

PREFACE

TALKING AND WRITING ABOUT PREGNANCY LOSS

Before taking readers through the experience of second trimester pregnancy loss in England, I need to explain my choice of language, and its relationship to the experiences of my participants and existing literature in the social science of reproduction. Language choices are important in writing about pregnancy loss, because language contributes to the construction of gender through reproductive discourse (Martin 1991) and in literature dealing with many types of reproductive loss (Letherby 1993, Jensen 2016, Moscrop 2013, Peel and Cain 2012, Lovell 1983, Jutel 2006). Medical terminology related to fertility difficulties, such as the notorious diagnosis of ‘incompetent cervix’ applied to some women¹ in my research, moves into everyday language use and carries with it gendered content about the responsibility of female partners in sexual reproduction (Bowker 2001). Observations about the judgement and responsibility implied by the term ‘miscarriage’ have been made elsewhere (Layne 2003, Jutel 2011b, Kilshaw 2020b) and these were echoed by women in my research, such as Helen, whose second child died *in utero* and was born at 16 weeks’ gestation in a traumatic incident at home:

I don’t like the word ‘miscarriage’ anyway. It’s just clunky and awful, and it feels like there’s blame there. It’s quite a clinical term, of a woman’s body just *mis*-firing, you know, it’s *missed* something, it’s a kind of *mis*-take. You know? It is a horrible word.

Language can be, and has been, used to marginalise or devalue women and their bodies in their reproductive endeavours, and therefore the choice of language in this work is a feminist issue.

By necessity, there have had to be some compromises made in this work, because shared understanding of language is important in the communication of research. For this reason, I will sometimes

use limited examples of the medical terminology to which women in my research objected. Where possible, however, I have avoided this unless quoting directly. I try to select the most neutral terms or the terms women used themselves. For example, I use ‘premature labour’ to encompass events such as preterm premature rupture of the membranes (PPROM) and also ‘incompetent cervix’, because both can result in preterm labour and birth. I use ‘termination for foetal anomaly’, however, rather than the more lay term ‘TFMR’ (‘termination for medical reasons’) often used in online discussions, because in this research terminations occurred specifically for foetal anomaly rather than because of any health complication of the pregnant woman. The medical term used is usually ‘TOPFA’ (‘termination of pregnancy for foetal anomaly’), but this phrase is cumbersome to use in the text and was not used by women themselves.

‘To Them, It’s Just a Foetus’: An Exploration of the Terms ‘Foetus’ and Baby

There is no neutral term in English to refer to the human conceptus (Lupton 2013). The medical and scientific term ‘foetus’ applies to all mammals, and therefore does not contain meaning related to specifically human social life, which limits its usefulness in this study. In England, ‘foetus’ also excludes foetal personhood claims because it refers to the live birth understanding of legal personhood acquisition in which there is no person until the foetus fully emerges from the pregnant woman’s body and ceases to be a foetus (Herring 2011). This is encapsulated by Holly’s story in the Introduction, in which she objects to medical use of the term for her daughter: ‘to them, it’s just a foetus’. Foetus and person are legally distinct categories, and so ‘foetus’ cannot be the only term used in a study which in part investigates personhood claims denied by the law. In addition, ‘foetus’ is not used in ordinary English speech about accepted pregnancy (Duden 1993, Rothman 1993). It has been argued that the use of the term with regard to reproductive loss is a deliberate depersonalisation of the experience which is an exercise in medical power (Hey 1989). Many women in my research strongly objected to the term ‘foetus’. Natalie, whose second son died *in utero* and was later discovered to have a serious congenital syndrome, explained her vocabulary choices:

'Foetus' is what's normally used as well when, you know, you don't want the baby. Someone's, you know, intending to not go through with the pregnancy. To sort of disassociate the fact that, with that baby. But yeah, as soon as you find out you're pregnant you tell everyone, don't you, 'I'm having a baby!' Not, you know, 'I have a foetus in my uterus!'

The main alternative to 'foetus', and the term used in lay contexts in England, is 'baby', observed in other studies of women in mid-pregnancy in the UK (Lie et al. 2019). This term was preferred by most of my participants, though significantly not by all of them. Using the term 'baby' has its own difficulties, in that the language contains a form of personhood recognition, and this can be seen as threatening to the pro-choice position on abortion, which will be discussed in the Introduction. Furthermore, even within medical discourse in England there is inconsistency in terminology. For example, the official NHS online guidance for parents-to-be uses only the term 'baby' from conception (NHS 2019b). The Royal College of Obstetricians and Gynaecologists uses 'baby' alongside 'fetus' when referring to late foetal death in professional guidelines (Royal College of Obstetricians and Gynaecologists 2010a). Categorisation of the second being in a pregnancy, the one which is not the pregnant woman, can be inconsistent or mutable, even in medical contexts (Williams, Alderson and Farsides 2001) or in contexts of abortion (Pfeffer 2008).

Other scholars, particularly feminist ones, have noted similar terminological difficulties (Jutel 2006) and have tried to resolve them with a variety of terms including 'unborn' (Duden 1999, Lupton 2013), 'prenatal being' (Giraud 2015), 'born-still' (Hayman, Chamberlain and Hopner 2018), 'fetus/baby' (Markens, Browner and Mabel Preloran 2010, Markens, Browner and Press 1999), 'foetal entity' (Ross 2016). In this book, I use 'foetus' in relation to medical description, but I prefer to use 'foetal being' in many other circumstances, because this term gives a sense of contested and contestable meanings and fluid boundaries, including the possibility of prenatal or posthumous personhood. I use the term 'baby' when this is used by participants in the research, as other UK studies have done (Death Before Birth Project n.d.). One of my participants, Paula, who had experienced termination for foetal anomaly, chose before the interview to use the term 'foetus' to refer to what she lost, although during the interview she also used 'baby'. In referring to Paula's story, I use 'foetus'. The other women

who experienced termination chose the term 'baby', and in line with other work (Mullin 2015, Ludlow 2008), this study will show that there is not necessarily an incompatibility between claiming foetal personhood and kinship with the foetal being, and taking a decision to terminate a pregnancy.

'Still Attached to Pain': Using the Vocabulary of 'Pregnancy Loss'

The term 'reproductive loss' has been used by other scholars in this field to include all forms of pregnancy loss including termination, maternal death, and other losses relating to reproduction such as the absence of a 'normal' experience in high-risk births (Earle, Komaromy and Layne 2012). I do not adopt it here because my field of inquiry is specifically defined and does not include, for example, maternal death. Furthermore, this was not the vocabulary used by my participants. Some used the term 'baby loss', which is the term used by many charities in relation to the UK memorialisation and recognition movement, connected to participation in the international 'Babyloss Awareness Week' (Sands 2023). However, not all participants saw themselves as having lost a 'baby'. An alternative widely used in the UK is 'pregnancy loss'. Although in the USA this term has been critiqued on feminist grounds as being uncritically close to anti-abortion campaigners (Reagan 2003), I believe that in the UK it has a different meaning. The term is widely used in lay discourse, particularly online, and is generally understood to include any woman who defines herself as having a loss, whether the loss was spontaneous or induced by termination. It has connections to the 'baby loss' movement, which in the UK can also include terminations, but does not fully adopt the position of baby loss. It is understood in medical discourse in the UK (Moscrop 2013). It also has a history of use in social science and related literature (see for example Layne 2003, Cecil 1996, McNiven 2016).

The phrase 'pregnancy loss' includes a wider definition of what a pregnancy is than alternatives such as 'foetal demise' or 'miscarriage', which focus on the foetal body alone, or impute blame to the woman's body, because 'pregnancy loss' includes the changes to the woman's body and the relational aspects of pregnancy (Parsons 2010). Whilst Parsons claims that the term 'loss' is not always sad, this is not the case in my study, where I use the phrase 'pregnancy loss' because the women in this research were talking about wanted,

planned or accepted pregnancies, as Natalie's comment on the term 'foetus' above illustrates. There was loss, of varying character and content, involving sadness, also of varying character and content, in all the stories I relate here. Amber had struggled to find ways to publicly speak about the death of her daughter due to termination for foetal anomaly after diagnosis of a foetal genetic disorder. Five years after the loss, she had found a form of words to use if people asked about her reproductive history:

'I'd a little girl that I lost.' I could say that, now. I felt really, like, when it first happened I really struggled with how to explain it. Whereas now I can. I know. I know the reality. But 'lost'. I feel like that's . . . acceptable. Palatable. For me.

For you, or for other people?

Both. Yeah.

Has that word got enough content in it for people to understand . . . ?

Yeah, it's general enough. And still attached to pain.

'Pregnancy loss' can act as an umbrella term to include spontaneous and induced foetal and neonatal deaths which are mourned, which might in other contexts be called 'miscarriage', 'stillbirth', 'premature birth', 'termination for medical reasons' or 'abortion', and this is the sense in which I use the term here. The phrase contains within it the sense of unwished for outcomes. In this sense it connects to wider definitions of relational loss which extend beyond bereavement (Miller and Parrott 2009) and does not exclude pregnancies which are terminated, since these may also be forms of loss even if a bereavement is not claimed (Hey et al. 1989, McNiven 2016, Sheach Leith 2009).

Anonymity and the Ethics of Using Names in Research

Although the default practice in social sciences is to offer anonymity to human research participants, this is not always the most ethical choice in research which claims to listen to people who are marginalised (Kvale and Brinkmann 2009). At the outset of the study, I decided to offer alternatives to full participant anonymity for three reasons: potentially challenging the stigmatised and marginalised topic of pregnancy loss; feminist acknowledgement of the role of participants in the creation of knowledge; and acknowledgement of the role of naming in the production of foetal personhood,

which is so central to the research topic. I decided that automatically conferring anonymity on research participants in the case of already marginalised women simply because this is the research convention risked compounding their invisibility. In other social research on pregnancy loss, decisions have also been made against automatic anonymity, with partial naming of participants (Healthtalk.org 2019, Peelen 2009, Oakley, McPherson and Roberts 1984), and naming of research participants has been used in feminist anthropology of pregnancy (Browner and Root 2001). Sociological ethnographic research in London has argued that the naming of participants, with their consent, acknowledges participant contributions to knowledge creation (Sinha and Back 2013).

Beside the potential naming of study participants, the naming of the beings who have died in pregnancy loss by their parents is a political act which asserts personhood, the child's place in the family, and one's role as a parent (Layne 2006). In British culture, individual and family names are conferred on children by parents, and it is parents who carry the primary responsibility for reporting a birth and registering a name with the state. These issues are further discussed over the course of the book, in relation to inclusion and exclusion from birth registration, and the kinship practices used by women in this research, especially in Chapters 4 and 6. The naming of individuals in memorial events can also be used to establish political or moral accountability (Bodenhorn and vom Bruck 2006). This has been seen in the UK in responses to the 1998 Omagh bombing, when unborn twins were included in a memorial representation, and in relation to the 2017 Grenfell Tower disaster, when stillborn Logan Gomes was included in casualty lists. Naming and including the post-viable unborn as persons in certain contexts is already part of UK culture. Women, such as those in this study, who name their children who die before 24 weeks are therefore making claims about the validity and importance of those beings. Excluding from written research the names of pre-viability foetuses who have died could be construed as an act of silencing of the women who gave those names to their dead babies and who use the names when referring to them. The complication here is that having a name is designated a child's 'right' under the UN Convention on the Rights of the Child (Bodenhorn and vom Bruck 2006) and therefore it could be argued that recognition of the naming of any foetus to some degree carries with it a recognition of a form of foetal rights. As discussed in the Introduction, arguments around abortion law in England are a constant presence in this book.

In my research, I offered choices to women who participated in interviews, ranging from complete anonymity, to the complete use of participants' real names throughout the project, with their consent. Professional funeral director LeighAnne Wright chose the latter option, as did participant Helen Woolley. In between these choices, I offered anonymity in relation to direct quotes and descriptions in the body of the research, in which the participants are pseudonymised in the body of the text. This level of anonymity conserves the privacy of the participants, so that quotes or behaviour are not attributable to any specific person, and protects the privacy of non-participants in the research, such as family members. I included an offer to publish participants' names in a general list acknowledging their contribution to the research, and/or to include any names of their dead babies if they so wished, in a memorial page, which both acknowledges the contribution of women to the research and allows them, if they wish, to link their participation to named babies. This page can be found at the beginning of the book. Most of the women who took part chose options meaning that either their own full or partial names, their babies' names, or both, are listed on these pages whilst they are pseudonymised in the text.

I decided not to pseudonymise babies at all, because it would undermine the significance of the names which were chosen for them by their parents. I therefore refer to them in the text in relation to the ontological claim made by the pregnant woman, such as [baby]. This was often an expression of their kin relationship, and these relationships were gendered where sex was known, such as [daughter]. This approach preserves the privacy of wider family members whilst honouring the naming decisions of participants. I extended this approach to other people referred to by participants, using relational terms referent to the woman who took part in the research, such as [husband], [partner], [boyfriend].

Except where participants have discussed details in direct quotes, I have not specified in detail why particular pregnancies ended. Instead I have given relatively general explanations such as premature labour, foetal death or termination for foetal chromosomal or congenital anomalies. In doing this, I seek to both preserve privacy, and to avoid any intrusive speculation about the reproductive decisions of my participants.

Note

1. The persons who took part in my research identified as women, and I therefore use this term throughout the book, but many of the findings about classificatory aspects of second trimester pregnancy loss and pregnancy in general are likely to have relevance for other birthing persons.