was like looking at her like what did she said? ... I said, I said it's not a birth it's a stillbirth er<tearfully>.

Our findings suggest that training be given to registrars and appropriate systems put in place to ensure that bereaved parents experience appropriate responses when they register the stillbirth.

(b) Parental Leave

We encountered very mixed accounts of how employers reacted to pregnancy loss and stillbirth. This is increasingly visible in public policy discourse with MPs calling for changes to statutory protections for leave from work following the death of a child. The opportunity to take time away from work was highly valued by bereaved individuals.

The importance of the ability to take time away from work was evident in the statement of Steph who had a termination at 27 weeks following a diagnosis of fetal anomaly:

[A]fter the 24 weeks I knew that I'd get my maternity leave. From work. Which is really basically used as bereavement leave in that circumstance and the fact that you know if that

happened a week before you'd be expected back at work is crazy. So obviously I knew that I'd have that time to you know just be off grieve properly.

This view is echoed in the words of one of the supporters we interviewed who worked as a doula:

For them [the couple] it was, practically, because those things were practically helpful because she'd have got maternity leave which meant that she didn't have to return to work in any... sort of, as a grieving parent It gave her breathing space, for definite.

For those who experienced pre 24 week losses there was variation in the support offered regarding return to work and bereavement leave. Harriette, who experienced a miscarriage, was not offered any information about whether she would be entitled to time off work:

Whether that'd be like an optional thing or an actual thing that has to happen. Because even I was like: do I need to tell my GP or do you tell them or do I? Do I get a sick note? Or? And they were like: 'no you just you have surgery and you go home.' I'm like: err okay.

The level of leave offered to partners also varied. Deborah and her husband were both able to take four months off after their son was stillborn:

Work were good. I was entitled to maternity leave anyway so and I I didn't even think about it, I didn't care. If I had to quit, I'd've quit. So they just said, when you're ready. Whatever you want. So that was fine. And they paid me in full for a month and then put me on maternity pay so that's and that's a nice gesture. [my husband]'s work paid him in full –no, half,) something like that, full then half. I don't know. We were off for four months in the end together so that was quite good. That was a nice support because we knew we would have time on our own? So work were quite helpful in that respect.

This contrasts to the time given to one of our focus group participants whose husband was expected back at work within two days:

He was expected to go back to work within 2 days. And we hadn't even, we hadn't even had the funeral at that point so he phoned up and they increased it to 3 days. So he went off sick and he lost his job. He lost 5 or 6 jobs in the first year because he they were just not understanding at all. They just expected too much of him and he really struggled like he just broke after about 6 months, he was just not able to work at all and there was no understanding that he'd been through the same loss I had and I was entitled to 9 months off work and he was not entitled to anything.

The experience of return to work goes far beyond statutory protections and there is currently a gap in existing human resource policies on how people who experience pregnancy loss should be supported in their return to work. Our findings suggest that many work places do not have clear policies and processes in place to facilitate time away from work following miscarriage and stillbirth. Although such policies may exist they were not always easily accessible to participants.

6. Miscellaneous

(a) Role of Coroners

We did not explicitly ask our participants whether they would like to have an inquest following stillbirth. However, our analysis does evidence the importance of finding out what happened to their baby and whether it would happen again. This largely arose in discussion of post mortems. For example, Deborah described her response to being offered a post mortem:

It was a no brainer for me, I don't see why you wouldn't. I needed answers. I need the information and I also wanted information that might be able to help someone else. If it was my future pregnancies or other people, so I just needed his legacy needed to be helping. So we did what we could.

Some participants experienced a delay in the return of post mortem results:

It took 17 weeks for any results to come back so that was really ... They said, I think they said 12 weeks, actually. But because it was July to August, there was, staff had gone on holiday, blah blah blah, notes ended up on the wrong desk with somebody who had left and it was just, you know, all those sorts of things but um ... So I had the funeral in that time which, again, was a really difficult day.

As such, our findings highlight two areas that may be worth discussing regarding the role of the coroner:

- The nature of the process:
 - what is the purpose to find out what happened to the baby/ to find out what happened in terms of care provided?
- Timelines and funding:
 - is there a danger of adding further delays and interruptions to the bereavement process?

During the course of our research it became apparent that there is variation in practice regarding determination of signs of life and variation in whether cases were referred to the coroner. Variation in referring to the coroner was sometimes explained by wanting to protect parents from the process.

(b) Disposal of Pregnancy Remains

This topic is discussed fully in our Report to the Human Tissue Authority on disposal of pregnancy remains (less than 24 weeks gestational stage):

<https://deathbeforebirthproject.org/research/htareport2017/>

Individuals who experience miscarriage have more options available to them for what they might do with the remains of pregnancy [cremation, burial, sensitive incineration, burial at home or at some other site subject to certain limitations]. The options available to those who experience stillbirth are circumscribed by law. In considering whether to change the definition of stillbirth, consideration should be given to this as many of our participants valued having a range of options available to them.

Appendix: Most common metaphors in dataset

Rank	Metaphor category	Example	No.
1	Reification	that grief comes in waves and in the beginning the waves of grief are close together and very rough (.) you know (.) erm but they are waves of grief (.) you go in and out of grief (.) but as time goes on the waves of grief do get further apart and they get more gentle so grief kind of changes (.) it doesn't go away it changes	674
2	Moving ego	it feels impossible to shift and move forward and imagine that they'll ever get beyond (.) this moment	589
3	Journey	I'm veering one way or the other people will I suppose (.) move forward on it in a way that I suppose is congruent with their conceptualisation of their experience it is a sort of your transition back out of raw grief to to er to where the world you're rebuilding life again	414
4	Physical location	they don't quite grasp where a bereaved person is it's meeting parents where they are in their grief as well	374
5	Body-related or embodied metaphors	what is your gut feeling, what's your what's your heart saying? are you gonna remain broken forever like this? we're all sort of left like (.) with this emptiness inside of (.) us which is (.) ve-very physical as well as emotional	212
6	Animacy	I'm quite happy to go with um a burial with other babies because that feels right, that then my baby is with other babies I said I want him to go outside I want him to see stars, and my husband went, 'oh right, okay' and he picked him up and he walked him outside the fire exit and stood outside with him for a couple of minutes, and then afterwards I was	169

		thinking, well, I should've been supported by the midwives to get into a wheelchair and and spend some time sort've outside with him or sitting outside and in the in the underneath the stars. But I was made to feel that wasn't an option.	
7	Metonymy	[MIDWIFE NAME] was really sweet, she said, you know I have to put a lid on him. I'm really sorry I have to put a lid and I know that sounds awful but we can't really go through the hospital... when we found out that they had twin to twin transfusion syndrome, erm (..) we were taken into a room. We ended up calling it the shit room, because whenever someone gets shit news you get taken into the shit room, so we got taken into the shit room	158
8	Container	it's kind of (.) you know, you move in and out of grief it will come and bite you on the bum if you bottle it all up	138
9	Seeing	lot of people have serious traumatic issues, er, it's very vivid, especially the long-ago bereaved. It's, you know, they can smell it, they - they're back at the hospital. It's very visual, it's proper trauma when we look back, it's like we were underwater. It's all a bit fuzzy	124
10	Agency, lack of agency	I'm taken upstairs to what I can only describe as a conveyor belt. it put (me) in a very- in a dark place for a, quite a while, you know. Erm, I think the only thing that pulled me out of it was this kind of, you know, this kind of need to be pregnant again	109
11	Divided Self	You can't be with yourself. you sort've have a bit of your brain that, that allows you to have all these things happen without you getting too	104

		emotional	
12	Crumbling, breaking, falling apart, fixing	<p>they was, like, trying to force me to do it cause they was thinking I will regret it but I knew what is the best for me in that moment cause I knew that if I gonna see them, I just, I just gonna, I don't know, die? I- I'm not gonna put myself back together</p> <p>I would say it's heartbreaking. I do feel, as I say, a few chips in my heart that are never gonna be kind've- and I know you don't get over it, you just kind've like any grief I think you just learn to live with it and the pain dullens over time.</p>	81
13	Presence, accompanying, absence	<p>even though he's gone you need t- to be creating those memories that're gonna stick with you forever.</p> <p>We will tell both, both children that they've got a sister. An older sister. We say goodnight to her every night, um, the girls say goodnight. The girls say good night but [NAME] looks out of the window and we say goodnight to [NAME] and I say goodnight to grandad. We do that every night um and she'll always be there.</p>	78
14	Physical sensation, pain	<p>it is common but it still hurts and that's the thing isn't it? Still hurts.</p> <p>you know [NAME] achieving a milestone is, is a knife in the heart every time</p>	77
15	Inside and outside	<p>I think the reaction of the GP, because he was quite dismissive, it has almost invalidated the experience so I very much almost blocked it out?</p> <p>I was still stressed although I knew he is alive. It is, like, just sits inside you.</p>	77

Acknowledgments

We would like to acknowledge the Economic and Social Research Council for funding this research (Project Reference: ES/N008359/1).

We would like to thank our project partners (The Human Tissue Authority; Antenatal Results and Choices; Miscarriage Association; SANDS) and project participants.

We are grateful for the advice of our stakeholder advisory group (Caroline Browne and Adam Whittaker, Human Tissue Authority; Ruth Bender Atik and Catherine MacLennan, Miscarriage Association; Jane Fisher, Ante-natal Results and Choices; Ross Jones, Stillbirth and Neonatal Death Charity; Rick Powell and Brendan Day, National Secretary of Federation of Burial and Cremation Authorities; Jessica Read, Chair of the Local Supervising Authority Midwifery Officers' Forum UK) and our academic advisory group (Prof Sarah Cunningham Burley, University of Edinburgh; Dr Elsa Montgomery, KCL; Prof Jonathan Montgomery, UCL; Prof Elena Semino, Lancaster University).

For further information about the project see: deathbeforebirthproject.org.