“It’s such a hard and lonely journey”: Women’s experiences of perinatal loss and the subsequent pregnancy

Thesis

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Dedication

This thesis is dedicated to my first baby, David
Your life was too short but no less precious to me
Your legacy lives on in these pages

Abstract

Background: Perinatal losses are devastating life changing events for mothers, with psychological consequences both after loss and in the following pregnancy. Societal taboos result in disenfranchised grief, with inconsistent support available.

Aims: This qualitative study aimed to understand the holistic journey of perinatal loss and the subsequent pregnancy from mothers with lived experience, exploring what support made a meaningful difference.

Methods: Qualitative data were collected via forty online surveys and five face-to-face semi-structured interviews with mothers who had experienced a perinatal loss followed by a living child. The data were then analysed using reflexive thematic analysis to develop themes that can inform policy and practice.

Findings: Under the overarching theme "losing [a baby] shaped who I am today" three main themes were developed, representing the development of the individual. The first theme centred on the embodied experience, capturing the unique nature of losses taking place within the living body, how this impacted women's relationship with their body and fed into the next pregnancy with a mixture of hope and trepidation. Secondly, language was developed by participants to challenge societal silence, legitimise the personhood of their loss, whilst creating a community of support. The final theme, "it's my body, it's my pregnancy" denotes women taking action to develop choice and ownership over their care and support needs, whilst navigating the reliance on and frustration with the healthcare system.

Conclusion: These findings have implications for therapeutic practice, as well as healthcare policy and practice more broadly. The lasting impact of perinatal losses suggests that fertility narratives need to be considered when developing psychological formulations. Counselling psychology can play a meaningful role in perinatal care by supporting healthcare professionals in developing empathic care pathways that validate grief responses, as well as challenging the pervasive medical language of both perinatal losses and distress.

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1. Background Literature and Study Rationale

1.1 Introduction

Perinatal loss includes any losses that occur during pregnancy or shortly after birth (Kersting & Wagner, 2012). This research explores women's experiences of perinatal loss and a subsequent pregnancy resulting in a healthy infant, particularly mothers' experiences of support throughout their fertility journey. Whilst there is a growing body of research exploring men's lived experiences of perinatal loss (Nguyen, Temple-Smith, & Bilardi, 2019), with a call for further evidence on the psychological distress of partners (Hunter, Tussis, & MacBeth, 2017), for the purposes of this project the choice was made to focus on the mother, due to the direct impact her wellbeing may have on any infant she carries (Hogg, 2013).

I will begin by examining what is currently understood about the psychological impact of perinatal loss, including the literature on post-loss support and interventions. Perinatal losses are often sudden and unexpected, compounded by the way in which, despite their prevalence, there is societal denial of such losses, through the assumption that they are uncommon, which can lead to a failure to recognise their importance (Murphy, 2012). Recognising the significance of perinatal loss, I will then explore perinatal mental health needs during the subsequent pregnancy, where the risks of depression and anxiety are shown to be elevated due to the loss experience (Hunter et al., 2017). The way in which women are supported by midwives during and following a loss has a significant impact on women's loss experiences and how they cope with the grieving process (Evans, 2012). Therefore, this will be followed by a discussion of the role of midwives in caring for women who are experiencing psychological distress both at the time the loss occurs and in a subsequent pregnancy. Finally, I will summarise the limitations of current research, including what I perceive to be the potential contribution counselling psychology research can make to this research area, and outline the aims of the current study.

1.2 The Psychological Impact of Perinatal Loss

Perinatal loss includes several types of losses; miscarriages, losses up to 23 weeks gestation; stillbirths, losses from 24 weeks, where there are no signs of life at birth; and neonatal loss, babies who live less than 28 days (Office for National Statistics [ONS], 2020a; 2020b). As many as one in five pregnancies end in miscarriage, resulting in over 45,000 hospital admissions annually in England (NHS Digital Secondary Care Analysis, 2019). In England and Wales, over 2500 stillbirths were recorded in 2019 and over 1700 neonatal deaths recorded in England in 2018 (ONS, 2020a; 2020b). Perinatal loss impacts women from all socioeconomic backgrounds and of all ages (Robinson, Baker, & Nackerud, 1999), with long-term economic and psychosocial consequences for families affected (Heazell et al., 2016). Despite the prevalence of perinatal loss, western societies often fail to recognise the significance of such losses and the psychological impact on those who experience them (Heazell et al., 2016; Mander, 1999; Martel, 2014; Peppers & Knapp, 1980). However, the psychological consequences can be significant, with depressive disorders directly following a miscarriage being reported in 10-50% of cases (Lok & Neugebauer, 2007) and post-traumatic stress disorder found to be seven times more likely for mothers bereaved by stillbirth or neonatal loss (Gold, Leon, Boggs, & Sen, 2016).

The expectation of having healthy babies that live into adulthood has increased over the last century in line with prosperity, and reduced infant mortality (Badenhorst & Hughes, 2007). Advances in modern medicine have meant that early confirmation of pregnancy and regular ultrasound scans are now commonplace, which can lead to a false sense of security in the belief that a perinatal loss will not happen (Robinson et al., 1999). Societal expectations and the cultural emphasis placed on motherhood, as well as a lack of recognition for the loss, and blaming oneself, can all contribute to isolation following perinatal loss (Worden, 2009). A second layer of marginalisation can compound this for those who have non-normative pregnancy and loss experiences, such as lesbians’ experiences of miscarriage (Peel & Cain, 2012). Wojnar (2007) found that the sorrow of a miscarriage for lesbian couples was compounded by the lengthy and often complex journey of becoming pregnant. This was described as the “amplification of loss” by Peel (2010, p. 724) due to the level of investment in the pregnancy from the earliest stages, resulting in even early losses having a devastating emotional impact (Peel & Cain, 2012; Peel, 2010; Wojnar, 2007). This illustrates that the emotional journey through pregnancy is not necessarily in line with the biological progression, making the medical labels attributed to the different forms of perinatal loss, such as miscarriage and stillbirth, largely arbitrary (O'Leary & Warland, 2016). However, perinatal loss research tends to focus on a specific type of loss, particularly drawing a distinction between early losses, such as miscarriage and ectopic pregnancies (for example Geller, Kerns, & Klier, 2004; Lee & Rowlands, 2015; Lloyd Jones, 2015), and stillbirth or neonatal loss (for example Boyle, Mutch, Barber, Carroll, & Dean, 2015; Cacciatore, 2013; Campbell-Jackson & Horsch, 2014; Cena & Stefana, 2020), which fails to fully represent women’s experiences. How a woman feels about her pregnancy, if it is planned or not (O’Malley et al., 2020), the level of investment in the pregnancy (O'Leary & Warland, 2016; O'Leary, 2004), such as that resulting from the use of fertility treatment (Harris & Daniluk, 2010), are all factors which may influence her response to a loss.

Cultural factors, including religious beliefs, can also impact individuals’ responses to loss, as well as they way in which their losses are framed by those around them. Mothers who experienced stillbirth in Ghana were actively encouraged not to speak or think about their loss, which limited communication with healthcare professionals (Meyer, Opoku, & Gold, 2018). Time with the deceased was discouraged and losses were framed as “God’s will”, with any reminders limited due to superstitions over the impact on future fertility (Meyer et al., 2018, p. 273). A study of women in Chhattisgarh, India noted the value placed on women’s ability to produce healthy children, with some reports of abandonment by partners after stillbirth, or replacement by another woman who could bear living children (Roberts et al., 2012). Different cultures may have traditional ways of framing perinatal losses, but grief responses are difficult to generalise, due to the variation on both religious and cultural practices even within ethnic groups (Whitaker, Kavanaugh, & Klima, 2010). There are complex interactions between socio-economic status, family context, religious beliefs and cultural norms in perinatal experiences (Squire & Sookhoo, 2017). For a multicultural society such as the United Kingdom (UK), the cultural differences between ethnic and religious groups take place within the context of increasingly medicalised pregnancies, which can fail to cater for diverse frames of reference (Einion, 2017; Squire & Sookhoo, 2017).

Language around early losses has developed in line with advancements in medical technology and societal expectations, with ‘miscarriage’ being favoured over the medical term ‘spontaneous abortion’ since the mid 1980s (Moscrop, 2013). For those whose losses sit on the margins between legal definitions of miscarriage and stillbirth the distinctions made through these labels can exacerbate distress, by failing to prepare women for the process of giving birth and invalidating their experience through the lack of legal recognition of their baby’s life (Smith et al., 2020). Therefore in order to develop meaningful research on the distress and support needs relating to perinatal loss, studies need to be inclusive of all types of loss experiences and explore the perspectives of those with lived experience.

Despite recent efforts to increase awareness of perinatal loss through charity campaigns, such as Baby Loss Awareness Week (SANDS, 2018b) there are still a lack of socially agreed norms in how such grief should be processed, and a lack of recognition of the severity of such losses (Markin, 2016). The surrounding culture and community have an important influence on the grieving process (Klass, Silverman, & Nickman, 1996; Testoni, Bregoli, Pompele, & Maccarini, 2020). For perinatal loss the influence of culture and society may be a hindrance rather than supportive, as the surrounding community may not respond to the loss in the way they might to other deaths (Peppers & Knapp, 1980; Worden, 2009). This has led to the term ‘disenfranchised grief’ being applied to perinatal losses (Worden, 2009). Doka (2009, p. 37) defines disenfranchised grief as “the grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, publically mourned or socially supported”. This can complicate grief responses and leave the bereaved feeling isolated.

Seigal (2017) describes the inadequacy of grief theories when applied to the loss of a child. In her experience of counselling bereaved parents, she describes the struggle to find meaning in the chaotic and overwhelming circumstances surrounding death, while at the same time searching for ways to remain connected to their lost child. Many of her observations apply as much to perinatal loss as the loss of an older child, particularly the way in which society has names for those who have lost a partner (widow or widower), and those who lose their parents (orphan) but there is inadequate language to represent parents' experiences of losing a child (Seigal, 2017). The death of a child seems unexpected because of the way in which it disrupts the 'natural order', which assumes that babies should outlive their parents (Jaffe, 2014). Perinatal loss may be a particularly unique form of grief due to the embodied experience of loss (Garrod & Pascal, 2019) and the combination of both guilt and connection of mothers to their lost child (Testoni et al., 2020).

A perinatal loss is not only a time of bereavement but can also become a threat to women's identities, due to societal pressure and cultural expectations around having children (Jaffe & Diamond, 2011a; Jaffe, 2014; Moulder, 2001), as well as personal expectations that can lead to feelings of failure and guilt (Murphy, 2019; Robinson et al., 1999). The perceived failure to nurture and protect the developing infant can lead to self-blame, despite the lack of control over the experience (Jaffe & Diamond, 2011b; Murphy, 2019; Testoni et al., 2020). This is compounded by the way in which the social elements of parenthood, such as taking care of and raising the infant, are privileged over biological elements of parenthood, such as contributing genetically and physically carrying the baby during pregnancy (Murphy, 2012). Stillbirth is particularly found to negatively affect women's self-esteem in comparison to those without a loss experience, perhaps related to the conflict between the internal role of mother, and the lack of external expression of this role (Wonch Hill, Cacciatore, Shreffler, & Pritchard, 2017). Murphy (2012) questioned if the term "bereaved parents" after a stillbirth was a contradiction in terms, due to a lack of societal recognition of parenthood where there is no living infant, despite legal entitlement to maternity benefits. The lack of legitimising early losses, through legal rules on when birth and death certificates are provided, can lead to women questioning the legitimacy of their grief (Jaffe & Diamond, 2011a; Smith et al., 2020). Recognising that perinatal loss is a significant life event, it is therefore important to ascertain what is helpful to those who live through these experiences.

Increased understanding of the importance of the grieving process, has led to active encouragement by professionals for memory making with the deceased infant (LeDuff, Bradshaw, & Blake, 2017; Reynolds, 2004), including the use of cold cots to extend the timeframe families can spend with their babies (Smith, Vasileiou, & Jordan, 2020). However, there is some evidence that those who hold their babies after a stillbirth are more likely to experience symptoms of depression and posttraumatic stress (Hughes, Turton, Hopper & Evans, 2002). A systematic review of the evidence on the impact of contact with the baby following stillbirth, on parental mental health and wellbeing, found not enough quality research to draw conclusions (Hennegan, Henderson, & Redshaw, 2015). Yet, using objects of comfort, such as blankets and clothing, in the making of memories is seen as helpful to parents in their grief process by recognising and giving meaning to their experiences (LeDuff et al., 2017; Seigal, 2017), and mothers do not regret their choices to hold their deceased infants (Hennegan et al., 2015). Finding meaning in the midst of the loss experience is thought to be an important process in order to adjust to life beyond the loss (O'Leary & Warland, 2016; Worden, 2009). Engaging in the grief response itself can serve as a continuing connection to the lost baby, and may be heightened by anniversaries, due dates or pregnancy (Jaffe, 2014).

The support provided to women after a perinatal loss varies widely (SANDS, 2016; 2018a; Siassakos et al., 2018), and there are mixed findings on what interventions are helpful (Hennegan et al., 2015; Koopmans, Wilson, Cacciatore, & Flenady, 2013; Reynolds, 2004). Social support plays a key role in loss responses and the healing process (Randolph, Hruby, & Sharif, 2015), with peer support playing a particularly significant role in giving bereaved mothers the opportunity to connect to those with shared experiences (Boyle et al., 2015). There is an increasing consensus for the need for improvements in bereavement care provided in the healthcare setting after the loss of a baby (Shakespeare et al., 2020), however this global effort focuses predominantly on stillbirths, which therefore does not acknowledge the needs of women who experience earlier perinatal losses. A number of charities have worked with the UK government to develop a 'national bereavement care pathway', which was piloted across 11 NHS trusts in 2017 and now includes 67 sites across England (SANDS, 2020). The latest report evaluating this initiative highlights an improvement in care within the trusts included, with positive feedback from both parents and professionals questioned (Donaldson, 2019). However, there are still examples of inconsistent or insensitive care within hospitals, and the report highlights the way in which on-going care is solely provided through referrals to outside agencies, relying heavily on the third sector to provide psychological support. This means that despite improving standards of bereavement care within hospitals and improving consistency across different trusts, there will remain different levels of support within the community depending on what is locally available.

Both social and professional post-loss support has been found to make a difference to the levels of psychological distress experienced by mothers (Badenhorst & Hughes, 2007; Bhat & Byatt, 2016; Kong, Chung, & Lok, 2014; Lok & Neugebauer, 2007). However, the literature on post-loss interventions does not indicate how these interventions might shape the experience of the following pregnancy. Despite on-going improvements to bereavement care in the NHS, the 'national bereavement care pathway' is focused on the care of those experiencing loss, and does not include bereaved parents who are pregnant again (SANDS, 2020). When considering the future, parents are unsure what care can be expected in subsequent pregnancies, which impacts the on-going fertility decisions of couples (Meaney, Sarah, Everard, Gallagher, & O'Donoghue, 2017). As many as 85% of women who lose a baby go on to become pregnant again within 18 months (Cuisinier, Janssen, de Graauw, Bakker, & Hoogduin, 1996). It is therefore important to examine how perinatal loss experiences impact upon the experience of a pregnancy following a loss.

1.3 Perinatal Mental Health in the Pregnancy Following a Loss

Perinatal loss and traumatic birth experiences are considered risk factors for a range of mental health problems, such as depression, anxiety and post-traumatic stress disorder (Biaggi, Conroy, Pawlby, & Pariante, 2016). Pregnancy is considered a time of high vulnerability to mental illness, including both the first onset of mental illness and the relapse of previous conditions (Hanley, 2015). Bereavement can also be a time of considerable distress, particularly in the case of experiences of disenfranchised grief such as perinatal loss (Worden, 2009). Whereas in a first pregnancy loss may be neither expected nor anticipated (O'Leary & Warland, 2016; Robinson et al., 1999), the pregnancy following a loss is experienced through the filter of the link between pregnancy and death (O'Leary, 2004). A pregnancy after loss is not only potentially a time of fear and anxiety due to previous pregnancy experiences (Jaffe, 2014; Moulder, 2001), it is also a time when the individual is still possibly grieving their loss. The intensity of their grief may be heightened by the experiences of the new pregnancy due to triggering memories of their previous pregnancy, particularly when antenatal care is being provided in the same clinic or hospital as the previous pregnancy (O'Leary & Warland, 2016). Those with a lack of social support are particularly at risk of experiencing perinatal mental health problems after a perinatal loss (Bhat & Byatt, 2016).

Measures of depression and anxiety have been found to be significantly elevated in women who are pregnant following a loss when compared to pregnant women with no perinatal loss history (Armstrong & Hutti, 1998; Geller et al., 2004; Hunter et al., 2017; Shapiro, Séguin, Muckle, Monnier, & Fraser, 2017). Despite the birth of a healthy child, the symptoms of depression and anxiety associated with a perinatal loss can persist in the postnatal period (Robertson Blackmore et al., 2011). However, even for individuals who do not reach psychiatric thresholds a variety of conflicting emotions may be experienced, with any subsequent pregnancy shaped by the previous death and anxiety over possible further loss (Mills et al., 2014). These experiences can be improved through emotional and psychological support, but care provided can be inconsistent due to the lack of clear evidence on what interventions are effective (Mills et al., 2014). A systematic review of the care before and during pregnancies after stillbirth found only trials relating to medical interventions and a lack of evidence on psychosocial interventions (Wojcieszek et al., 2018). This review considered it urgent to assess interventions that could address psychological distress during subsequent pregnancies. Positive relationships with midwives and informal social support can mediate the fears women may have during pregnancy by accounting for the individual's personal and social context (Fisher, Hauck, & Fenwick, 2006). Although women rely on and value the emotional support of healthcare professionals, there is limited access to professionals who are skilled at this provision, with inequality found across the UK (Mills, Ricklesford, Heazell, Cooke, & Lavender, 2016). In addition to this, exploration of support often focuses on support during a pregnancy after a stillbirth or neonatal loss, with the acknowledgment of the needs of women who have experienced earlier losses seemingly absent from the literature.

In a qualitative study that involved mothers writing diaries during the pregnancy after a loss, the metaphor of "navigating an uncertain journey towards the desired destination of a healthy child" was used to summarise the experience of the second pregnancy and birth of a healthy child (Moore & Côté-Arsenault, 2018). The authors characterised the subsequent pregnancy as a mixture of anxiety and hope, with anxiety more prominent in early pregnancy and hope increasing as confidence grew in the pregnancy going well. The diaries themselves were seen to be a useful tool for managing the mixed emotions the mothers experienced during the pregnancy. The women in this New York based study were part of an intervention that included receiving regular home visits, the positive impact of which featured regularly in their diary entries. An Australian based qualitative study of women with access to a specialist 'pregnancy after loss clinic' also found women expressed their anxieties over their pregnancies, desiring a greater understanding from healthcare professionals (Meredith, Wilson, Branjerdporn, Strong, & Desha, 2017). These women also found reassurance and support through access to the specialist clinic (Meredith et al., 2017). The data of both of these qualitative studies (Meredith et al., 2017; Moore & Côté-Arsenault, 2018) does not capture the experiences of women who rely on the standard treatment within the NHS in the UK, without such regular access to support and reassurance from healthcare professionals.

During pregnancy, psychological distress has unique consequences, not only impacting the woman's antenatal and postnatal experience, but also the development of the infant (Hogg, 2013; Hughes, Devine, Mesman, & Blair, 2020; Oates et al., 2012). Evidence suggests that antenatal depression and anxiety in the mother can be linked to a range of negative consequences for the child from birth to age 16, and possibly beyond, including emotional and behavioural difficulties (Bauer, Knapp, & Parsonage, 2016; Bauer et al., 2015; Hay, Pawlby, Waters, Perra, & Sharp, 2010; O'Donnell, Glover, Barker, & O'Connor, 2014). Antenatal depression, independently of postnatal depression, has been found to impact a mother's responsiveness to her child, with links to poorer infant development (Pearson et al., 2012). However, poor outcomes are not inevitable, and therefore there is a need for policy changes that prioritise identifying those most at risk to ensure prevention or early intervention (Stein et al., 2014).

The attachment relationship between a mother and her child, which develops throughout pregnancy, is considered important for children's physical and psychological wellbeing (Rowan, 2017). However, the development of maternal-foetal attachment can be delayed by antenatal anxieties (Rowan, 2017). In the pregnancy following a loss there is evidence of women employing self-protective measures including distancing themselves from the developing infant, for fear of a further loss (Côté-Arsenault & Donato, 2011; Lee, McKenzie-McHarg, & Horsch, 2017; Mehran, Simbar, Shams, Ramezani-Tehrani, & Nasiri, 2013; Schott, Henley, & Kohner, 2007). The diary entries of women in the Moore and Côté-Arsenault (2018) study indicated a withholding of attachment as a result of the fear of loss. The term 'emotional cushioning' has been used to describe the range of self-protective measures taken by women in the pregnancy following a loss to manage the combination of hope and fear that may result from their previous loss experience (Côté-Arsenault & Donato, 2011). In Lee et al.'s (2017) integrative review of the impact of perinatal loss on the 'maternal foetal relationship' in the subsequent pregnancy they found evidence for the use of coping mechanisms, including “emotional detachment from the foetus”, and an awareness by mothers of the impact this may have on the relationship with their infant. Lee et al.’s (2017) review focuses on the mothers’ response to loss, and coping strategies, and although the authors highlight an increase in healthcare utilisation in the next pregnancy, the review does not address the impact of the support these women receive, either post loss or during the next pregnancy.

1.4 Providing Perinatal Mental Health Support

Pregnancy is unique in terms of the number of times an individual is in contact with professional services, including midwives, doctors, health visitors and medical support staff more broadly (Oates et al., 2012). It is therefore an unprecedented opportunity to identify those with psychological difficulties and offer interventions that can prevent some of the long-term consequences of psychological distress during pregnancy (Hogg, 2013). Qualitative studies of women’s experience of pregnancy after loss found that they needed regular contact with their health-care team to voice concerns and receive reassurance (Meredith et al., 2017; Moore & Côté-Arsenault, 2018). It is not only the frequency of appointments offered, but also the quality of the care received that impacts upon outcomes, as highlighted by a study which found that satisfaction with healthcare services was linked to decreased symptoms of perinatal grief after miscarriage (Verdon, Meunier, deMontigny, & Dubeau, 2017). Perinatal mental health teams, where available, currently focus on those with existing psychiatric diagnoses or new-onset psychiatric illnesses (Oates et al., 2012). With the prevalence of perinatal loss, and associated distress both post-loss and during the subsequent pregnancy, the needs of those who do not meet psychiatric thresholds should be addressed. As midwives are those in most regular contact with women during pregnancy, it is important to consider the role they play in the psychological wellbeing of the women under their care.

Midwives and nurses play a significant role in both the care of those experiencing a perinatal loss (Alghamdi & Jarrett, 2016; Evans, 2012; Radford & Hughes, 2015; Roehrs, Masterson, Alles, Witt, & Rutt, 2008; SANDS, 2016) and recognising and supporting those with perinatal mental health issues (Jomeen, Glover, & Davies, 2009; Morrell, Cubison, Ricketts, Williams, & Hall, 2015; National Institute for Health and Care Excellence [NICE], 2016; Noonan, Doody, Jomeen, & Galvin, 2017; Russell & Lang, 2013). Although midwives are well placed in terms of contact with women who require care, both studies of midwives' perceptions of care (Alghamdi & Jarrett, 2016; Noonan et al., 2017; Radford & Hughes, 2015; Roehrs et al., 2008) as well as reports on current midwifery practice (Russell & Lang, 2013; SANDS, 2016) refer to the need for better training and support for these healthcare professionals. Healthcare professionals want to better understand bereavement and how to provide sensitive care to those experiencing perinatal loss, but lack confidence in how to interact with families (Richards, Graham, Embleton, & Rankin, 2016). The medicalisation of childbirth has led to the role of midwives being increasingly characterised by risk assessments and protocols, with a focus on the medical rather than social needs of mothers in their care (Einion, 2017). However, midwives are also responsible for the emotional wellbeing of mothers antenatally and in the early postnatal period (NICE, 2016), despite feeling underequipped to fulfil this role, particularly in relation to bereavement (Kelley & Trinidad, 2012).

The Stillbirth and Neonatal Death Society's (SANDS, 2016; 2018a) audits of bereavement provision highlight inconsistency in provision not only across the UK but also within trusts and health boards, and at times even within hospitals, where the provision is dependent on individual members of staff being present. They recommend a specialist bereavement midwife to be available in all services where perinatal loss occurs. However, there is no set standard for training or a nationally agreed job title for such a role, and therefore even in the sixty-two per cent of maternity units that reported this provision, there could be inconsistency about what this means (SANDS, 2016). Roehrs et al. (2008) found that the provision of support is heavily reliant on individuals, with decisions about who cares for those going through a loss being decided by who felt most able to cope on any particular shift. Only 12% of neonatal units made bereavement training mandatory, and even for those trained in bereavement care, staff were only able to provide support on an ad-hoc basis, as they lacked dedicated time in their schedule, requiring them to fit bereavement support around their existing workload (SANDS, 2018a). Healthcare staff may also experience grief in relation to perinatal loss, and the lack of acknowledgement and support for this has a knock on effect on their capacity to support bereaved families (Jonas-Simpson, Pilkington, MacDonald, & McMahon, 2013). Adequate support to help staff cope with the challenging emotional situations they face is required in addition to training in order to provide effective care (Alghamdi & Jarrett, 2016; Evans, 2012; Radford & Hughes, 2015; SANDS, 2016). Cacciatore (2013) advocates a mindfulness based training program for healthcare providers who work with perinatal loss. As well as providing a form of self-care to support them with their vulnerability to mood disturbances as a result of exposure to death in the workplace, this would support them in developing more meaningful relationships with patients, and therefore equip them to provide better bereavement care (Cacciatore, 2013). The way in which women are supported by midwives during and following a loss has a significant impact on women's loss experiences and how they cope with the grieving process (Evans, 2012). The midwives also have an important role to play in the experience of the subsequent pregnancy, where the risks of depression and anxiety are elevated due to the loss experience (Hunter et al., 2017).

For healthcare professionals, regular contact with pregnant women through routine visits provides a unique opportunity to identify those who are experiencing mental health problems. Midwives' understanding of the implications of a perinatal loss is particularly important in the subsequent pregnancy (Hunter et al., 2017). The NICE guidelines (2016) state that women should be asked about their emotional wellbeing at all routine appointments during pregnancy, in order to identify antenatal depression and anxiety at the earliest opportunity. However, despite the prevalence of antenatal depression being as high as postnatal depression, it is far less likely to be detected (Jomeen et al., 2009). Improved training to more adequately equip midwives with the skills and knowledge they need to identify perinatal mental health issues is one way to address this disparity. However this will have limited consequences unless there are clear referral pathways and support systems in place for those who are identified with needs (Noonan et al., 2017).

In the Boots Family Trust report on perinatal mental health (Russell & Lang, 2013) all midwives questioned reported compliance with the NICE guidelines (2016) regarding asking questions about emotional wellbeing; however, only one in ten women felt that they had been asked. The mismatch between these responses highlights the different perceptions about care at routine appointments between those giving and receiving that care. A study of perceptions of health distress found that midwives ratings of the emotional distress of their patients did not recognise those experiencing high levels of distress in relation to their pregnancy in a hospital setting, due to the challenging nature of the environment (Barber, Panettierre, & Starkey, 2017). Morrell et al. (2015) recognise that midwives not only need the relevant training, skills and knowledge, but are also working under intense time and workload pressure.

Perinatal loss research with midwives has been predominately qualitative, exploring the experiences of midwives faced with caring for women during a perinatal loss (Evans, 2012; Radford & Hughes, 2015; Roehrs et al., 2008), including the experiences of student midwives (Alghamdi & Jarrett, 2016). However, although there is some literature on midwives' roles in relation to perinatal mental health (Morrell et al., 2015; Noonan et al., 2017; Russell & Lang, 2013), there does not seem to be research that specifically explores how midwives respond to the care needs of women pregnant after a perinatal loss. With the unique challenges faced by midwives in addressing the complex individual care needs of those pregnant after a loss, it is important to understand from the voices of the women affected by perinatal loss, their experiences and the consequences of current healthcare provision. This would ensure that any change to midwifery training or practice is based on what is most meaningful to those who receive their care.

1.5 Summary and Aims

Research on perinatal loss to date has focussed on either the loss experience (Gold et al., 2016; Lok & Neugebauer, 2007; Verdon et al., 2017), including the impact of interventions and support (Johnson & Langford, 2015; Kong et al., 2014; Reynolds, 2004), or has focussed on the experiences of a pregnancy after a perinatal loss (Bicking Kinsey, Baptiste-Roberts, Zhu, & Kjerulff, 2015a; Bicking Kinsey, Baptiste-Roberts, Zhu, & Kjerulff, 2015b; Côté-Arsenault & Donato, 2011; Geller et al., 2004; Hunter et al., 2017; Hutti, Armstrong, Myers, & Hall, 2015). There does not appear to be any current research that explores the whole journey through loss and the subsequent pregnancy, and that includes women's perceptions of their experiences of support throughout this journey. The fragmented approach to research exploring perinatal loss has meant there is a lack of understanding of what makes a meaningful difference to women's experiences in a pregnancy following a perinatal loss. Understanding of the whole journey from loss to subsequent pregnancy from the perspective of those who have lived through the experience is vital in order to improve services in the future.

Research on perinatal loss is predominately found in midwifery or nursing journals (for example LeDuff et al., 2017; Lewis, 2015; Radford & Hughes, 2015) or obstetrics and gynaecology journals (for example Hutti et al., 2015; Johnson & Langford, 2015; Shapiro et al., 2017). Counselling psychology therefore can offer a unique perspective on this issue. The application of psychological theory can help to further the understanding of the experience of perinatal loss and the subsequent pregnancy, with the ultimate aim of improving healthcare provision for those affected. Counselling psychologists are required, not only to provide interventions, but also to "promote psychological mindedness and skills in other health, educational and social care professionals" (The British Psychological Society [BPS], 2017, p. 7). This research therefore is informed by the ethos of counselling psychology, with a focus on psychological distress and wellbeing, and responding to calls for counselling psychologists to work with other professionals.

A large proportion of psychological research on perinatal loss has been quantitative, with the focus on measuring psychological illnesses in women with experiences of perinatal loss, such as depression, anxiety and posttraumatic stress disorder, through thresholds of symptoms (for example Geller et al., 2004; Hunter et al., 2017; Hutti, Myers, Hall, Polivka, & Kloenne, 2018; Robertson Blackmore et al., 2011; Verdon et al., 2017). This has the impact of pathologising the distress experienced after a loss, or during pregnancy, and limits recognition of the significance of experiences that do not reach such thresholds. This was highlighted by the qualitative element of a mixed methods study that found miscarriage to be a significant life changing event, while the quantitative aspect of the study found no significant difference for symptoms of depression between those who had experienced miscarriage and those who had not (Lee & Rowlands, 2015).

A review of support after perinatal death highlighted the difficulty in developing meaningful findings from clinical trials, due to small sample sizes and the complex and delicate subject (Koopmans et al., 2013). In order to provide research that informs practice, the review recommended embracing other research designs. A systematic review of post-stillbirth interventions further highlights the lack of reliable research in this area (Huberty, Matthews, Leiferman, Hermer, & Cacciatore, 2017). Qualitative studies have been found to give a deeper and broader understanding of the issues faced with perinatal losses (Kelley & Trinidad, 2012; Randolph et al., 2015). For example, in Campbell-Jackson and Horsch's (2014) systematic review of the psychological impact of stillbirth, qualitative studies were reviewed alongside quantitative studies, and while the quantitative studies were used to draw conclusions on symptoms of anxiety and depression, it was the qualitative studies that allowed for an increased understanding of the grief and bereavement process.

The research presented is a qualitative study that aimed to explore the subjective experience of participants, which is in keeping with the philosophy of counselling psychology, in its broad definition of evidence, and value of "all research paradigms that explore and understand the different facets of human existence" (BPS, 2017, p. 6). With a value system based on both scientific enquiry and the importance of the counselling or psychotherapeutic relationship, counselling psychology seeks to move beyond traditional scientific psychology and develop phenomenological practice and research models (BPS, 2005). This approach validates first person accounts and engages with subjectivity and intersubjectivity, both in terms of understanding individual experience within a collaborative therapeutic relationship, as well as the exploration of individuals' perceptions through research (Strawbridge, 2016). This research sought to not only inform practitioners working with clients who have experienced perinatal loss, but also to move beyond the one-to-one work, in order to influence the experiences of those who may not directly work with a psychologist or therapist, through informing policy.

Therefore, the qualitative study presented in this report had two aims:

- To better understand women's experiences of perinatal loss and the subsequent pregnancy.
- To better understand women's perceptions of the support received throughout this perinatal journey, including what made a meaningful difference.

With the intention of providing a clearer picture of what makes a meaningful difference to women in their perinatal loss and fertility journey, in order to inform healthcare and therapeutic practice.

2. Methodology

2.1 Theoretical Frameworks

The research aims of this project are in keeping with a qualitative method of enquiry, which acknowledges the value of subjective experience and multiple perspectives (McLeod, 2011). This study required a methodology that could both challenge the way in which distress is either labelled or ignored by the use of quantitative measures (for example Hunter et al., 2017; Robertson Blackmore et al., 2011; Verdon et al., 2017), and expand upon and develop the findings of existing qualitative research (for example Moore & Côté-Arsenault, 2018; Randolph et al., 2015). This was achieved through using both qualitative online surveys and face-to-face interviews, which provided detailed and rich data about perinatal loss and subsequent pregnancies, whilst also demonstrating a breadth of experiences, adding complexity and nuance to the data. In order for the understanding developed from this data to have an impact on policy and practice, it was important for a method of analysis to be used that could be easily communicated across disciplines. Thematic analysis as well as being theoretically flexible (Braun & Clarke, 2006; Braun & Clarke, 2020), is used in research by practitioners working in diverse settings (Clarke & Braun, 2018), and therefore is an accessible way to produce findings that can be widely communicated.

Although thematic analysis allows theoretical flexibility, it is not atheoretical, and therefore it is important to acknowledge the ontological and epistemological assumptions that guided the data collection and analysis (Braun & Clarke, 2020). This research was done from a critical realist standpoint with a contextualist approach (Madill, Jordan, & Shirley, 2000), as I was interested in lived experiences embedded in context. Critical realism sits on the ontology continuum between realism, with the assumption that reality is completely separate from our ways of knowing, and relativism, which assumes not just one reality, but that human interpretation and knowledge create multiple realities (Braun & Clarke, 2013). A researcher working within a critical realist ontology accepts that there is a material reality beyond talk and text, but that their understanding of that reality is limited by the lenses of context, both at a societal and individual level (Ussher, 1999). From the critical realist perspective there is no superior status attributed to 'expert' knowledge, and therefore a variety of voices can contribute to increased understanding (Ussher, 1999). This intersects with feminist qualitative research that has long sought to 'give voice' to women by addressing the power imbalance in traditional approaches, which may constrain women's accounts (Hollway & Jefferson, 2007). Tebes' (2005, p. 222) assumption that "knowledge is situated and contextual" underlines the importance of understanding not only the experiences of the participants, but also the context that has influenced their perspectives. Therefore this research was from a contextualist epistemology, acknowledging the contextual nature of knowledge production, but also from a feminist standpoint, seeking to empower through recognising the importance of lived experiences in challenging the claims and assumptions of the 'expert' position (Hesse-Biber, 2012).

Research with a contextualist epistemology requires acknowledgment of the impact of the researcher's own cultural and personal perspectives (Madill et al., 2000). By acknowledging the subjective nature of the way in which knowledge is produced (Tebes, 2005), the research process is seen as a collaboration between the researcher and the participant, highlighting the importance of reflexivity. From a feminist perspective, I am also mindful of the way in which the research process itself can create hierarchies of power, and therefore recognise the importance of the way in which I engaged with participants (Hesse-Biber, 2012). In this project, I approached the interview and survey participants as an insider, not only because of similar demographics, being a woman of childbearing age, but also due to a personal experience of perinatal loss, followed by healthy pregnancies. This aided rapport building in the interviews and allowed empathy and connection to the participants (Madill et al., 2000). However, as context is continually changing, and my experiences of healthcare services are not current, I am somewhat situated as an outsider, whilst acknowledging my role in co-constructing the data (Jaeger & Rosnow, 1988).

2.2 Research Design and Data Collection

Data collection included forty completed qualitative online surveys and five semi-structured face-to-face interviews with women who had experienced a healthy pregnancy following a perinatal loss. The use of two forms of data collection gave participants choice about how to engage with the research, which increased accessibility (Neville, Adams, & Cook, 2016). The qualitative survey ensured that a diversity of experiences, not limited by geographical location, could be included in the research, giving participants the flexibility to respond at a time and place that was most convenient to them (Braun, Clarke, Boulton, Davey, & McEvoy, 2020). This was considered to be particularly important when recruiting mothers, where childcare needs may have prevented engagement in face-to-face participation. The survey was also used as a recruitment tool for the face-to-face interviews, and therefore four of the five interviewees first completed the online survey. The use of semi-structured interviews was in order to allow in-depth exploration of these women's experiences, with the ability to clarify, expand on and shape the discussion based on their responses (Birch & Miller, 2000). The use of both online qualitative surveys and face-to-face interviews, avoided the exclusion of those who could not attend a face-to-face meeting, allowing a greater number of women to participate and tell their story. Due to the prevalence of perinatal loss (ONS, 2020a; 2020b), and the desire of women to share their experiences (Jaffe & Diamond, 2011a) this research aimed to make participation as accessible as possible to those who wished to contribute.

Using these two sources of qualitative data provided both breadth as well as depth to the data, as it allowed multiple perspectives to contribute to the research, whilst also giving the opportunity for an in-depth engagement in this sensitive and very personal topic. For a project of this size it is recommended to have either ten or more interviews, or fifty or more surveys (Braun & Clarke, 2013). As both forms of data collection are included here, the combination of sample sizes are considered sufficient to provide a rich and complex dataset for thematic analysis (Braun & Clarke, 2013).

Online Qualitative Surveys (see Appendix A)

Qualitative surveys are an underutilised but flexible and useful tool to collect diverse and meaningful qualitative data (Braun et al., 2020). The use of qualitative online surveys means that a breadth of experiences could be included in the study, and the sample was not limited by location or availability for face-to-face data collection. Surveys also allow for high levels of anonymity and are therefore particularly suited to topics that may be considered sensitive (Braun & Clarke, 2013). Perinatal loss is considered a sensitive research area due to the personal and painful experiences that participants are being asked to reflect upon (Siassakos, Storey, & Davey, 2015), as well as the way in which those who have experienced loss may be considered marginalised due to societal silence around these experiences (Martel, 2014; Neville et al., 2016). Online surveys have been found to be an accessible way to engage marginalised groups in research, due to allowing participants complete anonymity, full control over how much or how little they share, choice over when and where they respond, as well as the opportunity to reflect on research questions prior to answering (Neville et al., 2016). Surveys have been successfully used to explore women's experiences of healthcare, including perinatal loss experiences, for example with lesbian and bisexual women (Peel, 2010), and therefore were considered a suitable and useful method of collecting data for this project. The surveys allowed for a wide breadth of data from mothers with a perinatal loss history, with the inclusion of diverse experiences from across the UK. The breadth or "wide angel lens" as well as detailed data provided by surveys is considered a valuable qualitative research tool because of the way in which including diverse voices and experiences on a topic can open up new perspectives, including highlighting areas for future research (Braun et al., 2020, p. 3). By including the perspectives from a range of experiences through the survey data it is hoped that this research can make a more meaningful contribution to the practice and policy development for perinatal healthcare.

In addition to providing broad and meaningful data, the survey was also used as a recruitment tool for the interviews, with the opportunity for participants to provide contact details if they were interested in sharing their experiences face-to-face. The survey responses, although not allowing the same level of engagement between researcher and participant as an interview, were often more focused and provided a breadth of relevant responses. The amount participants chose to write varied, and the nature of surveys meant that there was no opportunity to clarify meaning, or expand upon what was provided, however, the data generated still included detailed and reflective accounts of women's personal experiences.

Audio-recorded Semi-structured Face-to-face Interviews (see Appendix B)

Semi-structured interviews provide an opportunity for participants to describe and attribute meaning to their own experiences (Braun & Clarke, 2013). There is a long-standing tradition of using semi-structured interviews to explore the lived realities of health and mental health conditions from the perspectives of those who experience them (Barkham, Moller, & Pybis, 2017; Neville et al., 2016). A qualitative study by Kitzinger and Willmott (2002), which explored women's experiences of polycystic ovarian syndrome, illustrates the intersections of qualitative health and feminist research. The authors of this study were able to explore in-depth the experiences of women affected, as a counter-balance to previous research on this topic being largely from a medical or psychiatric perspective, and develop further understanding of wide implications of the illness beyond what had been provided by quantitative data. Similarly, perinatal loss research has predominantly been from a medical perspective, with distress measured through the use of psychiatric diagnoses (for example Hunter et al., 2017; Verdon et al., 2017). Using qualitative interviews can provide a more nuanced understanding of distress in the perinatal period, as shown by Highet, Stevenson, Pirtell and Coo (2014) who used interviews, to better understand the subjective experience of living through antenatal anxiety and depression.

Survey and Interview Questions

The survey questions (Appendix A) and interview schedule (Appendix B) for the participants of this study (women who have experienced a perinatal loss, followed by a healthy pregnancy), were designed to explore the holistic experience through the process of loss and grief, and the next pregnancy, with particular attention to the support received throughout this journey. Questions were developed based on the research aims and using my clinical experience of working with those who have experienced perinatal loss, to ensure sensitivity and minimise distress (Neville et al., 2016; Siassakos, et al., 2015), as well as through discussion with the supervision team. The questions aimed to provide an opportunity to understand this journey from those who have experienced it and to understand the provisions of the healthcare service from those with first hand experience.

The survey consisted of seven questions relating to the experience of loss, including coping mechanisms, professional and social support, and commemoration. This was followed by five questions about the pregnancy after loss, including antenatal support and their feelings towards their living child both during and after pregnancy. Questions purposefully began with an open opportunity to describe their story in order to allow participants choice about how to frame their experiences. For example, the first survey question was "*Please describe your loss experience in as much detail as you feel is comfortable*", which ensured that participants felt able to tell their story on their own terms. The survey also ended with an open question; "*Is there anything else you would like to share about your experience of loss and the next pregnancy? Please include anything you feel is relevant or important*", to give space for anything the participants felt they wanted to share but hadn't been adequately covered by earlier questions. Responses varied in length, most surveys being between 500 and 800 words, with some considerably longer (over 3,000 words), and a few briefer responses. However, all participants provided rich and varied data on all areas of the research. Most survey data was in response to the first question, with participants often covering aspects of later questions in this initial response.

The interviews were an opportunity for an in-depth understanding of how these women made sense of their losses, and how they perceive their loss experiences had impacted upon their experiences of a successful pregnancy. The interview schedule was based on the survey questions, with three questions on the loss experience, and three on the next pregnancy. However, each question also included a list of topic ideas, covering all areas included in the survey questions, to further explore participants' answers. The interview also began with an open opportunity for the participant to share their story. As a result of each participant responding differently to this opening question, the interview schedule was used as a guide for the areas to be covered, but not followed prescriptively, to ensure the data was produced in the natural exploration of their experiences, but following the participant's lead. Each interview ended with a further opportunity to raise anything the participant felt had been missed throughout the discussion. The interviews ranged in length from 49 minutes to almost an hour and a half, however, length and depth are non necessarily synonymous (Irvine, 2011), as the shortest interview provided a rich and reflective narrative of the participant's experience.

2.3 Recruitment, Sample and Participants

This research used purposive sampling of women who have experienced pregnancy after a perinatal loss. Purposive sampling ensures that the participants are best placed to provide rich data on the phenomena under scrutiny (Polkinghorne, 2005). As the aims of the research were to explore perinatal loss experiences, support following the loss, and the experiences in the subsequent pregnancy, women who had lived experiences of this were best placed to produce data that met these research aims.

Recruitment criteria

Participants for both the interviews and online surveys were women over the age of 18, English speaking, who had a living child under 5 years old, and experienced any form of perinatal loss in the previous pregnancy. This was to ensure that participants had a recent experience of healthcare provision. Postnatal depression can occur any time in the first twelve months after birth (NHS, 2016), therefore, women in the first postnatal year were excluded in order to avoid causing distress during this vulnerable time. There were no restrictions placed on the type of perinatal loss, as the differences between the medical labels attributed to losses, such as miscarriage and stillbirth, are based on gestational age, rather that relating to the way in which the loss is experienced (O'Leary & Warland, 2016). There was no requirement for these women to have accessed support services as a result of their losses, as I was interested in a variety of experiences.

Those who experience perinatal loss often want to be able to talk about their experiences; telling the story and reflecting on its meaning is considered part of the healing process (Jaffe & Diamond, 2011a). Therefore, I expected recruitment within the general population to be sufficient to find women who met the recruitment criteria. The women for the interviews and surveys were recruited through personal and professional contacts, and by using social media, such as Facebook (www.facebook.com) and Twitter (www.twitter.com). A Facebook page was created for the study and was then promoted on other social media platforms, such as Twitter, providing a direct link to the online survey (Appendix C). At the end of the survey, participants were asked to provide contact details if they wished to express an interest in being interviewed.

Initial recruitment relied on snowballing from personal contacts and word of mouth. I did not request promotion by any of the national perinatal loss charities, as this would limit participation to those who had already engaged with perinatal loss support online, and I wanted recruitment to be as open and accessible as possible. The initial Facebook advert, as expected, generated a lot of interest, including from many who were outside the inclusion criteria. However, despite the initial interest, this did not translate into as many completing the online survey as anticipated. In order to boost recruitment, a paid for Facebook advert was used which targeted women of childbearing age. I did not restrict the criteria for the advertising beyond this, as I wanted to ensure recruitment was as open as possible. This recruitment resulted in a total of 40 completed surveys, which came from a combination of the Facebook advert, and the study being shared on social media. None of the individuals' identities were used in the promotion of the survey, although some individuals chose to share it with their personal contacts. For the five women interviewed, four of them also completed the survey and the other one made contact in direct response to recruitment.

Demographics of Participants

There were a total of forty-one participants, forty of whom completed the survey, and five interviews (four of whom had also completed the survey). For those participants who both completed the survey and were interviewed the two sources of data were considered together, providing further detail of their experiences, rather than regarded as additional participants.

Table 1: Survey Participant Demographics		
Ages of participants	26-42 years	(mean 34.55, SD 3.83)
Racial/ethnic background	White (including White British, Irish & European) Other (including Asian Muslim & Mauritian)	38 (95%) 2 (5%)
Sexuality	Heterosexual Bisexual Preferred not to say	38 (95%) 1 (2.5%) 1 (2.5%)
Class	Lower/working class Middle class No class category	19 (47.5%) 15 (37.5%) 6 (15%)
Employment	Full-time employed Part-time employed Full-time student Other	14 (35%) 17 (42.5%) 1 (2.5%) 8 (20%)
Disability	Yes No	3 (7.5%) 37 (92.5%)
Relationship status	Married/civil partnership/partnered Divorced/separated/single	37 (92.5%) 3 (7.5%)

The survey participants (see Table 1) ranged in age from 26 to 42 years old, were predominately white (95%) and heterosexual (95%). Just under half considered themselves lower or working class (47.5%), with the rest considering themselves middle class (37.5%) or not specifying a class category (15%). Over ninety per cent of survey participants were partnered, including married and civil partnerships, and did not consider themselves to have a disability.

Table 2: Interview Participants Demographics		
Ages of participants	33-42 years	(mean 38.2, SD 3.49)
Racial/ethnic background	White/White British	5 (100%)
Sexuality	Heterosexual	5 (100%)
Class	Working class Middle class	2 (40%) 3 (60%)
Employment	Full-time employed Part-time employed Other	2 (40%) 2 (40%) 1 (20%)
Disability	No	5 (100%)
Relationship status	Married/partnered	5 (100%)

For the interviews, (see Table 2) the participants ranged in age from 33 to 42 years. All five participants were white, heterosexual women, who were partnered, and did not consider themselves disabled. Forty per cent considered themselves working class, with the remaining sixty per cent considering themselves middle class.

2.4 Project Development and Changes

The initial project design included collecting data from midwives, as a way to more fully understand the healthcare provision for perinatal loss from multiple perspectives. The intention was to organise focus groups as a way to engage these professionals, however, due to busy work schedules, and differing ethical approval requirements at different NHS settings this proved a complicated process, and recruitment strategies were ineffective. I therefore designed an online survey for midwives as an alternative to the focus groups, in the hope of providing a more accessible way for midwives to engage in the project. The details of this were presented to examiners at the progression viva examination (March 2019) who advised focussing on the data collection from mothers, and removing the midwife aspect from the project. As data collection with midwives at this point had not begun, the examiners, including a nurse who was able to offer insight and relevant expertise, felt the online survey was too long and therefore time consuming for midwives, which would have made the generation of meaningful data challenging. The data collected from mothers was considered enough for the size of project, and the examiners at this stage believed the project going ahead in this way could still make a meaningful contribution to midwives' understanding of perinatal loss care needs, despite not including midwives' perspectives directly. Therefore after discussion with the supervision team, the decision was made to follow the advice of examiners and not collect data from midwives.

At the progression assessment (February 2020) the intention was to continue data collection from mothers, in order to have at least fifty completed surveys and six interviews. However, this strategy was reconsidered in light of the COVID-19 pandemic, which resulted in lockdown in the UK from March 2020. In addition to this impacting the ability to do face-to-face interviews, it was also important to consider the way in which this may impact the participants, the way in which they reflect on their experiences, and therefore the data that any further recruitment might produce. Although the impact of COVID-19 requires research from a psychological perspective (Holmes et al., 2020), and there is likely to be considerable research in this area in the coming months and years, the way in which participants may respond to several months of living through lockdown, is at this point unclear. Antenatal services have altered drastically during this time, with reduced face-to-face contact with professionals; partners often excluded from appointments, and anxieties around health and healthcare provision prevalent in the general population (Ross-Davie et al., 2020). This may influence the way in which previous experiences of healthcare are framed, and comparisons may be made to what is currently available. In addition to this, public satisfaction with the NHS, which had already begun to increase in 2019 after years of decline, is likely to improve further, with the public narrative of needing to protect the NHS and a renewed sense of admiration for the work that is done (Appleby et al., 2020; Wellings & Appleby, 2020). For those pregnant after a loss, the knock on effect of these changes in public attitude as well as reduced antenatal provision remains to be seen, however, it led me to consider the data I would collect in this time as being in many ways different to the data I collected before COVID-19. The changes to the way in which experiences of perinatal loss and antenatal provision are framed as a result of the pandemic would make for interesting research; however, this feels like a different project to the one that is being presented here. Therefore the decision was made to stop collecting data, and to ensure that the analysis of the data collected to this point honoured the stories shared by the women who participated, and added helpfully to the conversation about the way in which services are shaped in the future.

2.5 Ethical Considerations

This project received ethical approval from the Health and Applied Sciences Faculty Research Ethics Committee at The University of the West of England (Appendix D), and adhered to the British Psychological Society's Code of Human Research Ethics (BPS, 2014). The participants were given detailed information about the purpose of the study and what participation entailed before taking part. All participation was voluntary and participants were informed about their right to withdraw at any time, but asked to do so within a month of taking part where possible, due to the difficulty of removing data from the study once it had been analysed. None of those who participated have made contact since participating asking to withdraw, and therefore all the data collected has been included in the analysis.

Online Surveys

On-screen participant information was provided, in a printable format (Appendix E). Consent was obtained through an onscreen tick box, in order to protect anonymity (Appendix F). Participants were asked to create a unique identifier in order that they could respond anonymously, but still request withdrawal if necessary. Any responses that included identifiable information were anonymised when compiling the data for analysis.

Face-to-face Interviews

Participants were provided with a written information sheet, including recruitment criteria (Appendix G). A signed consent form was obtained for each participant, and a copy, signed by myself provided for them to keep (Appendix H). Participants were made aware of their right to withdraw at any point. Data was anonymised during transcription to remove identifying information, making use of pseudonyms for each participant, and removing any other identifiable information, such as names of other people and place names.

All data, including audio recordings and transcripts, were stored on my secure UWE One Drive. As well accessing all data myself, anonymised data was accessible by the supervision team, and examiners when necessary. Audio recordings will be deleted once my final award has been obtained, and the research has been published, whichever is later. The use and security of the data was made clear in the participant information provided, and through the consent sought from participants.

I aimed to recruit from a healthy population, however, I recognise that the topic being studied can be distressing. I have worked with this population clinically for the last six years, within a charity that offers support for any form of baby loss. I have worked clinically with those who have experienced miscarriage, stillbirth, termination, traumatic birth experiences and neonatal losses both in the period following a loss, and during the pregnancy following a loss. This experience, alongside my counselling psychology training, means that I felt well prepared for dealing sensitively with any participants who experienced distress during participation. The questions for both the survey and the interview schedule were designed to minimise distress, by providing the participants the opportunity to choose how to tell their story, with open and general questions, for example; "*Please describe your loss experience in as much detail as you feel is comfortable*" (question 1 on the survey). As previously noted, those in the first postnatal year were excluded to minimise distress to those who were most vulnerable. Detailed information, including signposting to support agencies, was provided to all participants in order to minimise distress and ensure that those who needed to could seek additional support.

I also approached these participants as an insider, having experienced a miscarriage myself, followed by healthy pregnancies. This was shared with participants through the information sheet, in order to aid rapport building in the interviews, and to create a greater sense of empathy and connection with participants (Madill et al., 2000). Moulder (2001) highlighted the benefits of sharing with those who have had similar experiences of loss because of the sense of shared understanding. Those who experience perinatal loss often want to be able to talk about their experiences; telling the story and reflecting on its meaning is considered part of the healing process, by legitimising the loss and providing validation (Jaffe & Diamond, 2011a). Therefore, it is expected that participation may have had a positive impact on participants, through the opportunity to tell their story and express their feelings.

Interviews were arranged at locations that best suited the participants in order to aid recruitment, and help them feel as comfortable as possible with participation. This included rooms on university campus, other easily accessible buildings, such as community centres, or the participant's home. In order to minimise risk, standard safety buddy interview protocol were followed, and a designated person was contacted before and after each interview.

2.6 Analysis

Data from the two sources were analysed using reflexive thematic analysis within a contextualist approach, as this allows the flexibility of combining multiple sources of data (Braun & Clarke, 2006; 2020). Both forms of data provided accounts of perinatal experiences, and therefore were considered as one whole data set throughout analysis, rather than analysed separately. The inclusion of data from different perspectives, by not limiting the type of perinatal loss experienced, and offering multiple ways to engage with the research, allowed a rich understanding of the experiences being studied (Polkinghorne, 2005). However, despite the data providing a rich and complex picture of the participants' experiences, I acknowledge that any understanding that has developed though this analysis can only ever be partial, and therefore does not aim to completely capture the phenomenon under scrutiny (Tracy, 2010). An inductive approach was taken to analysis, working with the data from the bottom-up (Braun & Clarke, 2013), exploring the perspectives of the participants, whilst also examining the contexts from which the data was produced. Through the analysis I sought to identify patterns across the data in order to tell a story about the journey through loss and the next pregnancy. The six stages of Braun and Clarke's (2006;

2020) reflexive thematic analysis were used through an iterative process, in the following ways:

Phase 1 – Data familiarisation and writing familiarisation notes:

By conducting every aspect of the data collection myself, from developing the interview schedule and survey questions, to carrying out the face-to-face interviews, and then transcribing them, I was immersed in the data from the outset. Particularly for the interviews, the experience allowed me to engage with participants, build rapport, explore their stories with them, and then listen to each interview multiple times through the transcription process. I therefore felt familiar with the interview data before actively engaging with analysis. I found the process of transcribing the interviews a particularly useful way to engage with the data, as it slowed the interview process down, with a need to take in every word, and therefore led me to notice things that hadn't been apparent when carrying out the interviews. The surveys, as well as the interview transcripts, were read through several times. I used a reflective journal throughout this process to makes notes about anything that came to mind during data collection and transcription. This included personal reflections, what the data had reminded me of, led me to think about, as well as what I noticed about the participant and the way in which they framed their experiences.

Phase 2 – Systematic data coding:

Coding of the data was done initially for the interviews, and then for the survey responses (for an example see Appendix I). I began by going line by line through each transcript, paying equal attention to each part of the data, and applying codes to anything identified as meaningful. The majority of coding was semantic, sticking closely to the participants' understanding of their own experiences, however, as the process developed, and each transcript was re-visited, some latent coding was applied, that sought to look below the surface level meaning of what participants had said. Again, throughout this process, a reflective journal was used in order to make notes about my own experience of the data, to capture anything I felt may be drawing on my own experience, and to reflect on what I was being drawn to in the data.

Due to the quantity of data (over 70,000 words in the transcripts, and over 23,000 words of survey responses), this was a slow process, and required repeatedly stepping away from the data and coming back to it in a different frame of mind, reviewing data items in a different order, and discussions with peers and supervisors in the process. I noticed that my coding tended to be longer phrases, rather than one-to-two words, as it felt important to maintain some element of context for the codes, particularly as the stories being told had a sense of chronology to them, that seemed related to the way in which experiences were understood. The codes were then collated into a word document. Writing up the codes in this way separately to the data, it was important to ensure that the codes captured meaning in a way that could be understood in isolation. Therefore the wording of some of the codes was developed further at this stage. During the coding process I began to notice a number of patterns in the data, so alongside coding, I also developed some rough diagrams of ideas that could later be used in the development of thematic maps (see Appendix J).

Phase 3: Generating initial themes from coded and collated data:

The process of generating themes from the data was initially a process of collating the codes from both the interviews and the surveys, and organising them in a way that reflected some of the commonality in what participants had expressed. Despite each of the participants having a unique story to tell, with details specific to their personal context, there was also commonality found in these experiences. Through reflecting on the codes themselves, going back to the data, and using notes and diagrams that had been made throughout the process in my reflective journal, I began to further develop ideas about the patterns that I had identified from the data. Related codes were collated, and developed into potential theme and sub theme ideas. I used thematic maps to develop my thinking, and changed these as my understanding of the data developed. I was conscious that in the development of codes and theme ideas, I wanted to ensure that my analysis was firmly grounded in the data, and therefore, repeatedly returned to the raw data during this process. The use of my reflective notes was also vital at this stage, to ensure that I did not become too fixated on limited ways of seeing the data, but was able to remain open and willing to let initial ideas go.

Phase 4: Developing and reviewing themes:

Theme development was an iterative process of going back and fore between the codes, and the way that patterns had been identified, and the data, collating quotes to illustrate ideas. A number of thematic maps were created that aimed to illustrate the way in which participants made sense of their experiences across the data set, including identifying areas of contradiction and overlap. The use of thematic maps was particularly useful as a visual tool of the way in which different ideas and patterns were connected and related.

Phase 5: Refining, defining and naming themes:

Through the process of developing thematic maps, areas of overlap became evident, which led to further refinement of ideas. There were many possible ways in which the data could be described, and therefore defining and articulating ideas to colleagues and supervisors brought helpful clarity about what could be defined as a theme, where related ideas fitted together into sub themes, and also where separation of ideas was necessary. The theme names were developed once there were clear differences between ideas, and with the use of participants' quotes where appropriate, in order to keep close links between the themes and the data itself (see Appendix K).

Phase 6: Writing the report:

Writing up each theme required further clarity as I sought to articulate ideas, and illustrate these through multiple participant quotes. The process of writing a theme report required further refinement of ideas, and rather than just a final part of the process, still required the iterative process of revisiting earlier phases to ensure that the ideas being presented closely represented the data whilst meeting the research aims. At this stage links were also made to existing literature in order to expand upon patterns identified in the data. Referring to relevant existing literature also helped me to further question my interpretation of the data, and to expand upon my understanding of the participants' experiences.

3. Reflexivity

My story and the research process

I am a 39 year-old white, cis-gender woman, married with two growing children. Experiencing a miscarriage myself before having my two living children in part motivated this research. At the time, I was a naïve 23 year-old, with no knowledge of the commonality of miscarriage and with no peers yet with children. I was shocked by the loss, by the intensity of my grief reaction, and the lack of understanding from the medical professionals who cared for me. This was more shocking when I realised how common miscarriage is, and therefore how often these professionals must deal with grieving families. The awkwardness of the midwife who looked after us when the scan confirmed our fears that our pregnancy was over made me feel sorry for her. This care was worse in subsequent pregnancies where I felt that the previous loss and the impact on me went completely unacknowledged. Even after a healthy baby, I found the grief of my loss at times overwhelming, and only through supportive family and friends found a way to process my experiences. My third pregnancy, with a threatened miscarriage, led me to assume I would never bring my daughter home, and I struggled to believe I would get to keep her even after she was born. These experiences motivated me to want to seek change for others who had similar experiences. When my daughter started full time school I began to volunteer for a baby loss charity, and have continued working with perinatal loss throughout my counselling psychology training, alongside other clinical placements.

I am aware that the way I processed my own loss influences my perceptions around baby loss, however, even before beginning research in this area, there are assumptions and ways of thinking I have had to challenge in order to be effective in my clinical work with clients. I assigned personhood early on in my own pregnancies, but in working with miscarriage clients, I am aware of the individual differences in this, and have learned to make space for different ways of framing these experiences. Over the last six years I have seen many varied responses to loss, and grief reactions that are influenced not only by individual circumstances but also the wider social context. This allowed me to approach participants openly, without assuming they would frame their loss in certain ways. I was interested in the variety of experiences and the way in which this might helpfully shape the practices of caring for women in the perinatal period. Client work, as well as medical care, is never a one size fits all approach, and although I was looking for some commonality in the stories I collated, by using thematic analysis, I also wanted to highlight the different needs of individuals and the importance of listening to the needs of those who require care.

Researching a distressing topic has at times been challenging. Throughout data collection it was helpful to reflect on the process, particularly in the different roles of therapist and researcher, and how this impacted on the interview process. The surveys did not require any direct interaction with participants, and therefore were less demanding in researcher skills beyond designing the questions, however, the interviews required me to play a more active role. This was my first experience of carrying out qualitative research, and therefore the interviews conducted were my first experiences in the researcher role for qualitative interviews.

Although the interview process is at times perceived as similar to therapeutic work (Hallowell, Lawton, & Gregory, 2005), struggling to move from the role of therapist to researcher had been something we were made aware of during training; however, the challenge was initially greater than expected. Although I am used to hearing baby loss stories through my clinical work, and therefore did not expect to find this aspect distressing, what I had not fully anticipated was the difficulty in hearing these distressing stories and not being in the position of helping the individual to process their loss. As a researcher it felt as though they were sharing an important part of their lives with me, and I took that story away with me, leaving them to deal with their feelings and understanding about it, with simply a list of available support. I felt impotent while at the same time recognising that it is through research that the stories of these women in the future might change. It was also important to reflect on the way in which the opportunity to tell their story and be heard can itself be healing (Seigal, 2017) and should not be underestimated, despite not being able to offer the type of support that I would if they were my clients. Taking part in the interview allowed these women to talk openly about their experiences, which is likely to be something they do not regularly get the chance to do (Gilmour, 2009). I came to recognise that I was able to offer something important, even though I felt somewhat deskilled during the process, and therefore developed in confidence through each interview.

For each of the interviews, the stories that were told were produced within the context of my relationship with the participant (Hollway & Jefferson, 2007). Gilmour (2009) highlights the way in which what the participant was able to trust her with in the interview was related to how she was able to relate to them. It was therefore important to reflect and learn, with the support of supervision, to improve through the process. In the initial interview I was keen to communicate understanding, and therefore focused on the details of what had happened, rather than on what the experience meant and felt like to the participant. In subsequent interviews I practiced sitting back and allowing the participant more freedom to express themselves. I learned to be more explicit with participants before the interviews, to be clear about the process and my role so that it felt less uncomfortable for me and for them. Doing this seemed to aid rapport building, and I felt that we were able to enter into the emotional content more quickly than in the initial interview. This seems similar to the experience of Gilmour (2009), who felt that the when participants were given more space to find their own voice, richer data was produced.

In terms of the emotional demands of researching a distressing topic, I have found that the interviews themselves were an enjoyable and a fulfilling process. However, it was working on the transcription, in private, that emotions surfaced unexpectedly, particularly when their stories overlapped or held similarities to my own. Having an understanding of the background or context, and sharing in some way with the experience can aid participants' exploration of their story (Holstein & Gubrium, 1995), however, these overlaps also made the process more emotionally demanding. The first interview took place within my local village, with a woman who had lost her baby at the same hospital where I experienced my own loss, as well as the births of my two living children. As she described her experience of being in a private room on the maternity ward, I realised that I had been in that same room after the birth of my daughter. The reality of my experience of being there in the bed recovering, with my healthy baby in the cot next to me, in comparison to her experience of being there with both an empty cot and empty arms hit me more strongly in transcription than it had during the interview itself. I was keenly aware of the responsibility of taking what she willing gave to me by sharing her story and feeling the need to do something with it that honours that privilege.

The process of analysis meant engaging in the perinatal loss stories beyond the interviews, as I began to immerse myself in the survey data. It was at times overwhelming to be constantly absorbed in the narratives of loss of over forty women. In recognising the emotional demands of analysis, it has been important to access sources of support. While conducting research about domestic abuse Emma Williamson reported that she found it important to debrief, take time off between interviews and re-engage in hobbies (Hallowell et al., 2005). For me support has included my personal therapy, using the support of my supervision team, sharing the experience with course colleagues and also investing in life beyond the research and training, including enjoying time with my husband and children. I have also found that journaling throughout this experience has been a helpful way to process my experiences. A large proportion of the analysis took place during the national lockdown due to COVID-19. This added additional challenges, as my children did not attend school for several months, and I was therefore immersed in distressing data whilst also trying to support home education and adapt to clinical work online. This required finding new ways to self-care (including government sanctioned daily walks), regular contact with my supervisor and taking time to step away from the data and work on other aspects of the project. The process of analysis led to feeling a weight of responsibility for honouring the stories of the women and their children that had been shared with me, whilst also recognising the limitations of the scope the project, and the way in which my own frames of reference might limit the way in which the data is interpreted.

4. Findings and Discussion

4.1 Summary of Data

Each of the participants had a unique story to tell, with experiences of different types of losses and other difficulties with fertility, with each loss taking place in circumstances specific to them.

Survey Data

Table 3: Survey Participants
Living Children and Perinatal Loss History

Number of living children	1	17 (42.5%)
	2	18 (45%)
	3	5 (12.5%)
	(Mean 2)	
Ages of living children	0 -14 years	(mean 3.69)
Loss and living children	Living children before first loss	15 (37.5%)
	Loss in first pregnancy	25 (62.5%)
Gestation of losses	Less than 12 weeks	48 (61%)
	12 to 23 weeks	20 (25%)
	24 to 42 weeks	8 (10%)
	Neonatal loss	3 (4%)
	(Total losses	79)
Number of perinatal losses experienced	1	20 (50%)
	2	10 (25%)
	3	3 (7.5%)
	4	5 (12.5%)
	5	2 (5%)

For the survey participants (see Table 3), half of the participants had experienced one perinatal loss, with the remaining half experiencing between two and five losses, a total of seventy-nine perinatal losses represented. Participants had between one and three living children, ranging in age from birth to fourteen years. Fifteen out of forty survey participants had at least one living child before loss, and the remaining twenty-five experienced perinatal loss in their first pregnancy. There were losses throughout the perinatal period, with sixty-one per cent of the losses taking place in the first twelve weeks, a quarter between twelve and twenty-three weeks; ten per cent of losses were stillbirths and four per cent neonatal losses, with some participants experiencing losses at several stages of pregnancy.

Interview Data

Table 4: Interview Participants
Living Children and Perinatal Loss History

Number of living children	1	3 (60%)
	2	1 (20%)
	3	1 (20%)
	(Mean 1.6)	
Ages of living children	1 - 9 years	(mean 3.88)
Loss and living children	Living children before first loss	1 (20%)
	Loss in first pregnancy	4 (80%)
Gestation of losses	Less than 12 weeks	8 (80%)
	24 to 42 weeks	1 (10%)
	Neonatal loss	1 (10%)
	(Total losses	10)
Number of perinatal losses experienced	1	2 (40%)
	2	2 (40%)
	4	1 (20%)

The interview participants, (see Table 4) four of whom are included in the survey data, had ten perinatal losses between them, eight of which were in the first twelve weeks, one was a stillbirth and one was a neonatal loss. Two of the participants had experienced one perinatal loss; two had experienced two losses, while the other had four losses. Only one of the interview participants had a living child before loss. Participants had between one and three living children, ranging in age from one to nine years old.

Analysis and theme development was done for both the interview and survey data together, with quotes from both sources of data used throughout the discussion of themes. Extracts from any surveys are denoted by "S#", showing the survey number, representing the anonymity of survey participants. Interview extracts are labelled as "Interview #", with line numbers from the transcripts. Pseudonyms are used for all interview extracts, to represent the personal interaction between the participants and myself as researcher.

4.2 Thematic Analysis of Qualitative Data

Analysis resulted in the development of an overarching theme, which sits as an umbrella over the three main themes, and associated subthemes, as shown in Table 5 (see also Appendix K). These themes and subthemes reflect the voices of women from across both sources of data collection.

Table 5: Final Themes

Overarching Theme: **"Losing [a baby] shaped who I am today"**		
Theme 1: Blood, Sweat and Tears: The Embodied Experience	**Theme 2: Finding the Words: Language, Labels and Legitimate Distress**	**Theme 3: "It's my body, it's my pregnancy": Seeking Control and Agency**
Subtheme 1: Embodied distress: The developing relationship with the body	**Subtheme 1:** There are no words: Silence and denial of death	**Subtheme 1:** Realising and resisting the loss of control
Subtheme 2: The mind and body divide in healthcare	**Subtheme 2:** "Sunshine", "angels" and "rainbows": Developing a language for loss	**Subtheme 2:** The power of healthcare to provide and limit choice
Subtheme 3: Embodied rituals and reparative experiences	**Subtheme 3:** "We haven't got a word": The precarious identity of bereaved mothers	**Subtheme 3:** Navigating support needs

4.3 Overarching Theme: “Losing [a baby] shaped who I am today”

The story of the whole data set can be captured in the overarching theme: “*Losing a baby shaped who I am today*” (S31) signifying the process of change that was apparent in navigating through the journey of loss and then living children. There was a sense of directionality, in that these women could not go back to who they were before these experiences, but were changed by them, and continued to develop as they journeyed through their grief and subsequent decisions and experiences. The journey was described as a “*hard and lonely*” (S36) one, but also a shared experience by becoming part of a “*club*” (S4) of those with similar experiences. There are ups and downs along this journey; some participants described it as a “*rollercoaster*” (S40) but their understanding of themselves and the way in which they framed and made sense of their experiences showed a process of development through their narratives. The naiveté that was highlighted early in their journey was quickly replaced by knowledge through experience, which brought with it new ways of thinking, new understanding and new ways of behaving and relating to the world.

Baby loss, as well as being experienced in individual and existing systems, such as family and the workplace, also gave access to a community, “*one you would never sign up to*” (S4), but that became increasingly important to legitimising their response to loss. These mothers became part of the wider group of those who are bereaved by perinatal loss, with its unique challenges and assumptions. This group membership could simultaneously be rejected and embraced, as it was the most common way to access much needed support, but also required embracing a shared but unwanted identity. Engaging with raising awareness from a position of experience was perceived as not only a responsibility of all group members, but also the responsibility as a parent to acknowledge the significance of their lost child.

The developmental journey also had implications for the ways in which they perceived support, as their own experiences of developing understanding through experience led to assumptions that support could only be effectively provided by those with insider experiences. This included comments about male counsellors not being good enough, as well as highlighting the members of healthcare staff who provided empathic and compassionate care often disclosing their own experiences of loss. These assumptions seem at least to be partly based on recognising how their own way of thinking had changed. For some who had previously framed the early stages of pregnancy from a medical perspective, the emotional response was unanticipated:

> "*Before experiencing miscarriage I used to believe that if it happened to me I would be fine with it, I had quite a biological rational approach to it, thinking it's "just a few cells". Seeing the foetus on the [ultrasound] though changed this massively... I was shocked by how much it affected me, and for how long*" (S14)

The need for support to include shared understanding through experience was also the consensus of the studies included in a qualitative literature review (Radford & Hughes, 2015). This review went on to suggest the ways in which healthcare professionals can offer more empathic care through training, so that even without shared experience, the needs of those they care for can be met.

Although this study sought to explore the experience of loss and a subsequent baby in a focused way, the data immediately broadened the scope to consider fertility journeys more fully. The stories of perinatal loss and the subsequent pregnancy were clearly located within a larger fertility narrative. Many participants did not start their story with the loss, but with their plans, desires, hopes for their family size and historical decisions about this, including the fertility struggles that may have predated the loss. Fertility decision-making models fail to account for the impact of the fertility journey on future decision-making, both conscious and unconscious, with fertility often only being measured by childbirth rather than by pregnancy (for example, Brehm & Schneider, 2019; van der Sijpt, 2014). Not only existing children, but also experiences of perinatal loss and failed fertility treatment can profoundly impact both the emotional journey and decisions around eventual family size. Belief in an element of control over fertility decisions is altered by experience so that future fertility decisions are made in the context of uncertainty and awareness of the emotional cost of fertility decisions, demonstrating individual change through the journey. Many participants referred to the way in which their fertility decisions had changed or been shaped by loss:

> "*Having early losses affected our decision to only have one child*" (S7)
>
> "*I would love another baby, but I'm not sure I can cope with another miscarriage or the stress of another pregnancy… we are unlikely to have another child*" (S40)

These narratives were also given context by wider family systems. This included generational fertility narratives, babies lost by mothers and grandmothers, the context of family relationships and expectations. This clearly demonstrated the way in which these experiences sit not just within the individual or the couple relationship, but also impact on the wider family, friendships, workplace and even society more generally.

It is not only fertility difficulties and therefore associated anxiety but also trust in healthcare provision that are factors in fertility decision making (Meaney, et al., 2017). Participant narratives included the constant development of the individual as they interacted with different systems at different times on their journey. One key development was in the relationship of the individual or couple with the health service and how this changed not only in relation to the loss experienced, but also in relation to how care was experienced, and therefore where trust was developed or diminished. Negative experiences with healthcare leads to increased loss related distress (Bellhouse, Temple-Smith, Watson, & Bilardi, 2019). These women managed the contradictory position of both rejecting the health service's narrative about their loss, as well as losing hope in good care whilst also relying on and needing care in the subsequent pregnancy.

Whilst narratives expressed deep and prolonged distress, there were also examples of surprise at their own ability to cope and the resilience present in continuing on their painful journeys: "*I think I have done pretty well in coping*" (S36). Although some felt they hadn't coped, often detailing disappointment with the support offered, most participants were resourceful in seeking out required support privately, through the third sector or social support networks. Despite experiencing grief and fear of future loss, they still took the choice to go on to have further pregnancies after loss. Although the descriptions of these experiences often highlighted a lack of hope, their narratives imply that hope was more present than acknowledged, as the choice was made to pursue the end goal, of living children, despite the distressing consequences of this. The desire for a child seems to be highlighted as a powerful underlying motivator that overrode any sense of fear of harm and trepidation, even if once a living child was born, family size decisions were altered.

A key aspect of the development of the fertility journey was the need for reparative experiences; the opportunity to regain something that had been lost or to reframe a previous experience. It was these experiences that helped these women to reframe their history and to reflect on their on-going relationship with their deceased infant as well as with any living children. Reparative experiences took many forms, for some the experience of a subsequent pregnancy gave them an opportunity to experience aspects of the pregnancy, care and birth that weren't possible during the loss. Some participants described the reparative experience in therapy, of being heard, validated and understood, as well as the way in which this helped them to make sense of their experience, by applying new narratives to previous aspects of their journey. Constructing meaning in the aftermath of loss is considered an important aspect of adaption (Neimeyer, 2001). A key aspect of reparation was the opportunity to bring improvement for other parents who may experience similar losses. Many participants were motivated to take part in this research as part of that reparative narrative, wanting things to change in the future. For these participants reflecting on what was lacking in their own experience, became a key motivator in making change. Engaging in outward focussed work became not only an expression of grief, but also helped them to feel that they were able to bring something positive out of terrible experiences, whilst also honouring the memory of the child who was lost.

Overview of Main Themes

The narratives constructed by participants resulted in the development of three themes, and associated subthemes (see Table 5), which will each be covered in more detail. Firstly was the way in which narratives captured the embodied experience of loss and grief, with a developing relationship between the woman and her body. This is followed by an exploration of the development of language by the bereaved, to combat the silence surrounding perinatal losses, and develop their motherhood identities. Finally, ""It's my body, it's my pregnancy": Seeking control and agency", highlights the distress at the lack of control over pregnancy losses, including the power dynamics with the medical professionals who care for women in the perinatal period, and the ways in which women develop agency, in order to get their medical and emotional support needs met. Each theme highlights key aspects of the experience, which can help inform the practice of healthcare professionals and policy makers.

4.4 Theme 1: Blood, Sweat and Tears: The Embodied Experience

Each participant began their story of loss by describing what physically happened to them. This seems in part to highlight the significance of the embodied experience of loss but also may be linked to difficulty in articulating the more psychological aspects of the experience. It was apparent that the emotional implications were imbedded within the physical experience, both during the experience itself and in reflecting on what had happened to them afterwards. As they described their journeys through loss, grief and a subsequent pregnancy, the data showed a developing relationship between these women and their bodies. Losses caused a rupture in trust with the body; there was language of betrayal and rejection of the body, alongside feelings of guilt and responsibility for how the body responded despite lack of control over these physical processes.

The combination of the physical and emotional aspects of loss in the mothers' experiences was in stark contrast to the way in which these women reflected on their treatment by healthcare professionals, where their physical, or medical needs were treated separately and prioritised over any support with their emotional wellbeing. The experience of loss being firmly embedded within the body of the mother also had knock on effects for the next pregnancy, where trust in the body was diminished and the separation of emotional and physical wellbeing by healthcare professionals was perceived as problematic. The embodied experience of loss and grief led to a need for embodied reparative experiences. In the absence of societal norms, participants developed their own grief rituals to bring meaning to their losses, and reflected on the reparative nature of these as well as subsequently having a living child.

Subtheme 1: Embodied distress: The developing relationship with the body

Descriptions of the process of loss were often graphic, which seemed to imply the distressing nature of the experience, without always referring directly to the emotional implications. Many participants referred to blood, bleeding and pain, detailing what happened to them physically. For example:

> "*When the bleeding began, it happened fast and I lost the baby in the sac on my en suite floor*" (S15)
>
> "*My waters had broken and as I went to the toilet the baby's foot fell out me… the second later loss... hind water leak and membranes bulging through my cervix. I got sepsis and it resulted in ending the pregnancy*" (S36)
>
> "*They came in and scanned me and there was no heartbeat. I was told I was in labour and would have to deliver baby naturally. They thought it would happen quickly. Fast forward 12 hours, it still hadn't happened… the most awful thing was that I'd been left all night with my baby's arm hanging out of me… the Dr basically pulled my baby from me and we were presented with a lifeless baby girl*" (S15)

Participants describing not only the physical process but also including details like the loss being on "*the en-suite floor*" or "*in the toilet*" seemed to be important ways of communicating what it was like to live through. The memories of these events were vivid, and by describing them to me in such detail, it seemed that these women were asking me to join them in the experience. While language and context provide constraints to the interpretations of bodily experiences, research interviews themselves are considered a form of embodied communication (Ellingson, 2012). Even for the participants I did not meet in person, the surveys provided an opportunity for them to invite me as the researcher into their experience in a visceral way.

The graphic physical descriptions of the loss experience communicated distress implicitly and at times, explicitly. The following participant describes the traumatic physical process and the distressing grief in a way that shows the interwoven nature of the physical and emotional experience; both elements are part of the loss experience for the mother:

> "*I was offered a choice of treatments and chose to return home to wait a natural miscarriage. The process was horrific… it was nearly 3 months before I received a negative test. I can't describe the grief of everything you planned being ripped away*." (S3)

The participant links the long and painful physical process with the indescribable grief. Even the description of the emotional distress is physical, with hopes and plans "*ripped away*". This is a visceral description depicting the embodied nature of the experience. It also highlights that physical language provides ways to articulate emotional pain in a way that those outside of the experience can connect with. Evidence from neuroimaging studies suggest that people respond more readily to stories depicting physical pain than emotional pain, and that they may evoke distinct aspects of human empathy (Bruneau, Dufour, & Saxe, 2013). By telling their stories in such a way that created a visual depiction of an event that was both emotionally and physically painful these women may implicitly be activating a greater breadth of human empathy than if they had only articulated the emotional distress experienced.

Loss is rarely expected or anticipated during pregnancy (Badenhorst & Hughes, 2007; Murphy, 2019) and therefore the vivid physical descriptions also communicated the shock and contradictions embedded in the experience. Pregnancy is usually focussed on the life growing within the mother's body (Sawicka, 2017). However, not only does a loss crush this expectation, but also the process of loss often took a lot longer than expected, which meant carrying a baby that had been dead for several days or even weeks:

> "*I had experienced a silent miscarriage and I had to have a chemical abortion to make the foetus leave my body… it did not work and I carried it for 6 weeks before it finally left my body*" (S22)

> Louise: "*When we got to the till, she actually congratulated me, um, the lady behind the till… and that was the first time I thought, people are obviously not going to know, I've still got my bump obviously… I hadn't given birth by then*" (Interview 5, lines 209-214)

For these women, the shock of their baby's life ending was compounded by being required to continue to physically carry them. There are no other types of bereavement that require such close or prolonged proximity to the deceased. While seeing the dead body is considered beneficial to the bereaved in cases of sudden loss (Bower, 2010), it can also be deeply distressing (Pearce & Komaromy, 2020), and there does not appear to be any evidence on the impact of extended contact. Despite the body being hidden within the mother's body, the mother is acutely aware of what she carries, and the contradiction of death within life. Frost, Bradley, Levitas, Smith and Garcia (2007) found that some women sought immediate surgery due to being unable to tolerate carrying a dead foetus, but it does not seem that this is always possible. Louise's quote also highlights the lack of privacy that is part of the embodied experience of pregnancy. As the woman's body changes during pregnancy, the body comes to represent difference; the privacy of the pregnancy is compromised by the growing bump (Keizer, 2012). When a loss occurs, as with Louise above, this is hidden, the bump represents life, despite the lifeless baby inside. The body is a contradiction, deceiving observers and placing the woman in a difficult incongruous position.

Some of the descriptions of loss were very technical, with use of medical language rather than emotive terms, in a way that seems to deny the distressing nature of what is being described. For example, this description is notably absent of emotion:

> "*Long history of pregnancy related bleeding. Query of cervical ectropion causing the bleeds. A blood clot seen during a 20 week scan behind the placenta. Multiple hospital stays due to significant bleeds. Query water*

> *leaking 23+weeks and infection. Laboured at 24 weeks. Gave birth in hospital but staff did not recognise labour and gave birth in the labour ward toilet. Baby did not survive*" (S18)

Stating the facts and not the feelings seems here to be a defensive mechanism, the participant is telling the story in a way that feels possible for them. The participant seems to be distancing themselves from their own story, for example the participant never uses "*I*" or "*my*" to claim ownership of this experience. The later aspects of the story showed help seeking with the emotional aspects of the loss, so it is not that this woman was not distressed, but was unable or chose not to include these aspects of her experience in the telling of her story.

There were others who sought to distance themselves from their distress. This participant can only bear to reflect on her experience through observing it as an outsider:

> "*I often describe what happened next in terms of it being like an out-of-body experience. I don't know if that was how it felt at the time but that's certainly how I remember it looking back – as if detaching from that most unspeakable pain and horror is the only way I can bear to relive it. In my memories I am an observer watching my world crumble in front of me, like I am watching myself having been shoved violently off a cliff edge and can just see myself plummeting into a dark chasm with no chance of rescue.*" (S34)

This description highlights the deep distress and emotional turmoil of the experience of loss; the experience is violent and too painful to experience directly. Self-distancing from negative experiences can be considered adaptive, whilst less distressing than self-immersed reflection, it can allow perspective development that aids in meaning making, with added insight to reconstruct rather than solely recount experiences (Kross & Ayduk, 2011). There was evidence in the data of both self-immersed and self-distanced reflection, showing individual differences in how these experiences are processed by participants.

The following participant describes the losses that were less physically demanding as being considered easier to tolerate mentally, linking the physical and mental experiences:

> "*Two of my miscarriages were earlier than the other two and they were easier on me physically and mentally. My other two were missed miscarriages… my body believed the baby was still alive. These were very hard both physically and mentally as there was so much confusion around if there was still some hope left*" (S12)

It is clear from this quote that the experience within the woman's body is complex and demanding emotionally, with confusion for both the body and the mind. However, despite referring to both the physical and emotional elements of the loss, by saying "*the body believed*" she seems to give the body a separate mind to the mother's, where the body can believe one thing, while the mother is confused over when hope begins and ends. This distinction suggests the body is both unreliable and untrustworthy, as it can not only let the woman down through its failure to protect and nurture the growing infant, but is also deceptive, hiding the reality of the loss (Garrod & Pascal, 2019). Several participants describe their bodies in this way, as separate entities to themselves; that can 'believe' or 'know' things separately to the mother's mind:

> "*It was all over but my body wasn't doing anything about it*" (S13)

> "*Found out at 12 week scan, no symptoms that anything was wrong… Body wasn't able to miscarry by itself, waited a few weeks then had medical management to miscarry. During the waiting time body continued thinking it was pregnant... Second loss… Again body did not recognise any problems and did not miscarry by itself*" (S8)

This participant refers to the body as a separate entity to herself; the body was not able to miscarry by "*itself*", denoting a separation and rejection of the body. The rejection of, or diminishing trust in the body was referred to by several participants, where the loss is not only experienced as the tragedy of the death of a baby, but the mother's body is implicated through the assumed responsibility to nurture the growing infant and the failure to do this

(Murphy, 2019). This showed a clear development of the mother's relationship with the body, from the naïve hope and optimism at the time pregnancy is planned and discovered, to being an untrustworthy and distinct part of the self. The body has been described as an "antagonist" to the fertility goals of its owner, in relation to infertility (Brehm & Schneider, 2019, p. 12), the same observation could be made about perinatal losses. An increasing distrust in the body and its safety has been linked to increasing severity of depression, with distressed individuals either rejecting what the body communicates, or becoming hyperaware with increased anxiety around bodily sensations (Dunne, Flores, Gawande, & Schuman-Olivier, 2021; Scheffers et al., 2019).

While a woman's connection with both her body and her emotions is considered an essential aspect of healing after a perinatal loss (Hazen, 2003), the relationship with the body also has direct implications for the next pregnancy. The following infant is growing in the place death took place, not only emotionally impacting the mother through anxious thoughts, but also having to trust in her body again, when this trust has been lost:

> "*It made it one of the most terrifying experiences of my life. The whole 9 months I was living in fear. Words cannot describe how scary it truly was. I lived in a permanent state of anxiety and didn't trust my body or myself to know the baby was ok as it had failed me before.*" (S38)

Stating that she "*didn't trust (her) body or (herself)*" again highlights the separation between self and body, her physical body was no longer trustworthy, having previously failed. But also the self is considered untrustworthy, as it lacks knowledge about the baby's wellbeing.

The sense of separation between the mother and her body, directing blame, anger and distress towards her own physical being, seems to contradict the combined physical and emotional experience mentioned earlier. However, a separation between body and self is not possible, and therefore ultimately the frustration with the failure of the body, becomes self-directed and results in personal responsibility for physical responses outside the woman's control:

> "*I learned my beautiful boy had died. I thought I was going to die... I wanted to run away to keep him safe, I wanted to die with him. I was so scared… I tried my hardest to keep him inside… The guilt of not keeping my baby alive and ruining everyone else's life has crippled me*." (S20)

The quote above describes guilt at the failure to protect her baby, so the 'self' takes on responsibility for the failure of the body. The woman relies on her body to take care of a growing infant, and feels this responsibility despite having no control over the biological processes at work, resulting in self-blame (Bellhouse et al., 2019).

Whilst those surrounding the pregnant woman may assume a joyful and hopeful experience, moving on from loss, the embodied experience of the body's betrayal is embedded in the next pregnancy (Garrod & Pascal, 2019). This felt sense of responsibility is apparent in the responses of these participants, when asked how they felt about the pregnancy after loss:

> "*I was induced at 37 weeks as I couldn't cope emotionally anymore. I… was convinced my second baby was going to die too*." (S29)
>
> Emma: "*I felt like it was my burden to carry... I just think when you're the one carrying that baby you feel very much like that is your responsibility and I was very worried that anything that I would do would sort of ruin that*" (Interview 4, lines 107-112)

Carrying a baby whilst having to trust a body that had failed them in the past became a heavy burden for these mothers, resulting in distressing pregnancies, with the constant link to death.

Perinatal loss as a traumatic life event cannot be separated from the physical experience of it. Seigal (2017) describes the physical emptiness felt by parents who lose a child, and the sense of a part of themselves being physically removed, with the grief experience then also becoming part of the body. Models of grief tend to focus on different tasks or stages (Kübler-Ross, 2009; Worden, 2009), levels of distress (Wortman & Silver, 1989), and how grief can be incorporated into an individual's life and identity (Tonkin, 1996). However, none of these models represent the physical experience of death occurring within the living body, and the way in which this impacts on grief responses. The lack of recognition of perinatal losses as traumatic events, as well as the absence of the physical representations of grief in the literature seems to inadequately represent these experiences.

While studying the body in relation to psychological distress, including bereavement, is becoming more common, Gudmundsdottir (2009) points out that this has led to leaping from psychological models of loss, to investigating their biological and neurological components. This can still somehow miss the whole person or even the whole body, and the way in which loss is experienced. For perinatal loss, it is not only the impact of grief on the body that is of interest, but also the way in which the body is implicated in the loss itself. Critiques of linear models of grief, or even those, such as 'continuing bonds' that acknowledge on-going attachments, are that they still emphasise a mind/body split (Pearce & Komaromy, 2020). These models tend to focus on how bereavement is felt within the body, expressed through embodied activities and how the deceased remains embodied in the bereaved. For perinatal loss, the embodied nature of the experience goes beyond the absence or presence of the lost, and psychosomatic expressions of grief. The mother and baby's bodies are not separate during pregnancy, and therefore the loss of the baby can be experienced as a mutilation of the body, losing the baby is also losing part of the body (Gudmundsdottir, 2009). Embodied activities, such as giving birth, can therefore be important aspects of grieving.

This participant, who again describes the body with beliefs separate to her own, welcomes the physical pain of labour as a focus away from the emotional pain of the death of her baby:

> "*Neither my brain nor body wanted to believe this was really happening it seemed. I wanted everything to be over with as soon as possible… nothing could be worse than having been told our baby had died. I almost welcomed the prospect of labour as something to put my focus on other than starting to process the reality we were dealing with…*"
> (S3)

Immediate physical needs, such as labour, take priority over emotional pain, and therefore provide a reprieve where the emotional pain does not yet have to be faced. Even bystanders who witness distress are neurologically predisposed to give physical pain priority, until any physical threat passes (Bruneau et al., 2013), however this does not diminish emotional pain, but only delays the attention that it receives. This may be problematic for the support received by these women, where their physical needs take priority in the healthcare system, and the emotional pain is often not addressed sufficiently.

Subtheme 2: The mind and body divide in healthcare

While the participants gave vivid and distressing descriptions of their perinatal journey, they also highlighted aspects of their experiences that compounded the distress. Notably this included both the physical spaces they occupied during the loss, and subsequent pregnancy, as well as the way in which their physical health was prioritised and treated often without consideration for the meaning of these experiences. There was evidence of a developing relationship with healthcare professionals, that mirrored the relationship with the woman's own body. Starting off with hope and naïveté, feeling let down during the loss, leading to diminished trust, but also a necessary reliance on their support in the following pregnancy. There were examples of splitting healthcare professionals into good or bad, as well as examples of reparative experiences that were emotionally healing and helped develop the relationship into something more closely representing collaborative care.

For mothers, perinatal loss is both a physical and emotional experience. However, it was clear from the descriptions that these women perceived the physical and emotional aspects to be treated separately by professionals, with their emotional experience often going unacknowledged altogether:

> *"All professionals were very matter of fact and stated statistics. They cared that the baby had completely passed and that my physical health was looked after… No emotional understanding"* (S1)

> Chloe: "*There was no like, 'I'm really sorry', there was just… 'there's nothing there*'" (Interview 3, lines 59-61)

> "*Except for the diagnostics, there was very little aftercare… nobody offered anything beyond diagnosis and one doctor told me it would just be "like a period", which was completely untrue… I think emotional support needs to be better managed*." (S10)

For the doctors, the woman is the patient; the loss may be inevitable, considered a "routine pregnancy complication" (Bellhouse et al., 2019, p. 138) and is rarely a medical emergency (MacWilliams, Hughes, Aston, Field, & Moffatt, 2016). Through this medical lens the focus is on ensuring the woman's body has effectively managed to complete the loss. Whilst diagnosis and treatment are the role of doctors, the ambiguous personhood of the baby, especially with early losses, means that this is not always considered a bereavement (MacWilliams et al., 2016). The doctor has not lost a patient if the woman is still living. However, women's perceptions of the quality of the care they received are centred around emotional aspects of their care (Radford & Hughes, 2015).

The lack of acknowledgement of a death and the associated emotional distress was not just apparent in the way in which healthcare professionals approached their care, but also the lack of awareness of the emotional implications of other aspects of treatment, such as long waits, the location within the hospital and exposure to other pregnant women. There being no physical space for miscarriage, not only led to a lack of privacy and exposure to other pregnant women, but also seemed to represent the lack of space for miscarriages to be acknowledged as losses:

> Chloe: "*Me and [husband] were just left in a corridor… just to kind of absorb what happened… nobody came to speak to us*." (Interview 3, lines 68-71)

> "*Even simple things like not having to walk through a room full of pregnant ladies after a devastating scan - this felt like torture the first time and even worse the second as I knew what I had to face…*" (S8)

The lack of physical space, as well as the lack of support from midwives led to increased isolation for these women and their partners at a distressing and confusing time. This represents the social norms more broadly of the denial of early losses being the death of a loved one.

Healthcare professionals have a complex role to play in ensuring that the needs of women under their care are met, within a medical system that prioritises physical health. There were examples of the mother's life being at risk, which adds to the complexity of the life/death dynamics of these stories. The focus on saving the life of the mother by the medical professionals, does not allow space for the distress of the loss of her baby (Garrod & Pascal, 2019). The physical trauma can be distressing for all involved and it is easy for outsiders to focus on the mother's life being saved. However, for the mother, her body and the life of her baby are inextricably linked, and therefore the deep sense of loss, as well as processing the experience itself can override any relief:

> "*I had a heterotopic pregnancy, one twin in the womb and one in my Fallopian tube. The first I knew of this was at 8 weeks when the ectopic ruptured, nearly killing me… Two days after life saving surgery I had to go for another procedure, to remove the baby from my womb… I left hospital with no information on support.*" (S28)

> "*My tube ruptured overnight and I lost over 1 litre of blood. Surgery, loss... It was torture, I suffered with PTSD couldn't sleep, couldn't trust my body… It was very difficult for my partner… He thought I would die, I wished I had.*" (S3)

The ectopic pregnancy was so distressing for this last participant that she wished to have died with her baby. The impact was long lasting, with the emotional implications far outlasting the medical emergency that was responded to within the hospital. Even healthy pregnancies and live births can be traumatic and require targeted psychological intervention (Sheen & Slade, 2015), whilst causing permanent changes in women's bodies, which can leave women feeling excluded from pervasive social norms (Boon, 2012). With the embodied nature of grief related to the lasting impact of pregnancy and birth experiences, compounded by the loss of a child, perinatal loss has a long-lasting impact on both women's bodies and emotional wellbeing.

Perinatal loss is unique in that mothers are not only grieving the loss of their child, but also the changing relationship with their bodies. The embodied nature of this grief often goes unacknowledged by services, where the focus on physical health misses the psychological consequences of death and the experience within the hospital. To have a child after loss requires these women to put their trust in their own bodies, which have previously failed them, and to rely on the support of healthcare professionals to provide the care needed to make this possible. Treating women's physical bodies whilst ignoring the emotional impact of their history and current circumstances can result in unnecessarily distressing pregnancies.

Subtheme 3: Embodied rituals and reparative experiences

The lack of societal norms around perinatal losses leaves mothers unprepared for the mourning process (Hazen, 2003). The development and use of rituals has long been considered an appropriate therapeutic technique for the processing of grief, particularly where the client feels "stuck" (Rando, 1985; Reeves, 2011). As an activity or behaviour, that symbolises the emotions experienced, a ritual allows for an embodied experience of a psychological state, and through this supports grief processing (Rando, 1985). Perinatal losses lack access to some of the socially prescribed rituals around other deaths within Western society (Markin, 2016), however, this led to the development of individual rituals by women and their families, in order to communicate, remember, and process these significant losses.

Physical or embodied acts can bring a focus to the grief, providing some security when emotions may seem chaotic (Rando, 1985; Reeves, 2011). There were many examples of embodied actions used as grief rituals by participants, including one-off actions such as:

> "*Ran race in their memory*" (S37)

> "*Myself and husband have matching star tattoos on our little fingers and I have a babyloss ribbon tattoo on my foot.*" (S25)

> "*I remember making a picture out of beads after the first miscarriage of a little girl under a tree. The little girl represented the first child I lost and the tree represented that although I didn't have her any more, she was still safe. I then disassembled the picture as a way of 'letting go'. I found it a beautiful experience*." (S26)

As well as these one off experiences that helped women process or commemorate their losses, there were also examples of repeated rituals, which would be carried out on specific dates:

> "*We celebrate the due dates in the evening as we do with our living children. We have a glass of champagne and a cheese board*." (S4)

> "*We visit the beach every year and throw blue flowers into the sea*." (S18)

> "*Every year on the memorable dates I light a candle.*" (S28)

For each of these rituals what was important was that they allowed physical action or embodied acknowledgement that supported the psychological processing of the loss.

Ritual has been described as "a powerful cultural tool to acknowledge and confirm life-changing events" (Wojtkowiak, 2018, p. 463). With a disenfranchised grief, such as perinatal loss, it therefore follows that developing appropriate and meaningful rituals is an important process for the individual to declare that what has happened was life changing in a way that cannot be reversed. Beyond this, rituals also provide a process for change to the individual's psychological state, as well as their social relationships (Wojtkowiak, 2018).

Although there are a lack of social norms and rituals in relation to perinatal loss leading parents to develop their own, the reparative activities are still limited by the societal context within which they take place. There have been several studies about the way in which donating human milk after a loss can provide a grief ritual and reparative experience for mothers who are adjusting to their maternal role in the absence of a baby (Oreg, 2019; Oreg, 2020). However, milk donation is not a widely known possibility within the UK, despite a network of milk banks (UKAMB, 2021), and the guidelines for professionals promote providing women with lactation cessation advice, with no mention of donation as an option (Royal College of Obstetricians and Gynaecologists [RCOG], 2010). For Louise, the lactation cessation medication did not work, she reflects on the time after the loss of her daughter, and the felt need for this milk to nourish a baby:

> Louise: "*I just looked, and this just leaking colostrum down, and um, and I just like, wanted to ring the hospital, and say, "you must have got some babies that need some colostrum, I've got all this milk, I want to give it to you"*" (Interview 5, lines 1030-1033)

Despite a desire to donate her milk, this was not perceived as possible, with Louise assuming the midwives would "*think I'm a right lunatic*" (Interview 5, line 1035). However, this experience did add to the significance of the reparative experience of Louise being able to feed her living son sometime later: "*I was pleased that I could sit nursing him*" (Interview 5, lines 1037-1038).

Pregnancy changes the body, which forms part of a woman's adjustment to the motherhood identity (Hodgkinson, Smith, & Wittkowski, 2014). However, when the body goes through the experience of pregnancy but there is no child to mother, this can leave the woman not only bereft of the child, but the also the loss of who she was both physically and emotionally beforehand (Murphy, 2012). Even after the body has physically healed, this change is not just psychological, there is a "biological legacy of pregnancy" as foetal cells from even early losses remain present in the mother long term (Peterson, Nelson, Gadi, & Gammill, 2013, p. 136). This lasting physical legacy has been used to provide comfort to those grieving a perinatal loss, through suggesting that the baby has a lasting legacy that lives on inside the mother (for example in Clark-Coates, 2017). Although these participants may not have consciously known this, the data suggests that these women felt that they would never be the same in not just a psychological but also an embodied way. Many also sought to create an explicit legacy for their child as part of processing their loss.

Although participants were asked directly about what they had done to commemorate or remember their baby, an earlier question was "*What helped you to cope with the loss?"* It was often in answer to this that participants listed reparative actions they had taken. Making memories, commemorating their loss, doing things for others, and reparative pregnancies were all listed as things that helped them to cope with their loss. Legacy action, where involvement in altruistic activities is done in memory or honour of the lost is considered a form of grief ritual (Oreg, 2019; Rossetto, 2014). Many of the participants described commemorative acts such as "*raising money for charity*" (S37) and some even started their own charities, creating a lasting legacy that gave significance to their baby's life:

> "*Fundraising and setting up our own charity, it gave me a different focus. Does good and keeps his name alive*" (S20)

This was not only described as a way that supported them in their own grief, but also served as a reparative experience. Where reparation cannot be made for their own experience, mothers found comfort in reparative action for those who may follow them. Setting up philanthropic foundations has been found to help bereaved parents to find meaning in their loss experiences and was therefore mutually beneficial, creating purpose out of tragedy helping both the bereaved and those who benefited from their work (Rossetto, 2014). This was echoed by participants who found that what helped them to cope was "*feeling like I could try and make a difference and prevent other families from losing their baby, or having better bereavement care*" (S34). Whilst their own loss history could not be altered, passing some benefit onto others from their experience made some element of reparation possible.

As a result of the baby's body being physically part of the mother's body, the mother not only grieves the loss of a loved person but may also experience the loss as a physical loss of a body part, akin to amputation (Gudmundsdottir, 2009). Participants expressed the active nature of 'mothering'; being a mother is perceived as a physical activity, which makes the physical absence of a baby, and both and empty womb and empty arms, even more significant for mothers who experience perinatal losses (Murphy, 2012). For many, what was listed as helping them to cope was "*getting pregnant again*" (S9 & S11); their grief was transformed by an embodied reparative experience of a new pregnancy that led to a live birth:

> "*I have only been able to manage the losses since my son was born*" (S15)
>
> "*Finally I had another baby that was when the weight was truly lifted*" (S32)

This should not be misunderstood as a replacement for the lost child, and may be reparative alongside evoking complex feelings of grief and guilt (Reid, 2007; Testoni et al., 2020). However, a pregnancy after loss allows the woman to experience stages of pregnancy, birth and beyond that were not possible during the loss experience:

> Cath: "*Although, even though [baby girl 2], she'll never replace [baby girl 1] but I needed to have that baby*" (Interview 1, lines 605-606)

The experience of a pregnancy after loss not only provides an opportunity for maternal actions that were lost along with the perinatal loss (Garrod & Pascal, 2019), but also help repair the loss of trust in the woman's own body. Many of the rituals and reparative actions taken by participants continued long after the birth of a healthy child, establishing the lost as a member of the family, alongside living siblings. The connection between the child and the wider family or community, either through physical or symbolic bonds, often many years after the loss, is considered an important aspect in post-loss healing for mothers (Hazen, 2003).

4.5 Theme 2: Finding the Words: Language, Labels and Legitimate Distress

One area of development in these women's perinatal journeys was demonstrated through their use of language to describe their experiences. What initially stood out was the silence around their losses and grief, including not only the silence in the delivery room at the birth of a deceased baby, but also the lack of words from those around them who did not know what to say, exacerbating the felt isolation. Participants also highlighted the way in which labels used by others could minimise their experiences, such as the medical terminology attached to forms of perinatal loss that seems to misrepresent the experience. This led to what seemed to be a conscious effort to develop the words that might help break the societal taboos around perinatal losses. The development of common terms seemed to be both a result of and contribute to the creation of communities of others with similar experiences. Specific labels were introduced into their common language as a way to legitimise their loss or distress, including the labels that mothers attribute to their children, both living and lost. The experiences reported by participants highlight the need for greater understanding by those supporting bereaved mothers, of the power and importance of their words.

Subtheme 1: There are no words: Silence and denial of death

The birth of a child is usually considered a joyful much anticipated event, culminating in the sound of the first cry of the newborn child (van Manen, 2017). For these mothers, who were denied the anticipated cry at birth, a significant aspect of their experience of loss was the silence:

> *"On the 16th June our boy was born silently into the world." (*S20)

Silence represents death; dead babies don't cry, and this is often heightened by being experienced in the context of hearing the cries of the other babies within the maternity unit:

> Louise: *"It was very, very quiet… they didn't have a bereavement suite or anything, so you can hear the other babies, and that's quite hard… my baby's not crying"* (Interview 5, lines 279, 313-314 & 320)

The experience of her baby not crying was part of Louise's journey in recognising her death. The link between silence and death meant that fear of death in future pregnancies is symbolised through the fear of silence:

> Louise: *"I was really scared it was going to be quiet again… So I was like getting worked up just thinking, I just don't want him to come out dead"* (Interview 5, lines 997 & 999-1000)

Louise's goes on to express her relief at how loud her son's arrival was, the volume of his cries provide her with proof of his life and his health.

The silence at birth for perinatal losses is mirrored by societal silence, with losses considered taboo and hard to talk about (Layne, 2000; Martel, 2014). Several of the participants discussed the on-going silence around their loss by those who did not know how to speak to them and what to say, for example:

> "*Friends and family tried to support us but didn't know what to say, others avoided us and still do if I raise the subject*" (S3)
>
> "*Friends didn't know what to say… most avoided us*" (S24)

Those surrounding the bereaved seem unprepared for this support role, leading to avoidance; a physical separation that further marginalises these mothers. The lack of words from those in their social network was not only hurtful, by being experienced as a denial of their loss experience, it also added to the isolation and loneliness felt by these women:

> "*I think no one knew what to say so it was a very lonely time.*" (S11)
>
> "*Family and friends generally didn't know what to say… I felt quite alone most of the time*" (S15)

In developing a framework for a language for grief, bereavement is described as "a socially constructed status with both personal and societal meaning" in response to the "the death of a loved one" (Corless et al., 2014, p. 133). For perinatal loss these personal and societal meanings may conflict, leaving the status of the bereaved precarious. Society has established rituals; expected behaviour by both the bereaved and those who interact with them. By Corless et al.'s (2014) definition, bereaved status is achieved through the recognised death of a loved one; where perinatal loss is not acknowledged as such a death, the mother may therefore be denied the status of 'bereaved' and therefore not treated as such by either professionals or others within their social sphere. In the workplace, where all grief is to some extent disenfranchised due to societal discomfort with mortality, and denial through avoidance of the bereaved; silence around perinatal losses can lead to a "doubly disenfranchised" grief (Hazen, 2003, p. 149):

> "*I also found it very hard when people pretended that it didn't happen… I remember my first day back at work and a couple of colleagues were quite nonchalant when I first saw them. Although I was aware that everyone is different and they may not have known what to say… I found that very tough*" (S26)

The lack of acknowledgement by colleagues can be understood by the absence of cultural norms to guide their behaviour, and leaves bereaved mothers unrecognised (Sawicka, 2017). The difficulty in reengaging in a workplace that did not acknowledge the changes in these women's personal narratives led to many of the participants making changes to their careers and places of work as a direct result of their loss.

When words were offered by those surrounding these mothers, they were often unwelcome, as they demonstrated a lack of understanding:

> "*People had words of advice they thought would make me feel better but I felt it was very patronizing*" (S16)

As the poet, Land (2010), implies, silence in grief is often welcomed, rather than the well-meaning but misguided sentiments of those around the bereaved. During a pregnancy those around the woman may discuss the "baby" as a "new member of the family", but this is often contradicted in loss, where personhood is denied, and the social status of the lost infant becomes ambiguous (Sawicka, 2017, p. 234). The lack of cultural definitions and associated behaviours leads to a combination of silence and well intentioned but misguided attempts at comfort by the woman's social support network. Many participants described the way in which this led to changes in relationships:

> Cath: "*We lost so many friends after losing the baby… Because you have friends who, they are initially there… They're at the funeral, and then they don't get it, and so people just didn't talk to us or you know… Didn't know*

> *what to say, so instead of saying, I don't know what to say, I'm sorry, they just didn't bother*" (Interview 1, lines 1669-1677)

Friendships were both lost and formed on the basis of who was able to tolerate the distress experienced by these women, with those with shared experiences being particularly sought out as a way of finding safe places to be open about their grief. A desire to be supportive was not enough, it was assumed that experience was necessary in order to be able to understand and therefore offer effective support:

> "*My mum was great too, but not having been through anything similar was unsure about what to say*" (S13)

Those that seemed willing and able to talk about the loss were often those who had insider experience:

> "*Within a week of first sharing the news with close friends I received many phone calls from my female friends who shared that they had also miscarried*" (S26)

These miscarriages were only disclosed at the point of the participant becoming someone with a similar experience, as if the community exists, but only becomes visible once granted membership through the shared identity of shared experience.

The social networks in which losses take place influence the narrative of the losses experienced (Gilbert, 2002). Where existing social networks don't meet the needs of the bereaved, developing new networks of relationships was an important way to increase the narrative possibilities. For Cath, a key support following the loss of her daughter was a group provided by a national stillbirth charity:

> Cath: "*It's… one of those groups that no-one wants to join, because of why you join… However when you are there, there are amazing people…*"
> Lucie: "*So what is it that, what makes [charity] so amazing?*"
> Cath: "*People understand*" (Interview 1, lines 1346-1351)

Societal discomfort with perinatal loss has led to a silence around miscarriage and stillbirth that reduces support and exacerbates isolation, leading women to seek out those with shared experiences to find understanding (Bellhouse, Temple-Smith, & Bilardi, 2018; Scott, 2011). As participants reflected on their own increased understanding of loss through experience, they also often sought to provide that newfound knowledge and understanding to others seeking support.

Participants considered not only silence around perinatal loss but also the medical definitions that are widely used in society problematic. Changes to the medical terminology used to describe perinatal losses, whilst appearing to increase empathy towards women's experiences, seems to be largely driven by technological and legal developments (Moscrop, 2013). For the women in this study the use of labels by others, particularly healthcare professionals, that didn't represent their experience, were often distressing. This included the use of "*spontaneous abortion*" (S21) and "*foetal remains*" (S30) to describe miscarriage, as well as the use of "*miscarriage*" (S30) for losses that require giving birth:

> "*At a consultant appointment afterward the term spontaneous abortion was used, this broke me I didn't choose to lose my baby*" (S21)

> "*I went through labour at only 11 weeks pregnant. I didn't even know that was possible. There needs to be more information and support.*" (S30)

Despite grief responses being recognised in all forms of loss, including miscarriage, stillbirth, ectopic pregnancies and induced abortions, this grief is often invalidated by medical and social silence (Martel, 2014). The way in which labels can legitimise or dismiss not only the distress but also the personhood of the lost raises questions about what is counted as a baby, and how this differs between individuals, professionals and society more generally. The mother can attribute personhood from the earliest stages of pregnancy, despite this being "revoked" by cultural taboos in the face of a loss (Layne, 2000, p. 323). The labels linked to gestation impact not only the legitimacy of the baby's personhood, but also what treatment is available. For one participant this meant witnessing two of her babies dying without medical intervention:

> First baby: "*She wasn't dead she was breathing. We held her for about an hour then she passed. The doctor came and said they wouldn't revive her as she was not classed as a baby*" Second baby: "*He was alive and no one was trying to save him. He also lived for an hour. The doctor said he is classed as a foetus and can't save him as the law stated under 24 weeks is not a baby and they can't intervene. So we just held him until he passed*" (S23)

How losses are labelled also had a significant impact on the experience:

> "*I think there is very little information regarding loss in the middle months. Before 12 weeks it's classed as miscarriage after 24 weeks it's a stillbirth but what was I? The term used was a late miscarriage yet I gave birth I had full labour, my breasts produced milk for a baby that wasn't there*" (S21)

For this participant, the label of "*late miscarriage"* did not acknowledge the experience of giving birth and the postnatal period. This is echoed by a qualitative study with those on the margins between miscarriage and stillbirth, who felt unprepared for birth and spending time with their deceased infant, due to the use of the term miscarriage for losses up to twenty-four weeks gestation (Smith et al., 2020).

For those with earlier losses, there can be a perceived hierarchy to these labels that can be dismissive of the grief and distress experienced, and a barrier to seeking support:

> "*It would be nicer if early miscarriage could be acknowledged. There's a lot of focus on stillbirth and late term loss, but early loss is just considered "one of those things" when really it can be devastating*" (S11)

> "*Not accessing group support was a deliberate decision because I felt that I had no right to impose my loss on others who had experienced a*

> *later loss or stillbirth. I later acknowledged through therapy that dealing with others loss… was a barrier to my own healing as it belittled my genuine feelings of grief*" (S9)

This sense of hierarchy can be exacerbated by the assumptions of healthcare workers who consider later losses as more traumatic than early loss (Murphy, 2019). The lack of legitimacy, that is communicated through withholding support that might be available in other death or birth scenarios, is considered an important aspect of complicated mourning (Malacrida, 1999). The language used around loss is significant in shaping what is thought to be a 'normal' experience (Hedtke, 2002), and therefore the availability of accessible narratives that don't prescribe a single concept for bereavement is considered most helpful to those grieving (Rosenblatt, 2008).

Corless et al. (2014) propose a framework for understanding the "languages of loss", recognising the need to bridge a gap between professionals and the bereaved in the way in which grief is articulated. Kay (2017) in his personal account of his experience as an obstetrician describes the need to become desensitized to foetal loss in order to tolerate the role. Research with obstetricians and gynaecologists highlights regular exposure to traumatic events, with many experiencing symptoms of PTSD (Slade et al., 2020). There is also evidence for traumatic stress responses in midwives who are exposed to traumatic events as part of their role (Sheen, Slade, & Spiby, 2014). Although professional distance may be a necessary protection for those who are regularly exposed to loss, this can lead to grief labels and theory that do not connect with the experiences of the bereaved, through clinical rather than personal narratives (Corless et al., 2014). There is a need for cultural changes within obstetric services, and better systems of care for staff in order to reduce the impact that exposure to trauma within their roles has on healthcare professionals (Slade et al., 2020).

The way in which participants used labels to legitimise their losses, and the significance of their experiences, whilst rejecting the labels used by medical professionals, or the legal definitions for loss, highlights the emotive nature of language and how the ways in which labels are used can be supportive or dismissive of distress. The need for developing a common language seems to be an important part of breaking the silence and taboos around baby loss, however, the experiences of these participants shows the importance of this language being developed by rather than for bereaved parents, and the need for healthcare professionals to be aware of the power of the labels they use, and to be inclusive of the subjective experiences of those who they care for.

Subtheme 2: "Sunshine", "angels" and "rainbows": Developing a language for loss

There were key labels and terms used by many of the participants for their living and lost children, which seemed to allow them to describe their losses in terms that gave meaning to their experiences. The majority of participants used these terms without explanation of their meaning; therefore there was an assumption that I understood this language, which may have been as a result of me sharing my insider status. Participants used common terms to describe their children born before loss, "*sunshine babies*", the child who died, "*angel babies*", and the child after loss, "*rainbow babies*", in a way that reflected not only the different identities of their children, but also their changing motherhood identity. It seemed to be an attempt to develop social norms through common language, and also provided rich symbolism that represented the experience in terms that were socially acceptable.

The most commonly used term was "*rainbow*" to describe the pregnancy or baby that came after a loss. A symbol of hope, the rainbow seemed to represent having come through something difficult to a positive outcome. This term was used without explanation, highlighting how normalised this was within the baby loss community. For example:

> "*I had sessions from my loss right up to the birth of my rainbow*" (S18)
>
> "*Our rainbow baby boy… was born 2 days before the 1 year anniversary*" (S21)
>
> "*I moved hospitals… and finally got my rainbow baby*" (S36)

There was an assumption of this term being widely used and understood, but also a willingness to explain the term to those unfamiliar with it:

> Louise: "*Because when I was pregnant people said, 'is this your first pregnancy?' 'It's my rainbow baby'… And then I'd explain what that was*" (Interview 5, lines 1210-1213)

The term "*rainbow"* was not only a label of the living child after loss, but symbolic of this new life fitting into a wider family narrative, one where hope was only found after suffering. Symbolic language in grief is considered not only a way to represent the deceased, but also represents the relationship with the deceased (Colman, 2010). While not referring directly to the lost infant, the label of "*rainbow baby*" provides symbolism of the relationship between the lost and living children. Grief and the relationship with the lost is an evolving process, and the narrative develops and is shaped by the language available (Hedtke, 2002). "*Rainbow*" babies shape that narrative, because they represent an on-going grief and relationship with the lost infant, whilst simultaneously representing the hope present in new life.

"*Rainbow*" was also a term adopted by specialist services that catered for the pregnancy after loss, including NHS clinics as well as support provided in the third sector, for example:

> "*I attend a rainbow antenatal clinic and see the same consultant. They all know me and my partner and know what we have been through*." (S29)

> "*I actually found a rainbow baby support group on Facebook*" (S27)

Having a specific term used by both women who have experienced loss, and those who care for them suggested a clear recognition of any pregnancy that is experienced after a perinatal loss as different and therefore needs to be labelled as such. Whilst the label itself denotes hope and a happy ending, it also showed the importance of recognising how these women were changed by their history, and that a 'normal' pregnancy was no longer available to them. However, despite its common usage, there is also ambiguity in the term. While women commonly refer to the baby after any loss as a "*rainbow*" baby, the "*rainbow*" antenatal services are only usually available after late losses, such as stillbirth, while pregnancy after miscarriage is not treated differently from standard antenatal care (Heath & Summers, 2017). While this may be necessary due to the prevalence of miscarriage, it also excludes women who may need it from the recognition that they are not experiencing their pregnancy with the same hope and aspiration that may have been experienced prior to loss.

The term for children born before any experience of perinatal loss was "*sunshine*", a reference to clear weather denoting the way in which those children were born without the storms of distress that came afterwards:

> Louise: "*She's got a sunshine baby, so one that was born before*"
> (Interview 5, lines 1378-1379)

"*Sunshine*" is a term devoid of distress, which conjures up joy and optimism. This term is only applied if loss is then later experienced, and therefore can only be applied retrospectively. A baby becomes a sunshine baby only once a following sibling is lost. This shows the way in which experiences are developed and reframed based on the fertility journey. Having a healthy baby at the end of pregnancy is initially expected (Moulder, 2001), and would not be reflected on as special, until a loss is experienced and the individual is made aware of just how different that pregnancy was, without distress and grief. "*Sunshine*" babies are labelled after loss, at the time these mothers recognised how 'sunny' their initial experience was in the context of more difficult times. The term was used less often, partly because many participants experienced loss in their first pregnancy, but showed that for those with living children prior to loss it was important to refer to them differently:

> "*My sunshine baby, she's my life saver. If I didn't have her I know I would have taken my own life. My rainbow baby, she healed me in ways I never knew possible*" (S20)

The different terms for living children highlights the significance of a loss event, that for these mothers there is a before and after, there is a difference between "*sunshine babies*" and "*rainbow babies*". For this participant, her "*sunshine baby*" was considered as protective, a child that predated her loss, giving her a reason to continue to live despite the distress of loss. Her "*rainbow baby*", coming after the distress of loss, had a different role in bringing healing. This is consistent with research that found that a baby's death can disrupt the internal maternal script, but having a living child allowed expression of this role, and was therefore protective (Wonch Hill et al., 2017). Whereas the baby born after a loss can develop a sense of hope and reduce the psychological distress associated with grief (Moore & Côté-Arsenault, 2018; Verdon et al., 2017).

For the loss itself, there was more ambiguity about how to refer to it, which seems to partly reflect the lack of social norms for describing different losses as well as how participants make sense of their loss experience. For Chloe, it felt too early to refer to her lost pregnancy as a baby:

> Chloe: "*Yeah, I don't see it as a baby, well I don't know, I see it as a thing… that's probably a bit weird, I think maybe if obviously it had been further on…*" (Interview 3, lines 690-694)

Whereas other participants were clear that their loss should be considered a baby, despite the early gestation:

> "*I love my children, I love all 3 of my babies always and I'm not ashamed to say that even at 11 weeks gestation, I love my baby that I lost.*" (S30)

Some used the term "*angel baby*", which seemed to suggest that these babies still existed for these mothers, but as heavenly beings, for example:

> Cath: "*I've got living children as well as my angel*" (Interview 1, line 1402)
>
> "*I had to be sedated to have my angel girl removed*" (S19)

There were also other external representations of the presence of the deceased infant:

> Louise: "*When I went to the church yard in December after the funeral there was a butterfly on the wall and things, so it was things like that, that you felt like her presence*" (Interview 5, lines 469-471)

These representations imply a spiritual or supernatural aspect of the experience, bringing both comfort and connection to the deceased.

While medical language used to refer to losses, was perceived as denial of both death and personhood, most mothers referred to their losses as babies, often with a sense of their continued existence either in memories or life after death. The spiritual nature of how these babies are characterised was also found to be an important aspect of developing a continuing bond with the deceased in a qualitative study on perinatal grief (Testoni et al., 2020). The mothers in the study spoke of external representations of their babies' presence; describing their lost infant as an "omniscience presence above them" which embedded them firmly as part of the family (Testoni et al., 2020, p. 6). Sawicka (2017, p. 236) refers to a "cultural void" that is a result of the lack of available symbolism embedded in culture to represent and guide the narratives of perinatal loss. She reports on the women's use of perinatal loss online groups in collectively reframing their identity to fill this void. The use of the label "angel" babies, gave these women access to an identity of "mothers" in the absence of a child, because they can become "angels' mothers" (Sawicka, 2017, p. 237). The importance of collective symbolism was apparent in the data, with many participants accessing online support to connect with other parents with shared understanding, for example:

> "*[supported by] baby loss groups on Facebook angel mums*" (S19)

The names of the support groups imply that not only the deceased babies are considered angels, but also that parents become "*angel mums*". Shared language seems to be a way a establishing a supportive community, as well as communicate to 'outsiders' in terms that hold meaning.

Corless et al. (2014) describe several types of language for grief, including 'narrative', 'symbolism' and 'metaphor'. Narrative story telling requires an active listener, which was not always available to these women. However, symbolism allows meaningful representation of the loved one, and their relationship to the mourner, while metaphor uses language that speaks beyond words, expressing difficult to communicate meanings (Corless et al., 2014). The participants using new language to represent their experiences seems to be both a form of symbolism, representing their lost infants, and also communicates difficult subjects in more accessible language through the use of figurative language or metaphor. These are not only important expressions of meaning making through grief (Nadeau, 2006), but also develop a community through others who share in the language and identity that this gives (Sawicka, 2017). While metaphors can provide grievers with accessible language to express themselves around taboo and difficult to talk about subjects (Young, 2008), for these participants it was not the difficulty in telling their stories that seemed to be a barrier, but the difficulty in others hearing about them. Metaphorical language seemed to provide more socially acceptable language that helped bridge societal taboos.

Kessler (2019) assumes that 'finding meaning' is a final stage of the grieving process, proposing that an individual needs to fully experience going through Kübler-Ross's (2009) stages of denial, anger, bargaining, depression and then acceptance first. However, the data suggests that this process is often reversed for perinatal losses. Participants assigning meaning to their loss seemed to allow them to enter into a grieving process, even if those around them misunderstood this. Neimeyer, Burke, Mackay and van Dyke Stringer (2010) support this, linking the failure to go through meaning-making processes with complicated grief responses, which can lead to a fragmentation of the self in the struggle of the individual to make sense of their experience. It therefore may be an important role of practitioners working with perinatal loss to support the bereaved in finding meaning in the loss experience, through making symbolic and metaphorical language available.

Symbolism provides important cultural tools for understanding experience, and for prescribing emotional reactions to situations (Sawicka, 2017). Sawicka's (2017) research highlights that such symbols do not exist for miscarriages and stillbirths, leading to ambiguous emotional experiences. However, the data suggests that mothers were able to develop their own symbols and therefore support themselves and each other in the emotional processing of their losses.

Subtheme 3: "We haven't got a word": The precarious identity of bereaved mothers

Despite developing common language for babies in relation to perinatal loss, the lack of a word to describe a grieving parent was considered significant:

> Louise: "*I always wanted, that was my long term goal, was to get a word that meant the equivalent of orphan or widow, that you could use in society to explain that you have got a loss… that is something that's quite important is that, we haven't got a word*" (Interview 5, lines 1217-1236)

The lack of a word meant that there was a perceived failure by people to acknowledge the position of bereaved parents in society. Seigal (2017) agrees that the inadequacy of language to provide a label for parents who lose a child makes their role in society and identity as parents precarious. Participants also questioned the ambiguity of the term "*mother*", at what point this label applied, and when women could include this as part of their identity. After having a healthy baby one participant "*felt so lucky and blessed to be given a second chance to become a mum*" (S9), which implies that she did not consider herself a mother before this. For some participants it was an elusive identity, something longed for but unreachable:

> "*I had longed for as long as I can remember to be a mum… I couldn't understand how something seemingly so easy was so hard and painful.*" (S4)

In the face of uncertainty after multiple losses Joanne asks: "*would I ever be a mother?*" (Interview 2, line 233), but experienced the miscarriages after her daughter was born differently, as they didn't threaten this identity:

> Joanne: "*Having a healthy baby… there was just a lot of pressure taken off, 'cause I was like now I have a child, I am a mother*" (Interview 2, lines 956-959)

It seemed that "*mother*" was a term that was unavailable to women experiencing loss, but could be used in reflecting on their experience, as this in part gave validity to the personhood of the lost child. In the same way that labelling lost babies as "*angel babies*" helped give women the identity of "*mothers of angels*" (Sawicka, 2017), the acknowledgement of themselves as mothers from the time their pregnancy started, despite the outcome, gave validity to the personhood of their lost child. When asked if she considered herself a mother after the loss of her daughter, Cath responded:

> "*Then I wouldn't, now I would, I was a mother from the time I conceived [baby girl 1], I was a mother… Then I wouldn't, because I just felt lost… even though now I would say that no, I was a mother the whole time*" (Interview 1, lines 601-606)

Cath was unable to consider herself a mother until she had had a healthy baby, but in reflecting back was able to give herself this identity retrospectively for her first pregnancy. Cath has three living children, but "*if anyone asks, yeah, I say I'm a mother of four*" (Interview 1, line 1532), thereby including her lost child in her motherhood identity. Stillbirth and child death has been found to lower self-esteem in mothers, thought to be in part due to the lack of opportunity for external expression of internalised motherhood scripts (Wonch Hill et al., 2017). For Louise, not owning her identity as a mother impacted on her child's identity, but was a difficult title to claim without the ability to carry out what she perceived to be the actions of a mother:

> Louise: "*When I ordered the head stone, that really started to hit me because it was the first time I wrote 'mother' when it said 'relation to deceased'… Because that's what I kept feeling, well how can I be a mummy when I've not had chance to bath her and dress her and change her… that what I really struggled with, getting my head around*" (Interview 5, lines 561-568)

Despite the lack of opportunity to carry out the perceived necessary actions of a mother, Louise's response to choosing not to mention her stillborn daughter when asked how many children she had was considered an "*awful thing*" and a failure as a mother:

> Louise: “*That I’d dismissed [daughter]… Like she didn’t exist, and then that really, I felt like I’d let her down… That I’d, as her mummy, I should definitely be telling people that she was important, that she was alive*” (Interview 5, lines 1252-1257)

But despite her own struggles with her motherhood identity, in her desire to support other mothers, her definition of a mother is inclusive:

> Louise: “*To me, as soon as you see that blue line, you’re a mummy*” (Interview 5, lines 1144-1145)

Motherhood seems to be an ambiguous identity, where social discourses around mothers intersect with the personal frames of reference in making sense of perinatal loss. It seemed that these women were more able to claim the identity of a mother retrospectively, than at the time of the loss. However, all of the participants in this data had at least one living child. Therefore, it is unclear if they would have felt able to reflect on their roles as mothers to their lost children in this way, if these were their only children. The way in which women are positioned in society as mothers, and women’s lives are often considered incomplete without children feeds into the complexity of the motherhood identity (Morell, 2000). This is compounded by the social myth of becoming a mother being a natural and simple process, which not only sets unrealistic expectations, but also fails to make space for the many and varied challenges that may be encountered on the motherhood journey (Winson, 2017). Discourses of reproduction can make mothers the ‘producers’ of children, leading those who fail to ‘produce’ a perfect child to be perceived as defective (Landsman, 1998). For those who experience perinatal loss, the inability to protect and nurture their unborn child leads to feelings of incompetence as mothers, impacting on the availability of a motherhood identity (Murphy, 2019). Women bereaved by perinatal loss are not socially recognised as mothers, and the lack of adequate language to name this experience results in a lack of legitimacy to their position in society.

4.6 Theme 3: "It's my body, it's my pregnancy" Seeking Control and Agency

A theme that was apparent across the data set was the way in which women felt a lack of agency and control in their pregnancy and loss experiences, and how they describe decisions that they made in order to regain some control. This included reflections on the perceived control over fertility choices being shattered by the experience of perinatal losses; struggles with the random nature of losses and an attempt to understand the causes of loss and to gain control over their future. The battle for agency also included experiences within the healthcare system where women felt a lack of agency in terms of choices about their care, what could and could not be done to their bodies, as well as a sense of being at the mercy of a wider system. Participants described a conflicting reliance on, and resistance to the power of healthcare professionals in the process of their loss and antenatal experiences. This fed into not only care for their physical health, but also access to support with the psychological aspects of their experience. In navigating the systems available women often embraced the use of psychiatric labels as a way of legitimising their distress and gain access to services that might otherwise remain inaccessible.

Subtheme 1: Recognising and resisting the loss of control

As women described their loss and pregnancy journeys an important aspect of how they framed their experiences was the transition from a perception of choice and control over fertility to the feeling of powerlessness, and for many seeking answers in order to regain some control and certainty in the midst of this. The process of getting pregnant as well as going on to experience loss, highlighted the lack of control that these women had over their motherhood journeys:

> Chloe: "*We'd always said we want to have another one, and we waited the amount of time we said we were going to wait to have another one, and we were so, you know, excited about having another one… because you think well, I've had one, you know, why would I have an issue with another one? So, that was really hard*" (Interview 3, lines 102-116)

> Joanne: "*I was thinking, it's over, there's no way that this had been successful, and you know just really disappointed you know... all the plans we'd started making*" (Interview 2 lines 107-109)

Murphy (2019) found that healthcare messages, and behaviour modification during pregnancy leads women to assume that they can control the outcomes of their pregnancies. In an era of smaller family sizes, families often precisely control when to have each child, leading to a greater disruption to planning through loss (Frost et al., 2007). Societal narratives around reproductive autonomy tend to focus on women's choices to prevent or end pregnancy, or choices around birth (for example Heuser, Gibbins, Smid, & Branch, 2017; Judge, Wolgemuth, Hamm, & Borrero, 2017; Thachuk, 2007), with seeming silence on the complex nature of choice and often lack of control in fertility outcomes (van der Sijpt, 2014). The prevalent assumption that pregnancy leads to a living child makes the experience of loss all the more shocking (Murphy, 2019). Participants describe their confusion and disbelief at their unexpected losses:

> Emma: "*They told me that there was no heartbeat any more, um, and that we'd had a missed miscarriage, which I didn't even know existed... So I think that was a really big shock*" (Interview 4, lines 30-37)

> "*After a year of trying for a baby, I experienced a miscarriage at just under 12 weeks gestation… I had only just started to tell people, thinking it was ok to get openly excited about it at that stage*" (S9)

Deciding when it was "*okay to get… excited*" about a pregnancy was an assumption that shifted with experience; prior to loss women are guided by social norms of pregnancies being considered 'safe' to announce from around twelve weeks, or the first scan. This assumption of safety feeds into feelings of shock when loss occurs. In the pregnancy following a loss, these women were far more guarded both in their own excitement, and in disclosing the pregnancy to others.

The distress at the lack of control and lack of preparation for these experiences was evident in these participants' descriptions. The inevitability of a loss, over which the mother had no control, highlighted a shift from pregnancy and fertility planning, to experiences that could not be planned:

> "*A miscarriage was inevitable*" (S40)
>
> "*I started bleeding and in pain went to A&E and the doctor… was really rude and said go home, if you are going to miscarry then you will.*" (S6)

Louise immediately begins to question what she or the baby has done, questioning why, and is then faced with the unknown of what needs to happen next:

> Louise: "*Your life is just turned upside down in that instant, I was on my own, I was just like, screaming… I can't believe this is happening, my baby was alive, I could feel her… not long ago, and now what's happened? What's she done? What've I done? What's, what's, why is this happening? But also like at a practical element, I'm just like, well what now?*" (Interview 5, lines 150-156)

As a way to address this powerlessness, for many there was proactive searching for a reason for their loss, with an assumption that gaining knowledge would lead to greater future control. However, this knowledge was often not available, and therefore seemed to increase the sense of powerlessness over their reproductive choices:

> "*We opted for a full post mortem as there had been no risks or signs that anything was wrong*" (S21)
>
> Joanne: "*I, at the time, it was, there was a lot of unknown, of like would I ever be able to have a successful pregnancy*" (Interview 2, lines 209-210)
>
> "*No cause of death had been found, and to this day we are none the wiser why she died. Although of course I have since invented a million and one reasons why it is all my fault.*" (S34)

In the absence of medical reasons, self-blame was common, and a desire to gain more control over the future was apparent through hyper vigilance in the subsequent pregnancy. It is common for women to feel responsible for their losses, and assume that they should have known of any problems, even when there are no obvious symptoms (Murphy, 2019). O'Leary and Warland (2016, p. 50) advocate for supporting women in reframing their narrative of self-blame into one of a "mother who did all she could" in order to help them rebuild the necessary trust in themselves in the subsequent pregnancy as well as to avoid the associated complicated grief.

Despite no control over the loss itself, some women were given a choice of treatment in how to manage their loss:

> "*I was offered a choice of treatments and chose to return home to wait a natural miscarriage*." (S3)
>
> "*I was given a number of options but opted for "medical management" and returned a few days later for the procedure.*" (S13)

Although requiring decisions that these women would never have wanted or expected to make, the availability of choice is important. Wieringa-de Waard et al. (2002) assessed the psychological impact of both expectant management and surgical evacuation in early miscarriage. However, it was not the type of treatment that was most influential on psychological distress, but whether the woman had chosen their treatment rather than being randomly assigned. Those who were given choice, and therefore control, over their treatment had the best psychological outcomes. The 'unpredictability of childbirth' was the overarching theme of a meta-synthesis of the moderators of fears around childbirth, which included themes of loss of control and inadequate care (Sheen & Slade, 2018). Perinatal losses highlight not only the unpredictability of the birth process, but of pregnancy outcomes more broadly, and therefore this suggests a greater need to support women in gaining as much choice and control as possible throughout the experience.

The choice to give birth was for this participant a way to maintain at least some agency in the process, despite being unable to control the loss:

> "*I wanted everything to be over with as soon as possible, but resisted [husband's] suggestion that I should have a c-section. I wanted no such*

> *thing. I couldn't bear the thought that my baby would be surgically removed from me, like some kind of tumour. I wanted to do our little bean the honour of at least delivering them the way we had planned, to see it through and know that I'd been able to do that last act for them, and for me*" (S34)

This participant framed her experience and choice of giving birth as a loving act towards her deceased child. In the absence of the opportunity to perform other aspects of the maternal role, these choices held great significance. She went on to acknowledge the need for choice in order for women to have some control in the context of the emotional and physical distress experienced:

> "*[I] cannot fathom how cruel it is that we make women go through labour with no hope of any happy ending after all of that emotional and physical stress*" (S34)

This suggests a need to take into account the context of a woman's experience when making birth decisions, the distress and lack of hope making the process of labour and birth a "*cruel*" one. Lack of control and feeling disempowered is considered a significant personal dimension in fears around childbirth (Fisher et al., 2006). This was echoed by a qualitative study of mothers, which found fearing unwanted interventions and lacking a voice in decisions relating to giving birth as key elements of fear of childbirth (Slade, Balling, Sheen, & Houghton, 2019). For women who are giving birth to a deceased infant, this is likely to be more pronounced, due to the absence of a possible positive outcome.

Lack of choice was also considered a cruelty, when dead babies were not shown the same consideration as a living baby, due to the prioritisation of the mother's physical health. The least medically invasive procedure did not meet the psychological need for Louise to continue to protect her baby, even in death:

> Louise: "*If she got stuck in the birth canal they'd have to cut her, and I just remember saying to my mum, pleading with my mum saying, 'do not let them decapitate my baby, please do not let them cut her', I could not*

> *imagine, I knew I was only going to get a cuddle… I could understand, obviously they are going to prioritise my life, um, and didn't want to get her stuck, but I said 'what would you do if she was alive?' they said, 'we'd give you a section, we'd give you a choice', so why put me in that position?*" (Interview 5, lines 227-235)

Louise is questioning why options that are available to mothers of living babies are not available to her, putting her in the position of possible further trauma in the birth process. The Royal College of Obstetricians and Gynaecologists provides guidance for healthcare professionals on supporting women through 'Late intrauterine fetal death and stillbirth' (RCOG, 2010). This guideline clearly outlines the need to support women in making choices in relation to their care, and the psychological consequences of imposing care at such a vulnerable time. They recommend providing information, but not seeking to persuade parents of any specific course of action, including decisions around the birth, memory making activities and post mortems (RCOG, 2010). However, medical professionals hold a clinical responsibility for healthcare decisions, and may hold different priorities to the patient (Vegni & Borghi, 2017). Parents' decisions around the treatment of their stillborn child are likely to be influenced by the local healthcare culture, despite the lack of conclusive evidence on the consequences for mothers (Hennegan et al., 2015). Where parents are given choices, such as whether to hold their deceased infant, it is important that the options available are all normalised, in order that they don't perceive the request to choose as implying that they may be doing something wrong (Üstündağ-Budak, Larkin, Harris, & Blissett, 2015).

The experience of care at the time of the loss has an impact on the women's healthcare decisions and behaviour in subsequent pregnancies. There has been a push towards collaborative care within a relational midwifery model, which seeks to empower women in their pregnancy and birth choices through developing trusting relationships with their midwives (Thachuk, 2007). However, this seems contradictory to the medical model of childbirth in the UK, where midwives become managers of risk, in high-pressure healthcare settings, where continuity of care is often impractical, hindering their relational capacity with patients (Einion, 2017; Page, 2003). Participants often referred to a lack of continuity of care, as part of a negative healthcare experience, and this seemed to be a key element of diminished trust between women and the healthcare providers:

> Chloe: "*Something I've found really difficult is the change in midwife… There was no consistency*" (Interview 3, lines 267-273)

> "*Seeing different consultants each time during my second pregnancy added to my concerns that something might be 'missed'*" (S34)

To develop trust patients need to feel not only known to their healthcare provider, but also that the practitioner is working in their best interests (Wei, Xu, & Wu, 2020), which did not always seem to be the case:

> "*The overall impression I got was that miscarriage was very common in the first trimester, therefore it was just all in a days work for them*" (S4)

Through the perceived dismissal of their loss experience it seemed that women became increasingly cynical of the motivations and priorities of healthcare providers.

Subtheme 2: The power of healthcare to provide and limit choice

Although the majority of perinatal losses discussed by participants were without a known cause, there were examples of those who believed their losses were preventable, and therefore the sense of powerlessness was not only about accepting the lack of certainty in their motherhood journeys, but also related to the way in which they interacted with those whom they held responsible:

> "*We had to remove his life support due to medical negligence during my labour*" (S24)

For these mothers, the lack of agency was linked to being at the mercy of the healthcare professionals and the system within which they operated.

> Cath: "*I trusted who I thought were the experts… It annoys me that basically they've carried on as if nothing ever happened and that*

> *literally I am just a name on a bit of paper as far as they're concerned*" (Interview 1, lines 122-123 & 527-529)

Cath felt that her trust was misplaced, after medical negligence led to the loss of her daughter. Her perception of the lack of impact on the professionals involved, highlights the loss of trust and her need to not only seek care elsewhere for her subsequent pregnancies, but also be more assertive through questioning, and demanding agency in her own care.

The expert status of doctors places them in a position of trust, and pregnant women rely on this expertise for the care of themselves and their babies, however, there were several participants who highlighted what medical staff would or would not 'let them' do, which suggested that with their expertise came power over these women's choices and their bodies. Participants frequently referred to the battle with medical professionals over choices or worry that felt unheard. For example:

> "*I had gone into hospital to get checked following change in movement, was checked but my concerns were dismissed*" (S38)

Emma reflected on seeking medical help due to her concerns:

> Emma: "*They reassured me that it was completely normal, nothing to worry about, um, and I just felt like something was wrong, and I pushed and pushed*" (Interview 4, lines 24-26).

But despite battling to be heard, her concerns were dismissed. She later experienced a missed ectopic pregnancy, which ruptured, putting her life at risk. She goes on to express her feelings about the way she was treated:

> Emma: "*I feel really angry about that… Like really, really angry… because also I think, you know, they might have been able to treat me, differently… they could have maybe treated me non-surgically, or they could have treated me surgically but without the removal of my tube, if it hadn't ruptured… it's just the fact that none of those options were available for me*" (Interview 4, 401-414)

The lack of agency at the help seeking stage resulted in reduced choice for medical treatment, therefore had both emotional and physical consequences for Emma.

These battles not only impacted the women themselves, but also the safety of their unborn children, as highlighted by one participant's response to the survey:

> "*I cannot accept the second later loss... I asked to be monitored and they said no... I asked for a stitch they said no... yet again the same thing happened… the consultant actually laughed at me said hadn't got anything wrong with my cervix etc. so I moved hospitals had a stitch placed and finally got my rainbow baby. I wasn't willing to lose another baby under the same hospital or consultant.*" (S36)

In this case, having unsuccessfully battled with the medics involved in her care, the woman takes control by changing her healthcare provider. There were further examples of women seeking out support in order to allow them to have the choice and control over the care that they desired:

> Chloe: "*I went through a whole battle as well, because I wanted to have a natural birth with [daughter] and because [son] was a C-section, I was under a consultant who refused to let me have a natural birth, she just wanted me to have a section, and so, um thanks to a support group… that specifically helped people want natural births after sections, and they said that I had a right to have the birth that I wanted. And of course I never just even realised that…*" (Interview 3, 278-289)

Chloe was being subjected to surgery that she did not want, where the wishes of the consultant seem to overrule the patient's wishes about what happened to their body. This quote highlights the way in which knowledge itself is powerful; in the medical system the professionals have knowledge that isn't always readily available to their patients, and this can mean women accepting treatment due to a lack of awareness of what possibilities are:

> Chloe: "*It took me a long time to realise that it's my body and my pregnancy, and I have that right to do that*" (Interview 3, 356-358)

The NICE (2017) guidelines for antenatal care emphasise collaborative treatment, recognising the birth process as an emotionally demanding and significant life event. There are clear links made between informed consent and patients' rights to a clear discussion, which put women in control of their own care (NICE, 2017). However, a study of women's experiences of planning a vaginal birth after caesarean characterises the maternity system as patriarchal, diminishing women's sense of agency and control through requiring subordination (Keedle, Schmied, Burns, & Dahlen, 2019). This issue is prevalent enough that a charity exists specifically to support women in establishing their rights for birth (Birthrights, 2020), with information for midwives that characterise agency in this process as an issue of human rights (The British Institute of Human Rights, 2016). Einion (2017) considers informed choice a fallacy, arguing that women are unable to makes informed decisions when they rely on information that is provided by, and therefore also restricted by, the healthcare system. Lack of information being provided by the healthcare service was itself considered a cruelty, as the experience of miscarriage was often physically worse than expected and distressing without medical help:

> "*It is almost heartless to just discharge a couple home with absolutely no information of what is going to happen*." (S10)

Miscarriages, whilst a traumatic event for the individual, are not medical emergencies, and therefore do not always appear to be taken seriously by medics (Lee & Slade, 1996). In a medicalised system, women lack the power that comes with knowledge to assert their voice and right to make choices about their care (Einion, 2017). It is important to recognise that even when women are given choices, the healthcare system still has the power to limit those choices, and the medical justification isn't always clear to patients:

> Chloe: "*I really wanted to be midwife led, but they wouldn't let me*" (Interview 3, lines 486-487)
>
> "*I was begging the doctor to refer us for tests but it was only after I had 3 natural miscarriages (so 4 losses) I was then referred*." (S25)

Due to the commonality of miscarriages, investigations are not widely accessible, with a requirement for at least three losses before individuals can seek help (RCOG, 2017). This was found to be frustrating for women who had experienced two losses, particularly when there was concern over their age, as the system, rather than individual needs, dictated care (Meaney, Corcoran, Spillane, & O'Donoghue, 2017).

While doctors, and the system, decide treatment options made available to patients, individual doctors may have different perceptions about the power that they hold. Nimmon and Stenfors-Hayes (2016) questioned medics from various specialities and found that they fell into three distinct categories; those who acknowledged and therefore sought to manage their power, those who saw their power diminished by changes to healthcare culture and thirdly, those who denied a power dynamic, perceiving themselves to be on a "level playing field" with patients (Nimmon & Stenfors-Hayes, 2016, p117). Only those in the first category, who acknowledged their power, went on to discuss ways in which it manifests in the patient-doctor relationship. In order for power to be used ethically and with integrity it first needs to be acknowledged. Nimmon and Stenfors-Hayes (2016) suggest that it is not only the unconscious internalising of values, beliefs and knowledge from the field of medicine that determines the doctors' perceptions of power, but also their personal frames of reference from values and experiences developed outside of their role. These experiences were evident in making a difference to how the women experienced care in this data. Where examples were given of positive experiences of care, this was often linked to them having some form of shared experience, for example:

> Joanne: "*The fertility… consultant that I saw had… said she had PCOS as well, um, she'd experienced a loss as well*" (Interview 2, lines 164-165)
>
> Cath: "*The one who came out was lovely, she was actually the grandmother of a baby who had died, um, so she was lovely*" (Interview 1, lines 325-326)

The experience of empowerment and agency is not only dependent on the attitudes and behaviour of healthcare professionals, but also on the expectations and assumptions of the patients. There were examples of those who found safety in the decisions being made by medical professionals, and despite being encouraged to fight, felt the safety of their baby was better served by trusting medical intervention:

> Joanne: "*I was fine having, with being in more of a doctor led, type process, and the other thing that because I was forty they um, said I had to be induced on my due date… Which again I had a lot of people telling me 'oh you don't have to do that, you could fight it' and I was fine with it because honestly like I knew like if they were going to induce me on my due date they would know that she was okay and get her out safely*" (Interview 2, lines 823-830)

For Joanne, additional medical attention did bring reassurance in the pregnancy after her miscarriage experiences, but this was reflected on in light of her daughter being born safely.

There is on-going tension between the autonomy of patients and medical responsibility. Literature around end of life care is relevant here, because although obstetrics isn't traditionally linked with end of life, the decisions being asked of parents during perinatal loss is more akin to palliative care settings than maternity wards. Palliative care literature recognises the weight on patients and their family of the expectation to make decisions, highlighting the importance not only of the relationship with healthcare providers, but also the willingness of clinicians to take responsibility for decisions in order to unburden patients (Vegni & Borghi, 2017). However, choices about end of life treatment, such as in the field of oncology, are made in the context of a long relationship between doctor and patient, where end of life decisions can be discussed well in advance of needing to enact a patient's wishes (Gori & Zagonel, 2017). For perinatal losses, there is less time to develop such a relationship, and health care has been based around the expectation of a living child. When this changes, parents are making decisions they never expected or were prepared to make, relying on the advice of practitioners with whom they have not had the opportunity to develop trust. It is further complicated by often only the mother being recognised as the patient, and therefore clinical decisions being based on the patient's need, without always acknowledging the treatment of the infant. A key aspect of establishing a healing relationship between a patient and their doctor is the recognition of the patient as a person, rather than as a set of symptoms (Razzaghi & Afshar, 2016). For perinatal losses, not only the mother's personhood, but also the parents' perceptions of the personhood of the infant is an essential element of any relationship with healthcare providers.

Patients' health behaviour and decisions are influenced by their perception of risk; the perceived likelihood of a negative outcome, and the relationship with healthcare providers is key in the development of this risk perception (Wei et al., 2020). Past experiences will influence risk perception, and therefore perinatal loss diminishes trust in both healthcare and the woman's body, or ability to reach a positive pregnancy outcome. If patients are able to trust their healthcare provider, that leads to greater confidence in the good intentions of healthcare professionals and therefore an increased likelihood in listening to their advice and allowing them to guide decision making (Wei et al., 2020). For these participants, trust was often eroded in the perinatal loss experience, and this lead to a complex relationship in the subsequent pregnancy, where reassurance was sought from healthcare providers, but was not believed, and therefore multiple sources of information and support were often required. The lack of trust may also have the negative consequence of patients withholding information or misleading doctors in an attempt to redress the power imbalance that is linked to the clinicians perceived "information superiority" (Wei et al., 2020, p. 384).

Perinatal losses are likely to cause dissatisfaction with healthcare providers because causes are often unknown and loss unpreventable, increasing the uncertainty and risk perception in the following pregnancy. However, the perceived vulnerability is exacerbated by poor communication from medics and diminished trust. In the absence of women's agency and control over their perinatal experiences, healthcare professionals need to be more aware of the ways in which they can offer collaborative treatment to patients:

> Louise: "*You don't have many decisions or control obviously during pregnancy, the decision of finding out the gender, and opting for a*

> *section are the only like empowering decisions that you can really make"… "But throughout all the, whatever we've done with the hospital, I've always said it's to do with choices… to make that family able to make their own decisions about what's right for them*" (Interview 5, lines 978-980 & 1101-1108)

The medicalisation of pregnancy and birth has led to a reliance on the expert knowledge of doctors and other healthcare professionals for the care of women and their babies. However, despite their reliance on this expertise, the power dynamics of a system which privileges knowledge can be disempowering and limits women's choices and understanding of their options for their own treatment. In the pregnancy after loss women are more likely to engage in healthcare provision, however, in order for these experiences to develop confidence in their bodies and their pregnancies, these women need an opportunity to develop their sense of agency through their relationship with their healthcare provider.

Subtheme 3: Navigating support needs

Another important aspect of women's interactions with healthcare that stood out in the data was seeking help with the psychological consequences of loss. The lack of acknowledgement of the emotional impact of perinatal loss experiences, with the associated consequences in subsequent pregnancies, led to the use of psychiatric labels, as a way to legitimise their distress. Psychiatric labels were used by women throughout the data, in a way that seemed to be an attempt to justify needing help, and to validate their distress, signifying that the medical model of distress was used by many in making sense of their experience. However there were also those who actively rejected these diagnostic labels, because they did not want their grief experience to be medicalised or pathologised by either doctors or those in their social network.

The availability of psychological support post loss or in the perinatal period can vary widely (Mills et al., 2014), relying heavily on the third sector to provide bereavement care (Donaldson, 2019). Access to perinatal mental health services usually requires a clinical diagnosis with a mental health disorder (Oates et al., 2012), and therefore these services respond to distress in a very binary way. Despite very few of the participants receiving mental health treatment within the NHS, this binary access to services was reflected in the data by diagnostic labels being referred to as a specific entity, something they perceived they had or did not have. Although they connected, for example, anxiety to their experience, there seemed to be a perceived tipping point where it went beyond the normalised experience of worry after loss, and became an 'illness', that had been brought on by their experience:

> "*During the losses I felt very alone, with very little support. I didn't know at the time but I was suffering with anxiety*" (S15)
>
> "*My anxiety was terrible*" (S36)
>
> "*I didn't cope well with loss, I had l a lot of anxiety blame depression over it*" (S39)

When asked how their loss impacted their next pregnancy one participant responded that it "*gave me anxiety*" (S23), which seems to suggest that she had been given a 'mental illness' through the loss of her previous pregnancy.

Labels, such as 'anxiety' and 'depression', were specifically used to highlight the lack of support, and legitimise the need for further intervention. It was not always clear if the individual had received a diagnosis, or was self-diagnosing as a way to legitimise their own distress, but the labels seemed to be used as a way of communicating needs. For example, this participant expected better support from family based on her mental health label:

> *"They distanced themselves and then blamed me for not talking even though I was the one with depression*" (S23)

This seems to suggest that there was an expectation that 'mental illness' such as 'depression' required further understanding and to be better supported.

There were many examples of individuals feeling that they needed further support in their subsequent pregnancy that was not available to them, and used these labels as way to express their need and highlight the disparity between needs and service provision:

> "*The additional appointments during my subsequent pregnancies helped give me reassurance for a short time but didn't really address the anxiety I was experiencing. I would have benefited from more specialist support*" (S34)

> "*I think there should be more support available for loss and also subsequent pregnancies, just seeing my midwife more often would've eased my anxiety but this is just not an option*" (S3)

Psychiatric labels seemed to signify that something more than standard antenatal care was necessary, despite experiencing the lack of availability or access to such interventions. Midwives are required to check on women's emotional wellbeing during pregnancy as standard (NICE, 2016). However if the right questions aren't asked, distress can remain hidden, and continue to impact the pregnancy, showing how specific care is needed to acknowledge the needs of those pregnant after loss:

> Emma: "*So they knew that I'd suffered with depression in the past… but that I wasn't currently on any medication and didn't feel depressed, um, but I suppose they never really asked me if I was anxious… And I never raised it because I don't think that there was ever that direct question*" (Interview 4, lines 571-577)

Anxiety particularly, was discussed in two ways; one as an experience, of feeling anxious, and separately as something an individual had or did not have. It was not always clear how the participant reflected on these terms, and whether they were describing how they were feeling, or using anxiety as a diagnostic term:

> "*I could not enjoy it fully because I was constantly anxious. I had just started to relax and let go of the anxiety when I delivered the baby early*" (S9)

However, discussing 'anxiety' as something they had, could also help in exploring interventions to manage the experience of living with 'anxiety', and allowed this mother to accept and manage her feelings:

> "*I found a number of techniques helped me deal with the anxiety over losing the baby and the birth. I practiced mindfulness and hypno-birthing as much as possible. Although the anxiety was still there, it helped me accept the anxiety as valid given my experience but not let it sour my relationship with the baby I did successfully give birth to.*" (S9)

For the participant above, the label of anxiety was empowering in that it led her to seek out tools that helped, whilst simultaneously validating her emotional response to her experiences.

The use of terms such as 'postnatal depression' and 'PTSD' were clearer references to diagnostic labels, and seemed to be further ways of communicating distress, and the way in which the loss had lasting effects, including on the individuals' mental health after the birth of a healthy infant:

> Emma: "*I suffered really badly with PTSD afterwards… So like for about three months after the ectopic I couldn't, I just couldn't sleep because when I, as soon as I closed my eyes it was like replay from the moment we arrived at the hospital to the moment we came home… I think this is what bled into the pregnancy… and even now*" (Interview 4, lines 418-426)

> "*The ache inside never goes it just hazes. I had horrendous postnatal depression it crippled me, I was suicidal. Terrified anything would cause us to lose our child that we had longed for… The experience was difficult I had antenatal as well as postnatal depression. I was very ill.*" (S4)

Postnatal depression is referred to as an illness, although still directly linked to the experience of loss. The sense of this distress needing to be under control, and that struggling to cope implied illness, a deficiency in the individual, highlights the prevalence of the medical model in available discourses for distress. The label 'postnatal depression' is a short cut for communicating how distressing this time was, in a way that is commonly understood. Postnatal depression has been characterised as a form of grief for the losses apparent in the transition to motherhood even without a perinatal loss history; not having sufficient support is particularly considered a significant risk factor (Highet et al., 2014).

Previous experiences of diagnosed mental health problems, and the lack of adequate help could be a barrier to help seeking around some mothers' pregnancy related distress:

> Emma: "*I didn't even consider going to my GP, because I suffered with depression previously when I was a lot younger and I know that there's very little support*" (Interview 4, lines 490-492)

Lack of trust in the healthcare service led to an assumption that appropriate help was not available, and led instead to seeking third sector support. Health behaviour is linked to assessment of risk, based on a number or factors including previous experiences, communication and trust (Wei et al., 2020). In this case, trust has been previously ruptured, and care during her perinatal experiences was not sufficient to risk communicating her on-going psychological needs.

Some participants made direct links between how they were treated, including the lack of support after their loss, and their experience of perceived mental health problems:

> "*When I returned to have my second baby the staff were awful to me and my labour experience left me with PTSD. I was treated awfully considering my previous experience*" (S31)

> "*After attempting suicide, I had intense support from therapy and medication… I found it difficult as the practitioners weren't trained in postnatal depression just depression. It felt very clinical.*" (S4)

It took a suicide attempt for this last participant to receive support, and even that was not felt to be specialist enough to understand her specific distress. This highlights the battle these women perceived they needed to go through in order to access the necessary help, and the consequences of this not being readily available. Miscarriage is considered a risk factor in maternal depression and suicide (Shi, Ren, Li, & Dai, 2018), however midwives can still fail to recognise distress in women under their care (Barber et al., 2017). Chloe makes a direct link between her loss and her postnatal depression and anxiety in the following pregnancy:

> Chloe: "*It took a while for me to be diagnosed with PND and uh, anxiety as well, after I had [daughter] and it wasn't until after I had counselling for that, that it all came out that I hadn't really grieved properly*" (Interview 3, lines 222-226)

Chloe suggests that she did something wrong by not "*grieving properly*", which caused her subsequent postnatal depression and anxiety. Although this implies personal responsibility and an element of self-blame, this participant framed her experience in light of the lack of support available at the time of her loss. This insight was reached with the support of therapy and therefore the link validated her grief response, whilst also prompting frustration at the healthcare system for not providing what was needed sooner. Chloe wants the standard testing that takes place after birth to identify postnatal depression, to be applied to perinatal loss as well:

> Chloe: "*They do that scoring test don't they, after you've had your baby, to work out whether you've got postnatal depression… They could do something similar to that after… miscarriage… everyone reacts differently don't they?*" (Interview 3, lines 1103-1110)

Believing that her experience in the pregnancy after loss, and the postnatal difficulties she'd experienced could have been different if offered the right support at the time of her loss.

Louise felt that access to support postnatally after her daughter was stillborn was absent due to the lack of a baby:

> Louise: "*Because there wasn't a baby I just struck off, didn't need to be seen anymore*" (Interview 5, lines 1090-1092)

This implies a sense of rejection by the healthcare system, and can further add to the isolation experienced post-loss through the loss of postnatal care for the mother being linked to the loss of a baby. Postnatal support services for women have understandably been designed around supporting mothers, who are caring for their infants, for example Grant and Caton (2016) show care pathways developed by centring around the baby. However, for those who experience the postnatal period without a child, due to loss, there is ambiguity about the responsibility of midwives and healthcare professionals. With no baby to care for, these women are also not adequately cared for, and lose access to those who may be best positioned to recognise their distress.

With the increasing medicalisation of childbirth, characterised by risk management (Einion, 2017), it follows that discourses of psychological distress may also reflect this risk language, with research into perinatal mental health focused on risk factors for the child (for example Stein et al., 2014). The language that is used by healthcare professionals and women themselves is important because "language is able to both describe and potentially determine human experience" (Sanders, 2019, p. 27). With perinatal mental illness, such as anxiety and depression, being described as pregnancy complications (O'Hara & Wisner, 2013), rather than normalised responses to stressful life events, including perinatal loss, the way in which this is experienced by women can be deeply stigmatising and create barriers to support, through assumptions about available treatment options (Hadfield & Wittkowski, 2017).

Although the medical model discourse of distress was prevalent throughout the data, there were also those who described their grief differently. Louise was expecting 'mental health problems' as a result of her history, but this is not how she experienced the loss of her daughter:

> Louise: "*I always thought, that because I have had depression in the past that I would have post traumatic stress or, I'd have like postnatal depression, but even with her, um, I didn't, I was obviously very, very sad*" (Interview 5, lines 406-409)

There were also examples of direct rejection of the labels of mental illness, especially when this was perceived as an attack on the mother, with the suggestion that there was something wrong with her due to the distress she experienced after her difficult experiences:

> "*My now ex who is very narcissistic has used the baby losses against me to say I've mental health issues (which I haven't) I think I have done pretty well in coping on my own with help from close friends*" (S36)

Although this mother rejects mental illness, this is due to her perceived ability to cope with the distress she has experienced. It is unclear how she would frame this experience if she felt that she hadn't coped. For Louise there is a difference between experiencing depression, which she has been diagnosed with in the past, and the sadness of grieving her daughter:

> Louise: "*If they'd said to me, 'are you depressed?' I'd just be like, 'no I'm just sad*'" (Interview 5, lines 1090-1092)

Even the question "*Are you depressed?*" here shows how easily grief seems to be pathologised. For Louise she felt able to name her feelings as sadness, and sought support from others who had had similar experiences rather than from professional services.

It is clear that psychiatric labels are used in a variety of ways by women to communicate, validate and legitimise their distress, to gain access to services and in some cases to evidence emotional harm in legal battles. However, these labels seem to fail to acknowledge the complexity of distress and grief following a perinatal loss, and can leave women assuming something is wrong with them for their perceived failure to cope. Although labels can be used in useful ways, they can also be used against women to diminish their resources and ability to manage their complex perinatal journey. They also create a binary difference between illness and wellness, assuming that those who are 'ill' need treatment, and those who are 'well' are coping fine. This fails to acknowledge the range of presentations of distress, and therefore prevents access to the right support at the right time to create a meaningful difference to these women's experiences.

5. Conclusion

5.1 Summary of Findings

The aims of this research were to better understand the experiences of women who had experienced at least one perinatal loss, followed by a pregnancy resulting in a living child and also to explore what made a meaningful difference in terms of support throughout the journey. This has been achieved by exploring the holistic perinatal journey through both survey and interview data, which provided rich and diverse accounts. Taking this holistic approach, rather than the segmented focus of much existing research, allowed for the development of themes that capture the development of the individual across the whole experience. Despite the prevalence of perinatal loss, this was described as a "*hard lonely journey*" (S36), capturing the felt isolation of these women as they navigated unexpected circumstances. The overarching theme "*losing [a baby] shaped who I am today*" (S31) conveys the personal change that took place, and this included both positive aspects of personal growth, as well as the loss of who they were before and the new knowledge gained through experience.

Exploring these women's perinatal experiences, as well as the support received, led to themes denoting individual development in three main areas. This included the embodied experience of grief, with the unique nature of losses taking place within the living body of the mother. The embodied nature of distress led to vivid and visceral accounts. Women often rejected or separated themselves from their own bodies, in a developing relationship of diminished trust and a felt sense of failure. This relationship fed into the next pregnancy where the body was both feared and relied upon in a mixture of hope and trepidation. The second theme captures the way in which women developed language to reflect their experiences. This highlighted the need to address the pervasive silence around perinatal losses, and for labels to be developed by rather than for bereaved parents in order to ensure that the labels themselves do not exacerbate distress. The development of common terms also reflected the development of a community of support through shared experience, and this was relied on in the perceived absence of understanding from both social support networks and healthcare professionals. The final theme, “it’s my body, it’s my pregnancy” denotes the increased agency that developed throughout the journey, where women who were initially shocked by the lack of control over their fertility journeys, took action to develop choice and ownership over their care. The relationship with healthcare services was an important aspect of the experience, characterised by the contradictory need of reliance in the context of diminished trust. Seeking agency included not only the choices made to protect subsequent pregnancies, but also the embracing of the medical model of distress to assert their need for psychological support.

The importance of reparation was evident throughout these three areas. For the embodied experience, there were examples of embodied grief rituals and reparative action, which included the following pregnancy providing a reparative experience. The development of language showed the use of symbolism and metaphor to establish the identity of the lost, and their lasting legacy within the family. In terms of seeking agency, reparative action was not only about choices that protected their own future pregnancies, but was also about advocacy for those who may follow them, with those who experience losses often becoming the advocate and support for those with shared experiences. These findings contribute to an increased understanding of women’s needs during their perinatal journey in order to inform healthcare practice and policy, as well as the role of psychologists in shaping these services. They also provide an increased evidence base for the significance of perinatal loss and fertility journey experiences in therapeutic encounters. These implications will be explored more fully after discussing the limitations of this study and possible avenues for future research.

5.2 Limitations and Opportunities for Future Research

Regional Differences in Healthcare

Despite data that provided rich and varied accounts that met the study aims, there are a number of limitations that are important to discuss. This study sought to gather a range of experiences from across the UK, in order to be able to comment on current healthcare practice. However, in addition to the varied practices between different trusts and hospitals, healthcare has also been a devolved area of government since 1999 (Nicholson & Shuttleworth, 2021). Therefore there may be policy differences between the four nations that form the UK, which may have impacted on differing experiences of healthcare amongst participants. Because the research took place whilst studying at the University of the West of England, Bristol, and living in South Wales, even amongst the interviews there were participants from both sides of the Welsh/English border, who therefore may be sharing experiences from different healthcare systems. The findings are thought to be useful to inform policy across the NHS, however, specific implementation of changes to practice are likely to need more thorough knowledge of the challenges specific to each region.

Homogenous Sample

The sample of women who participated was predominantly white British, heterosexual and with partners, with therefore limited representation of minority groups. Perinatal loss charities were not used to recruit participants as I aimed to include a breadth of experiences, not restricted to those who had accessed third sector support; nevertheless, engaging with a larger organisation may have aided recruitment. Perinatal loss is considered a disenfranchised grief, however further marginalisation may be apparent for those from other marginalised areas of society such as minority ethnic and religious groups (Fernández-Basanta, Coronado, & Movilla-Fernández, 2020), as well those with non-normative pregnancy experiences, such as lesbian couples (Peel & Cain, 2012). Specific studies aimed at capturing the experiences of those who may be doubly disenfranchised would help to further shape policy that it more appropriate for accommodating the diverse experiences within society. With the findings highlighting the importance of developing meaningful rituals as part of the grieving process, cultural fluency for practitioners is important. In a diverse nation such the UK, not only do practitioners need to be mindful of normalising the many and varied expressions of grief within the different cultures that exist here, but also further research with minority populations would add usefully to this developing understanding.

Terminology

Existing literature as well as the findings in this study suggest that terminology related to perinatal loss is significant to the experience (for example, Moscrop, 2013; Sawicka, 2017; Smith et al., 2020). Throughout this report the use of medical terms such as 'embryo' and 'foetus' have been avoided, and instead the loss has been referred to as a lost or deceased 'baby' 'child' or 'infant'. This was purposeful to honour the personhood parents assign to their losses (Layne, 2000), and to reflect the predominant language of the data. Theme two shows the use and rejection of specific labels by participants, and the way in which this was meaningful to the their development as they processed their experiences. It is therefore important to consider the use of terminology in the questions, and the limitations this placed on data collection. In the survey, the initial questions were purposefully vague to encourage participants to describe their experience in their own words. Participants were asked about their "*loss*" without specific reference to what was lost, until question seven, when they were asked if they had done anything to commemorate their lost "*baby/babies*" (see Appendix A). Although most participants referred to their loss as a baby, there were those who did not, and the wording of this question may therefore have either been considered an assumption, or as implying that they should have considered their loss or remembered them in specific ways. One participant, who did not refer to any of her pregnancies as a 'baby' responded to the question about commemoration with: "*No, I don't want to remember*" (S11), which leads me to consider if the wording of questions and terminology used may have been alienating for those who framed their experiences differently. Another participant specifically rejects the language of 'baby' in the question:

> "*No. I don't feel like I lost a baby. It was a foetus that didn't work out. Having IVF put that into context a lot (i.e. a one stage I had 13 fertilised embryos, and they couldn't all survive)*" (S17).

This further highlights the importance of context on framing the individual experience, and also the difficulty in finding the appropriate terminology. There is no neutral language when discussing loss, all language is imbued with meaning, and this meaning is understood differently in different contexts, as well as limiting the way in which experiences may be understood (Corless et al., 2014; Moscrop, 2013; Polkinghorne, 2005). Therefore, despite collecting rich and varied data, I am aware that this data was coproduced in the context of the terminology I used in the questions, and this may have been a limitation on what participants shared.

Further Research opportunities

This research purposefully had a broad scope in order to explore how women framed their subjective experience of perinatal loss and the subsequent pregnancy. The findings of this could be used to explore aspects of this experience more fully. For example, participants were not asked directly about their bodies, although the relationship with the body was clearly apparent in the data. Therefore the embodied nature of perinatal loss and grief warrants further investigation. Existing models of grief do not account for the bereaved being implicated in the death through the life and death of their baby taking place within their own living body. There is also an absence of evidence on the impact of prolonged contact with the deceased linked to the delay between finding out that the baby has died, and delivering the body.

The scope of this study was focused specifically on the experiences of mothers who had lived experiences of pregnancies resulting in both lost and living babies. With the importance of both social support and that provided by healthcare services apparent in existing literature and these findings, further research including perspectives from those who surround the mother would be helpful. Exploring the subjective experiences of others in the perinatal journey, including partners, family and healthcare professionals could add meaningfully to policy and practice.

5.3 Implications for Practice

The results of this study confirm many of the findings in existing literature, that place perinatal losses as significant and life changing events for those who experience them (Furtado-Eraso, Escalada-Hernández, & Marín-Fernández, 2020), with an on-going legacy that impacts following pregnancies (Hunter et al., 2017). By exploring the whole journey this study contributes to the evidence that can inform both healthcare policy and practice, as well as the role of psychology and therapeutic practice.

Implications for Healthcare Practitioners & Policy Development

Due to the lack of social norms in responding to perinatal losses (Markin, 2016), the data clearly demonstrated the powerful roles professionals could play in normalising and validating experiences during a perinatal journey. These findings suggest healthcare practices need to pay close attention to women's context and fertility journey, including perinatal loss history, in order to provide empathic care. This study also goes further by identifying specific areas for focus by professionals that could make a meaningful difference to women's experiences. These include the need for holistic care that takes into account the embodied experience, but also the psychological consequences of this; the need for more awareness and sensitivity around language, and a recognition of the lack of control women have over their fertility and care, with the inevitable power dynamics between patient and healthcare provider. There is a need for those providing care to acknowledge this power, and ensure it is used ethically and with integrity, with access to appropriate information and increased opportunity for shared decision making for patients.

Individuals may need support in finding helpful outlets for their grief, which requires being treated in more holistic ways than the current healthcare services allow. Reeves (2011, p. 416) highlights the importance of bringing the "whole self to an experience" when discussing grief rituals. Participation alone is not enough, there needs to be congruence and that means that the timing for the individual is key, in terms of when and how they feel able to express their grief and process their loss in both physical and emotional rituals. There are key times along the perinatal journey where there are contacts with services that could make a meaningful difference, including during and post-loss, as well as throughout any subsequent pregnancy. Healthcare professionals should not assume that a healthy infant results in the resolving of any previous grief. Women need monitoring in the post natal period, normalising the grief that may be re-experienced, and be given access to bereavement care alongside their postnatal care.

This research also has implications for healthcare policy. The data confirmed findings that the medical labels for the different gestations of losses do not denote the emotional experience. It is therefore important that within antenatal settings the hierarchy of losses is challenged. Support pathways seem to predominantly focus on stillbirths and neonatal losses (Shakespeare et al., 2020), with those with early or mid-term losses uncatered for. With the significance of not only the understanding of healthcare professionals, and the need for greater empathic care and communication, but also the location within the hospital, the support pathways for all perinatal losses needs to be considered in order to further minimise the distress experienced and often exacerbated by the setting. Although the data suggested an assumption that adequate support required knowledge through experience of loss, changes to policy as well as further training for those in contact with women in the perinatal period can make a difference to their distress and ensure that grief reactions are normalised and the meaning of these experiences acknowledged in any subsequent pregnancy.

Implications for Counselling Psychology

Counselling psychologists are called to work with other professions (BPS, 2017), and often make a valuable contribution to multidisciplinary teams. However, for perinatal care, these teams are often part of the mental health care system, and therefore their impact is limited on those who do not carry a psychiatric diagnosis during the perinatal period. Existing literature (Meredith et al., 2017; Noonan et al., 2017), as well as the data from this study highlight the way in which midwives and health visitors are frontline in women's psychological care and play key roles in identifying and supporting women who experience psychological distress. With perinatal losses prevalent throughout society and identified as key life changing events, there is scope for psychologists to play a more meaningful role in the training and support of healthcare professionals who are most likely to be in direct contact with those who live through these experiences. Counselling psychologists may have a role in challenging the pervasive medical language that often downplays the significance of such losses, through valuing the subjective experience of individuals. This role of advocacy within the healthcare setting fits well with the ethos and values of counselling psychology, particularly the commitment to social justice not just at an individual but also at a systemic level.

In addition to having a greater role for psychologists in healthcare settings, the findings also highlight the needs of women who seek therapy to receive greater understanding around perinatal loss experiences. In a therapeutic relationship, an individual's personal and family history often plays a key role in formulating the client's current difficulties (Johnstone & Dallos, 2013). This study provides evidence for the lasting impact of perinatal losses, and other aspects of a challenging fertility journey, and how individuals understand this within their family and cultural contexts. With the prevalence of perinatal losses, therapists in every setting are likely to come across those with related experiences. It is therefore vital that those providing therapy are aware of the significance of such experiences, and avoid the pervasive societal norms of silencing or dismissing such losses. This study seeks to inform practice, so that however long ago the experience occurred, clients are provided with safe and validating environments to explore their fertility history, the way in which this has shaped them as an individual and be supported in creating reparative experiences.

Psychologists can also be guilty of perpetuating the mind/body divide that was described within the healthcare setting (Pearce & Komaromy, 2020). Whilst doctors and other healthcare professionals may privilege physical needs over emotional ones, psychologists can do the opposite and consider the psychological consequences of the experience without acknowledging the embodied nature of the distress. This study provides evidence for the need to treat clients as whole beings, which includes their physical bodies, their emotional distress and also the important spiritual aspects of their experiences. For many of the participants who had accessed therapy, this was within third sector organisations that specialised in perinatal losses and was a significant aspect of them understanding and processing their experience. An increased awareness of the significance of these experiences across the psy-professions would further support the work with clients in all settings, by including the way in which they have been shaped by the perinatal journey in any formulation.

6. References

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7. Appendices

Appendix A: Online Survey

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Appendix A: Online Survey

Perinatal Loss and the Next Pregnancy

Online Survey

NB The survey will be proceeded by the information sheet and consent question below, and the sources of support will be repeated at the end.

Some questions about you

In order for us to learn about the range of people taking part in this research, we would be grateful if you could answer the following questions. All information provided is anonymous.

1	How old are you?			
2	I am:	Full-time employed	Part-time employed	Full-time student
		Part-time student	Other: ____________________	
3	If you work, what is your occupation?			
4	How would you describe your sexuality?	Heterosexual Bisexual Lesbian Gay Other: ____________		
5	How would you describe your racial/ethnic background? (e.g., White; Black; White Jewish; Asian Muslim)	____________________		
6	How would you describe your social class? (e.g., working class; middle class; no class category)	____________________		
7	Do you consider yourself to be disabled?	Yes	No	
8	How would you describe your relationship status?	Single Partnered Married/Civil Partnership		

		Separated Divorced/Civil Partnership Dissolved Other: ____________________
9	Age(s) of child(ren)	
10	Perinatal Loss History – please provide date (year) and gestation (no. of weeks) of any losses	

Questions about your Loss and Pregnancy Experience

You can write as little or as much as would like, but it would be helpful for my research if you could tell me as much as possible about your experience. The boxes will expand as you type to give you as much space as you need.

Your experience of loss
1. Please describe your loss experience in a much detail as you feel comfortable.
2. What helped you to cope with the loss?
3. What support from professionals, if any, did you receive?
4. How did you feel about this support? Could it have been improved in any way?
5. What sort of support did you receive from family and friends, or the wider community?
6. Did you seek out any other types of support (e.g. online support groups)? If yes, please tell me about that.
7. Have you done anything to commemorate or remember the baby/babies that you lost?
Your next pregnancy
8. How did you feel about being pregnant again?
9. What, if any, support did you receive for your emotional wellbeing during this pregnancy, from professionals such as your midwife?
10. How do you feel your experience of loss impacted on your most recent pregnancy experience?
11. How did you feel towards the baby during pregnancy and after the birth?
12. Is there anything else you would like to share about your experience of

loss and the next pregnancy? Please include anything that you feel is relevant or important.
I’m conducting a small number of interviews with mothers for my study, if you would be interested in talking more about your experiences, and live in or near South Wales, please write your email address or a contact telephone number here:

Thank you for taking the time to share your experiences as part of this research. If you have any questions or comments you can contact me by email (Naomi2.Wheeler@live.uwe.ac.uk) or contact my supervisor Victoria Clarke (Victoria.Clarke@uwe.ac.uk)

This research has been approved by the Health and Applied Sciences Faculty Research Ethics Committee (FREC)

Appendix B: Interview Schedule

Perinatal Loss and the Next Pregnancy

Interview Schedule

1. Can you tell me a bit about your experiences of pregnancy loss?
    - Loss experience
    - Meaning making/commemorating
    - Coping mechanisms

2. At the time of losing the baby, what support did you receive?
    - NHS/midwives/other professionals?
    - Family/friends/partner?
    - Other/third sector?
    - How did you go about finding support?
    - What support would you have liked?
    - How did you experience the support you received?

3. Have your feelings about the loss changed over time since the initial experience?

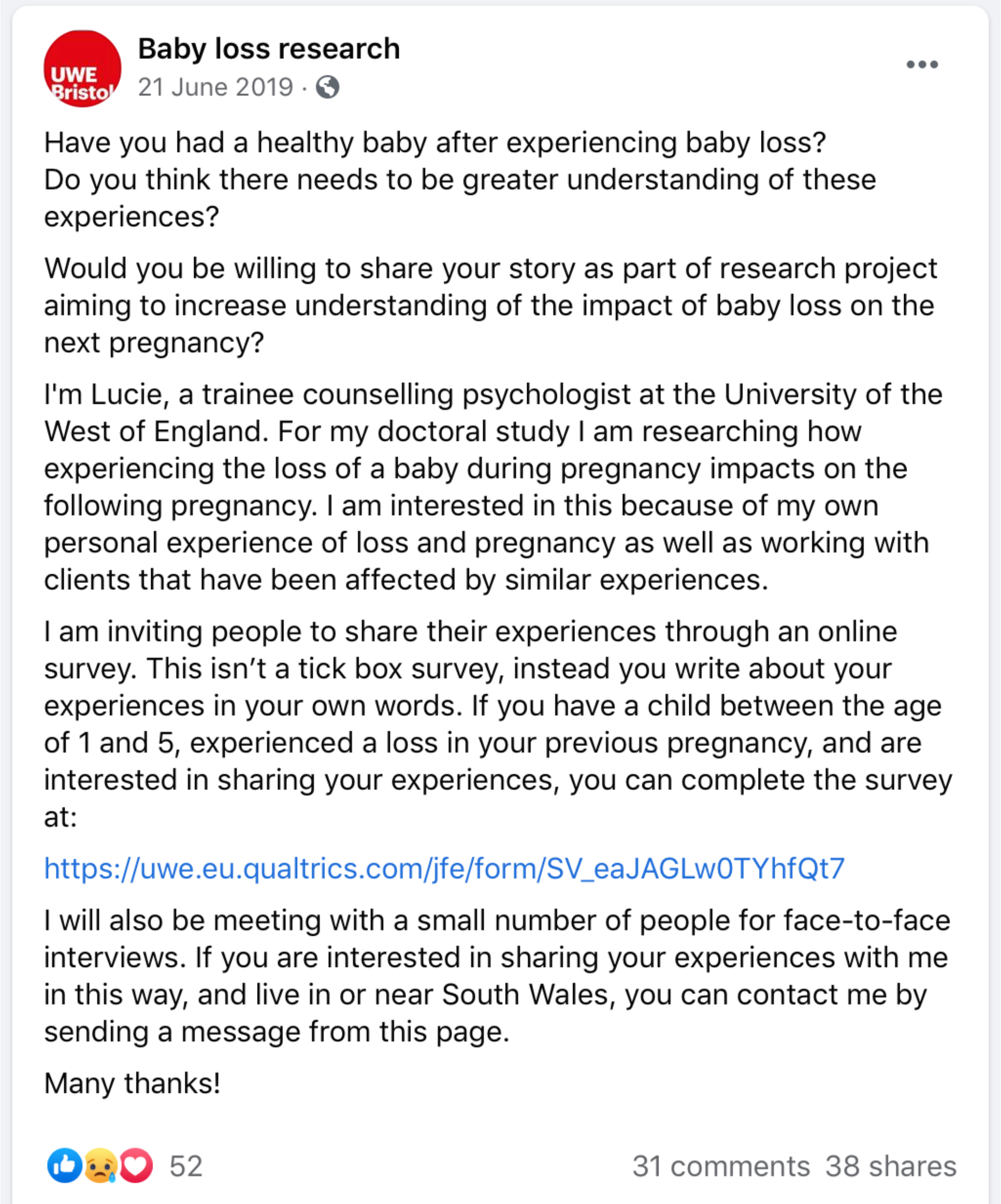
4. How did you feel about being pregnant again?
    - Stages of pregnancy/milestones
    - Thoughts about loss/previous baby
    - Awareness/support during pregnancy – was it enough?
        - Midwife/other professionals
        - Partner/family/friends
        - Other

5. What was it like once baby arrived?
    - Feelings towards new baby
    - Feelings about previous baby
    - Feelings about yourself as a person and as a mother
    - Bonding/attachment

6. Now that you have a healthy baby, how do you feel about your previous loss experience?
    - What ways do you remember the baby that you lost?
    - How have those around you responded?
    - Would you have liked them to respond differently?
    - How are anniversaries marked?

7. Is there anything else that we haven't talked about that you would like to share about your experience of both losing a baby and having a healthy baby?

Appendix C: Facebook Recruitment Advert



Baby loss research
21 June 2019 ·

Have you had a healthy baby after experiencing baby loss?
Do you think there needs to be greater understanding of these experiences?

Would you be willing to share your story as part of research project aiming to increase understanding of the impact of baby loss on the next pregnancy?

I'm Lucie, a trainee counselling psychologist at the University of the West of England. For my doctoral study I am researching how experiencing the loss of a baby during pregnancy impacts on the following pregnancy. I am interested in this because of my own personal experience of loss and pregnancy as well as working with clients that have been affected by similar experiences.

I am inviting people to share their experiences through an online survey. This isn't a tick box survey, instead you write about your experiences in your own words. If you have a child between the age of 1 and 5, experienced a loss in your previous pregnancy, and are interested in sharing your experiences, you can complete the survey at:

https://uwe.eu.qualtrics.com/jfe/form/SV_eaJAGLw0TYhfQt7

I will also be meeting with a small number of people for face-to-face interviews. If you are interested in sharing your experiences with me in this way, and live in or near South Wales, you can contact me by sending a message from this page.

Many thanks!

Appendix D: Ethical Approval Letter

(Page 1 - REMOVED DUE TO IDENTIFYING PERSONAL INFORMATION)

(Ethical Approval Letter Page 2 –

REMOVED DUE TO IDENTIFYING PERSONAL INFORMATION)

Appendix E: Survey Onscreen Participant Information

Perinatal Loss and the Next Pregnancy

Survey Onscreen Participant Information

Who are the researchers and what is the research about?

Thank you for your interest in this research about women's and midwives' experiences of perinatal loss and the following pregnancy. My name is Lucie Wheeler and I am a trainee counselling psychologist at the University of the West of England, Bristol. I am completing this research for my doctoral thesis. I am interested in this subject because of my own personal experience of loss and pregnancy as well as working with clients that have been affected by similar experiences. My research is supervised by Associate Professor Victoria Clarke. If you have any questions about the research you can contact her at the Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY, Tel: (0117) 3282176; Email: Victoria.Clarke@uwe.ac.uk.

What does participation involve?

You are invited to complete an online qualitative survey (where you write the answers to questions *in your own words*, rather than ticking boxes). It should take no more than 30 minutes to complete. There are *no right answers* – I am interested in the range of opinions and thoughts that people have. You can write as much as you want, but it would be very helpful for my research if you could provide detailed answers. Before the main survey questions, there are also some *demographic questions* for you to answer (some of these will be tick box questions). This is for me to gain a sense of who is taking part in the research. You also need to answer a consent question, to confirm that you agree to participate, before beginning the survey.

Who can participate?

Anyone over the age of 18, who gave birth to a healthy child, now between the ages of one and five and who experienced a loss in their previous pregnancy.

How will the data be used?

The data will be anonymised (i.e., any information that can identify you will be removed) and analysed for my research project. This means extracts from your survey responses may be quoted in my thesis and in any publications and presentations arising from the research. The demographic data for all of the participants will be compiled into a table and included in my thesis and in any publications or presentations arising from the research. The information you provide will be treated confidentially and personally identifiable details will be stored separately from the data.

The personal information collected in this research project (e.g., online using the *Qualtrics* survey software) will be processed by the University (data controller) in accordance with the terms and conditions of the Data Protection legislation. We will hold your data securely and not make it available to any third party unless permitted or required to do so by law. Your personal information will be used/processed as described on this participant information sheet. You have a number of rights in relation to your personal data. For data protection queries, please write to the Data Protection Officer, UWE Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY, or dataprotection@uwe.ac.uk.

What are the benefits of taking part?

You will get the opportunity to participate in a research project on an important issue. It will also give you an opportunity to share your personal story and contribute to an increased understanding of the experiences of pregnancy and loss.

How do I withdraw from the research?

If you decide you want to withdraw from the research please contact me via email (Naomi2.Wheeler@live.uwe.ac.uk) quoting the unique participant code you will be asked to create before completing the survey. Please note that there are certain points beyond which it will be impossible to withdraw from the research – for instance, when I have submitted my thesis. Therefore, I strongly encourage you to contact me within a month of participation if you wish to withdraw your data. I'd like to emphasise that participation in this research is voluntary and all information provided is anonymous where possible.

Are there any risks involved?

We don't anticipate any particular risks to you with participating in this research; however, there is always the potential for research participation to raise uncomfortable and distressing issues. For this reason, we have provided information about some of the different resources which are available to you.

If you feel distressed as a result of answering the survey questions, the **Stillbirth and Neonatal Death Society** (SANDS) and the **Miscarriage Association** offer helplines. SANDS are available on 0808 164 3332, or email: helpline@sands.org.uk, the helpline is available 9:30am to 5:30pm Mondays to Fridays, and also 6pm to 10pm on Tuesday and Thursday evenings, more information is available at https://www.sands.org.uk/support-you/how-we-offer-support/helpline.

The **Miscarriage Association** can be contacted on 01924 200799 or email info@miscarriageassociation.org.uk, and are available Mondays to Fridays, 9am to 4pm. There is also online support available at https://www.miscarriageassociation.org.uk/how-we-help/

If you would prefer to speak to someone face-to-face, there are a number of **local charities** that offer support to those that have experienced the loss of a baby, to find the centre nearest to you please visit: https://www.pregnancychoicesdirectory.com/centreservices/miscarriage-counselling

If you have any questions about this research please contact:

If you have any questions about this research please contact my research supervisor: Associate Professor Victoria Clarke, Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY, Tel: (0117) 3282176; Email: Victoria.Clarke@uwe.ac.uk

This research has been approved by the Health and Applied Sciences Faculty Research Ethics Committee (FREC)

Appendix F: Survey Onscreen Consent

Perinatal Loss and the Next Pregnancy

Survey Onscreen Consent

Thank you for agreeing to take part in this research on women's and midwives' experiences of perinatal loss and the following pregnancy. My name is Lucie Wheeler and I am a trainee counselling psychologist at the University of the West of England, Bristol. I am completing this research for my doctoral thesis. My research is supervised by Associate Professor Victoria Clarke. She can be contacted at the Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY, Tel: (0117) 3282176; Email: Victoria.Clarke@uwe.ac.uk if you have any queries about the research.

Before we begin I would like to emphasise that:

- your participation is entirely voluntary

- you are free to refuse to answer any question

- you are free to withdraw at any time, however, there are points where it will be impossible to withdraw from the research, such as once my thesis has been submitted.

You are also the 'expert'. There are no right or wrong answers and I am interested in everything you have to say.

Please tick this box to show that you have read the information on this screen and that you consent to participate in the research.

This research has been approved by the Health and Applies Sciences Faculty Research Ethics Committee (FREC)

Appendix G: Interview Participant Information Sheet

Perinatal Loss and the Next Pregnancy

Interview Participant Information Sheet

Who are the researchers and what is the research about?

Thank you for your interest in this research about women's and midwives' experiences of perinatal loss and the following pregnancy. My name is Lucie Wheeler and I am a trainee counselling psychologist at the University of the West of England, Bristol. I am completing this research for my doctoral thesis. I am interested in this subject because of my own personal experience of loss and pregnancy as well as working with clients that have been affected by similar experiences. My research is supervised by Associate Professor Victoria Clarke. If you have any questions about the research you can contact her at the Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY, Tel: (0117) 3282176; Email: Victoria.Clarke@uwe.ac.uk.

What does participation involve?

You are invited to participate in a qualitative interview – a qualitative interview is a 'conversation with a purpose'; you will be asked to answer questions in your own words. The questions will cover your experience of losing a baby, of being pregnant again after this loss, and the support received throughout this journey. The interview will be audio recorded and I will transcribe (type-up) the interview for the purposes of analysis. On the day of the interview, I will ask you to read and sign a consent form. You will also be asked to complete a short demographic questionnaire (i.e. questions about your age and so on). This is for me to gain a sense of who is taking part in the research. I will discuss what is going to happen in the interview and you will be given an opportunity to ask any questions that you might have. You will be given another opportunity to ask questions at the end of the interview.

Who can participate?

Anyone over the age of 18, who gave birth to a healthy child, now between the ages of one and five, who experienced a loss in their previous pregnancy, lives in or near South Wales and who is happy to take part in a face to face interview with me.

How will the data be used?

Your interview data will be anonymised (i.e., any information that can identify you will be removed) and analysed for my research project. This means extracts from your interview may be quoted in my thesis and in any publications and presentations arising from the research. The demographic data for all of the participants will be compiled into a table and included in my thesis and in any publications or presentations arising from the research. The information you provide will be treated confidentially and personally identifiable details will be stored separately from the data. The audio recordings will be deleted once the thesis has been assessed or the research has been published, whichever is later. The transcripts will then be archived as part of the record of my thesis.

The personal information collected in this research project (e.g., the interview audio recording and transcript, and the demographic form) will be processed by the University (data controller) in accordance with the terms and conditions of the Data Protection legislation. We will hold your data securely and not make it available to any third party unless permitted or required to do so by law. Your personal information will be used/processed as described on this participant information sheet. You have a number of rights in relation to your personal data. For data protection queries, please write to the Data Protection Officer, UWE Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY, or dataprotection@uwe.ac.uk.

What are the benefits of taking part?

You will get the opportunity to participate in a research project on an important issue. It will also give you an opportunity to share your personal story and contribute to an increased understanding of the experiences of pregnancy and loss. Many find that talking about their loss and sharing their story is a positive experience.

How do I withdraw from the research?

If you decide you want to withdraw from the research please contact me via email (Naomi2.Wheeler@live.uwe.ac.uk). Please note that there are certain points beyond which it will be impossible to withdraw from the research – for instance, when I have submitted my thesis. Therefore, I strongly encourage you to contact me within a month of participation if you wish to withdraw your data. I'd like to emphasise that participation in this research is voluntary and all information provided is anonymous where possible.

Are there any risks involved?

We don't anticipate any particular risks to you with participating in this research; however, there is always the potential for research participation to raise uncomfortable and distressing issues. For this reason, we have provided information about some of the different resources which are available to you.

If you feel distressed as a result of participating in the interview, the **Stillbirth and Neonatal Death Society** (SANDS) and the **Miscarriage Association** offer helplines. SANDS are available on 0808 164 3332, or email: helpline@sands.org.uk, the helpline is available 9:30am to 5:30pm Mondays to Fridays, and also 6pm to 10pm on Tuesday and Thursday evenings, more information is available at https://www.sands.org.uk/support-you/how-we-offer-support/helpline.

The **Miscarriage Association** can be contacted on 01924 200799 or email info@miscarriageassociation.org.uk, and are available Mondays to Fridays, 9am to 4pm. There is also online support available https://www.miscarriageassociation.org.uk/how-we-help/

If you would prefer to speak to someone face-to-face, there are a number of **local charities** that offer support to those that have experienced the loss of a baby, to find the centre nearest to you please visit: https://www.pregnancychoicesdirectory.com/centreservices/miscarriage-counselling

If you have any questions about this research please contact:

If you have any questions about this research please contact my research supervisor: Associate Professor Victoria Clarke, Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY, Tel: (0117) 3282176; Email: Victoria.Clarke@uwe.ac.uk

This research has been approved by the Health and Applied Sciences Faculty Research Ethics Committee (FREC)

Appendix H: Interview Consent Form

Perinatal Loss and the Next Pregnancy

Interview Consent Form

Thank you for agreeing to take part in this research on women's and midwives' experiences of perinatal loss and the following pregnancy. My name is Lucie Wheeler and I am a trainee counselling psychologist at the University of the West of England, Bristol. I am completing this research for my doctoral thesis. My research is supervised by Associate Professor Victoria Clarke. She can be contacted at the Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY, Tel: (0117) 3282176; Email: Victoria.Clarke@uwe.ac.uk if you have any queries about the research.

Before we begin I would like to emphasise that:

- your participation is entirely voluntary

- you are free to refuse to answer any question

- you are free to withdraw at any time, however, there are points where it will be impossible to withdraw from the research, such as once my thesis has been submitted.

You are also the 'expert'. There are no right or wrong answers and I am interested in everything you have to say.

Please sign this form to show that you have read the contents of this form and of the participant information sheet and you consent to participate in the research:

_______________________ (Signed)

_______________________ (Printed)

_____________ (Date)

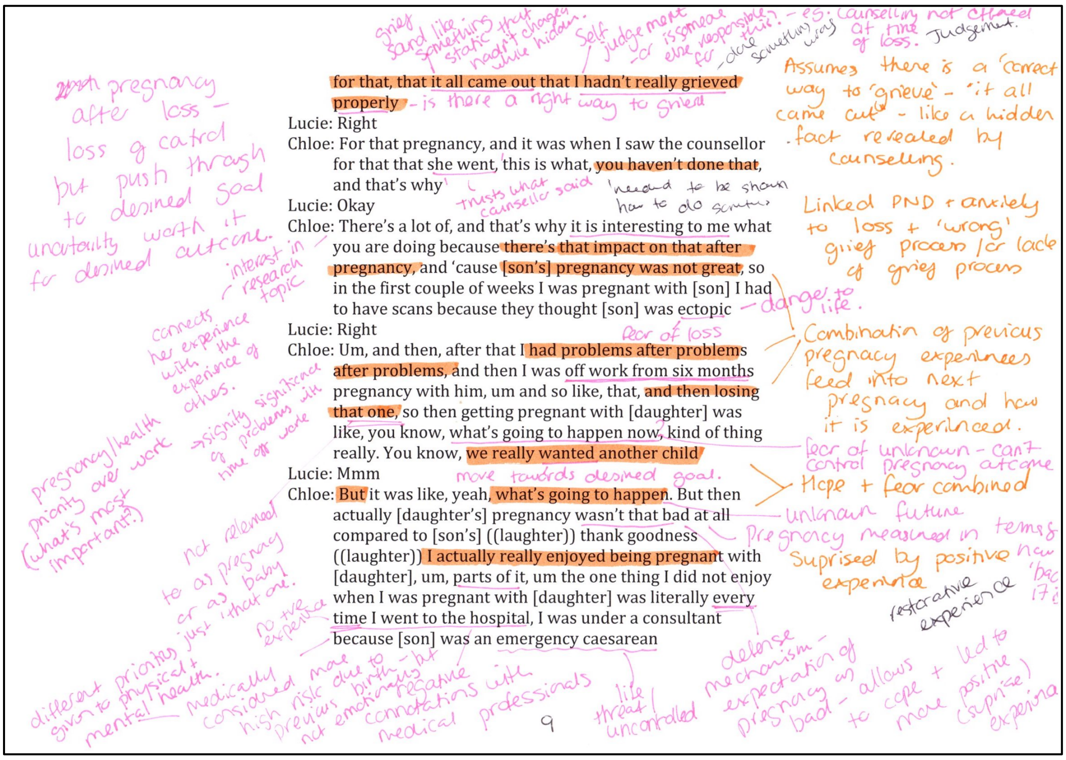
Please return the signed copy of this form to me.

Researcher signature _______________________

Date _______________________

This research has been approved by the Health and Applied Sciences Faculty Research Ethics Committee (FREC)

Appendix I: Sample of Initial Coding



for that, that it all came out that I hadn't really grieved properly

Lucie: Right

Chloe: For that pregnancy, and it was when I saw the counsellor for that that she went, this is what, you haven't done that, and that's why

Lucie: Okay

Chloe: There's a lot of, and that's why it is interesting to me what you are doing because there's that impact on that after pregnancy, and 'cause [son's] pregnancy was not great, so in the first couple of weeks I was pregnant with [son] I had to have scans because they thought [son] was ectopic

Lucie: Right

Chloe: Um, and then, after that I had problems after problems after problems, and then I was off work from six months pregnancy with him, um and so like, that, and then losing that one, so then getting pregnant with [daughter] was like, you know, what's going to happen now, kind of thing really. You know, we really wanted another child

Lucie: Mmm

Chloe: But it was like, yeah, what's going to happen. But then actually [daughter's] pregnancy wasn't that bad at all compared to [son's] ((laughter)) thank goodness ((laughter)) I actually really enjoyed being pregnant with [daughter], um, parts of it, um the one thing I did not enjoy when I was pregnant with [daughter] was literally every time I went to the hospital, I was under a consultant because [son] was an emergency caesarean

grief seen like something that static hadn't changed while hidden.

Self judgement / or is someone else responsible for this? – done something wrong

– eg. counselling not offered at time of loss. Judgement.

– is there a right way to grieve

2nd pregnancy after loss – loss of control but push through to desired goal uncertainty worth it for desired outcome.

trusts what counsellor said

'needed to be shown how to do something

interest in / research topic

Assumes there is a 'correct way to 'grieve' – "it all came out" – like a hidden fact revealed by counselling.

Linked PND + anxiety to loss + 'wrong' grief process / or lack of grief process

– danger to life.

connects her experience with the experience of others.

fear of loss

Combination of previous pregnancy experiences feed into next pregnancy and how it is experienced.

→ signify significance of problems with time off work

pregnancy/health priority over work (what's most important?)

fear of unknown – can't control pregnancy outcome

move towards desired goal.

Hope + fear combined

unknown future

Pregnancy measured in terms of how 'bad' it is

Suprised by positive experience

restorative experience

not referred to as pregnancy or as baby just 'that one'.

no +ve experience

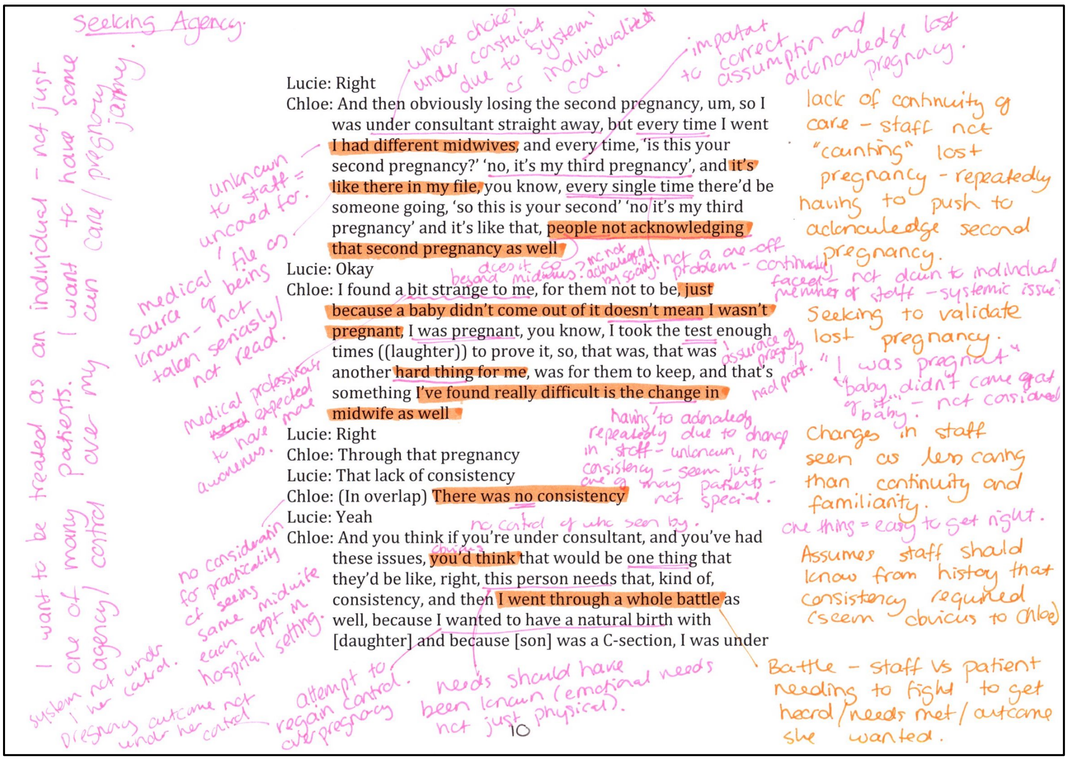
different priorities given to physical + mental health.

medically considered more high risk due to previous birth – but not emotionally negative connotations with medical professionals

9

life threat / uncontrolled

defense mechanism – expectation of pregnancy as bad – allows to cope + led to more positive (suprise) experience



Lucie: Right

Chloe: And then obviously losing the second pregnancy, um, so I was under consultant straight away, but every time I went I had different midwives, and every time, 'is this your second pregnancy?' 'no, it's my third pregnancy', and it's like there in my file, you know, every single time there'd be someone going, 'so this is your second' 'no it's my third pregnancy' and it's like that, people not acknowledging that second pregnancy as well

Lucie: Okay

Chloe: I found a bit strange to me, for them not to be, just because a baby didn't come out of it doesn't mean I wasn't pregnant, I was pregnant, you know, I took the test enough times ((laughter)) to prove it, so, that was, that was another hard thing for me, was for them to keep, and that's something I've found really difficult is the change in midwife as well

Lucie: Right

Chloe: Through that pregnancy

Lucie: That lack of consistency

Chloe: (In overlap) There was no consistency

Lucie: Yeah

Chloe: And you think if you're under consultant, and you've had these issues, you'd think that would be one thing that they'd be like, right, this person needs that, kind of, consistency, and then I went through a whole battle as well, because I wanted to have a natural birth with [daughter] and because [son] was a C-section, I was under

Seeking Agency.

I want to be treated as an individual – not just one of many patients. I want to have some agency / control over my own care / pregnancy journey.

whose choice? under consultant due to 'system' or individualised care.

important to correct assumption and acknowledge lost pregnancy.

lack of continuity of care – staff not "counting" lost pregnancy – repeatedly having to push to acknowledge second pregnancy.

unknown to staff = uncared for.

medical file as source of being known – not taken seriously / not read.

does it go beyond midwives? me not acknowledged by society? not a one-off problem – continually faced – not down to individual member of staff – systemic issue?

Seeking to validate lost pregnancy.

"I was pregnant" "baby didn't come out of it" – not considered baby.

assurance of pregnancy / had proof.

medical professionals expected to have more awareness.

having to acknowledge repeatedly due to change in staff – unknown, no consistency – seem just one of many patients – not special.

Changes in staff seen as less caring than continuity and familiarity.

no control of who seen by.

one thing = easy to get right.

choices

no consideration for practicality of seeing same midwife each appt in hospital setting.

Assumes staff should know from history that consistency required (seem obvious to Chloe)

system not under her control.

pregnancy outcome not under her control

attempt to regain control over pregnancy

needs should have been known (emotional needs not just physical).

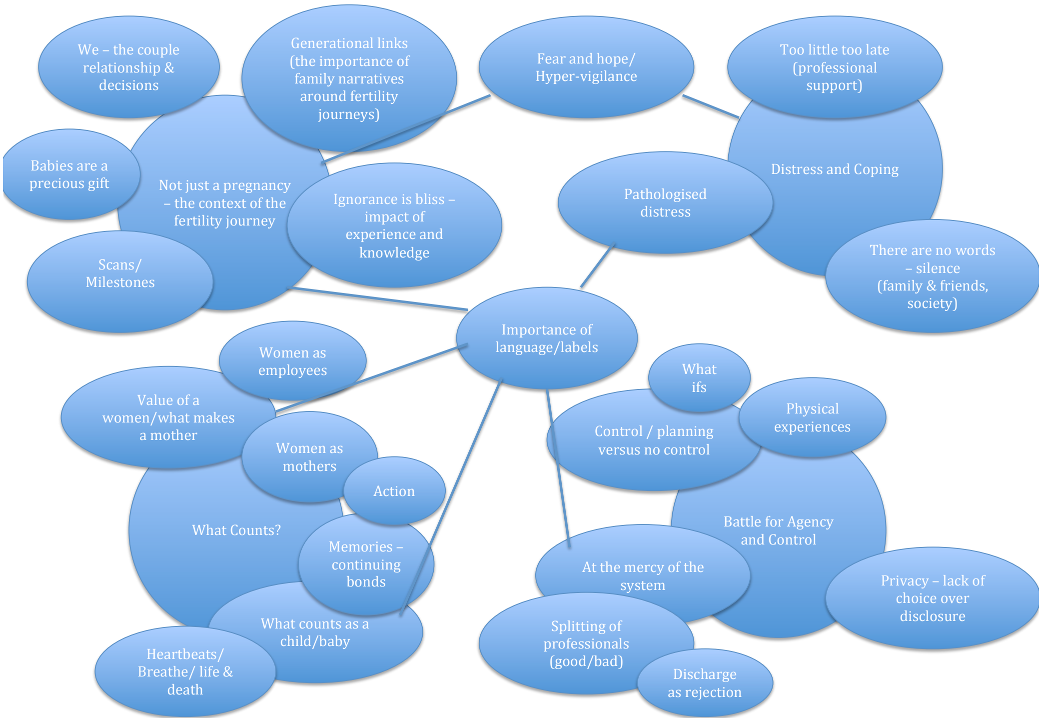
10

Battle – staff vs patient needing to fight to get heard / needs met / outcome she wanted.

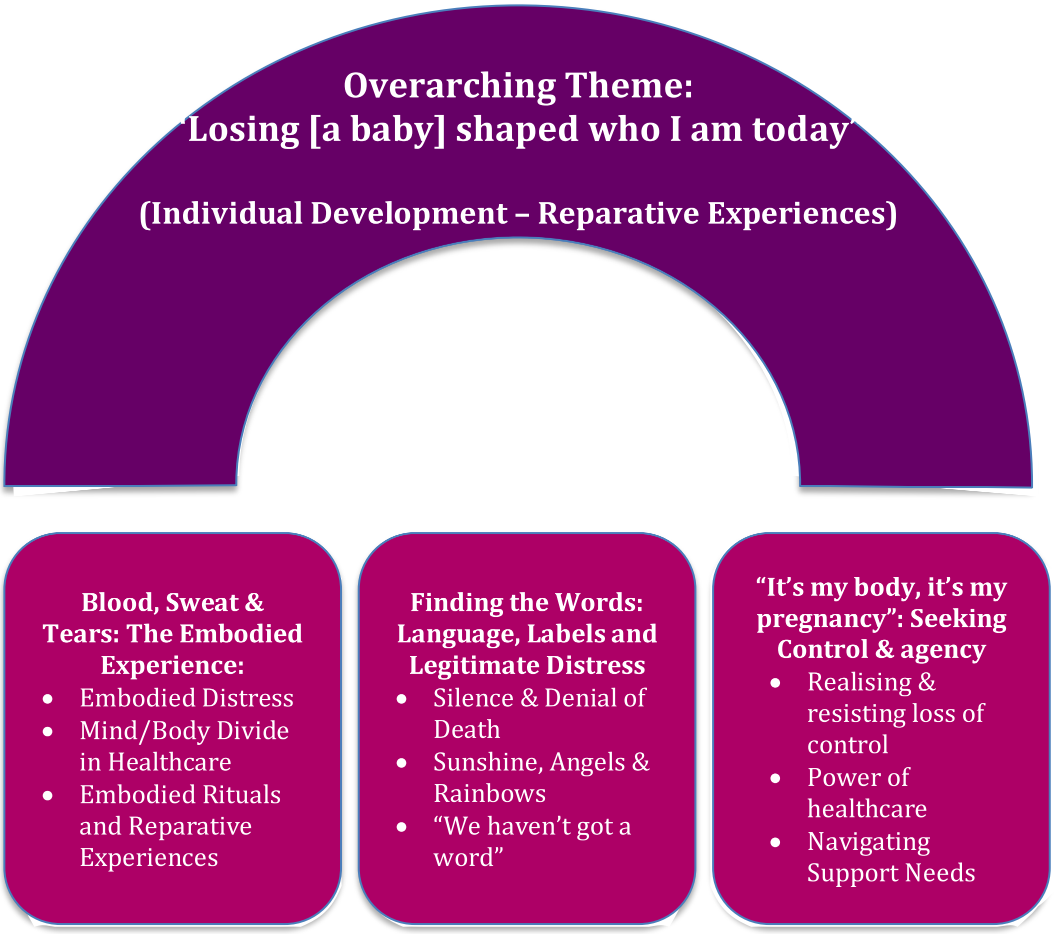
Appendix J: Early Thematic Maps

Exploration of ideas within the data:

Early Thematic Map:



Appendix K: Final Thematic Map



Overarching Theme:
'Losing [a baby] shaped who I am today'

(Individual Development – Reparative Experiences)

Blood, Sweat & Tears: The Embodied Experience:

- Embodied Distress
- Mind/Body Divide in Healthcare
- Embodied Rituals and Reparative Experiences

Finding the Words: Language, Labels and Legitimate Distress

- Silence & Denial of Death
- Sunshine, Angels & Rainbows
- "We haven't got a word"

"It's my body, it's my pregnancy": Seeking Control & agency

- Realising & resisting loss of control
- Power of healthcare
- Navigating Support Needs

Appendix L: Journal Article

"Sunshine", "Angels" and "Rainbows" – The importance of language developed by parents bereaved by perinatal loss

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Abstract (150 words)

Background: Perinatal losses are devastating life changing events for mothers, with psychological consequences both after loss and in the following pregnancy.

Aims: This qualitative study aimed to understand the holistic journey of perinatal loss and the subsequent pregnancy from mothers with lived experience.

Methods: Qualitative data was collected via online surveys (n=40) and face-to-face semi-structured interviews (n=5) then analysed using reflexive thematic analysis.

Findings: Under the overarching theme "losing [a baby] shaped who I am today" the theme "finding the words" was developed from the way in which participants used language to challenge societal silence, legitimise the personhood of their loss, whilst creating a community of support.

Conclusion: Midwives play a key role in women's experiences during the perinatal journey. Language used can either validate or be dismissive of distress. The researcher recommends the adoption of labels developed by rather than for bereaved parents in order to provide empathic care.

Keywords: *perinatal loss; miscarriage; stillbirth; grief; midwives; bereavement, qualitative methods*

Background and Rationale

Perinatal loss includes any losses that occur during pregnancy or shortly after birth. As many as one in five pregnancies ends in miscarriage, resulting in up to 45,000 hospital admissions annually in England (NHS Digital, 2019). In England and Wales, over 2500 stillbirths were recorded in 2019 and over 1700 neonatal deaths recorded in England in 2018 (ONS, 2020a; 2020b). Despite the prevalence, western societies often fail to recognise the significance of such losses and the psychological impact on those who experience them (Heazell et al., 2016; Martel, 2014). Depression and anxiety levels have been found to be significantly elevated in women who are pregnant following a loss (Hunter, Tussis, & MacBeth, 2017). A pregnancy after a loss is not only potentially a time of anxiety due to previous pregnancy experiences (Moulder, 2001), it is also a time when the individual is still possibly grieving their loss.

Pregnancy is unique in terms of the number of times an individual is in contact with professional services (Oates et al., 2012), providing unprecedented opportunity to identify those with psychological difficulties and offer support (Hogg, 2013). Midwives play an important role in the psychological wellbeing of women under their care. However, both studies of midwives' perceptions of care (Noonan et al., 2017) as well as reports on current midwifery practice (SANDS, 2016) refer to the need for better training and support for these healthcare professionals. Existing literature focuses specifically on perinatal loss or the subsequent pregnancy and is predominantly quantitative (for example Hunter et al., 2017; Hutti et al., 2018; Hutti et al., 2017). This results in a fragmented approach in existing evidence, and means distress is measured through psychometric scores which fails to represent the experiences of those or do not meet psychiatric thresholds.

Aims and Study Design

This qualitative study aimed to explore the subjective experience of women who had lived through a perinatal loss and a subsequent pregnancy, particularly what support made a meaningful difference to their experience. The research was undertaken as part of a counselling psychology doctoral thesis, and identified the life changing nature of such experiences, demonstrated through three themes. For the scope of this report, one of these themes will be reported with the aim of informing midwifery practice.

Methods

Data collection included forty completed qualitative online surveys and five semi-structured face-to-face interviews with women who had experienced a healthy pregnancy following a perinatal loss. The use of two forms of data collection gave participants choice about how to engage with the research, increasing accessibility, whilst providing both breadth and depth to the data (Neville, Adams, & Cook, 2016).

Purposive sampling through social media platforms was used to recruit women who had experienced pregnancy after a perinatal loss. Participants were women over the age of 18, English speaking, who had a child under 5 years old, and experienced any form of perinatal loss in the previous pregnancy. This was to ensure that participants had a recent healthcare experience. As postnatal depression can occur any time in the first twelve months after birth (NHS, 2016), those in the postnatal period were excluded to avoid causing distress at this vulnerable time. There were no restrictions placed on the type of perinatal loss, as the differences between the medical labels attributed to losses are based on gestational age, rather that relating to the way in which losses are experienced (O'Leary & Warland, 2016).

Table 1: Participant Demographics

Ages of participants	26-42 years	(mean 34.55)
Racial/ethnic background	White Other	39 (95%) 2 (5%)
Sexuality	Heterosexual Other	39 (95%) 2 (5%)
Class	Lower/working class Middle class No class category	19 (46 %) 16 (39%) 6 (15%)
Employment	Full-time employed Part-time employed Full-time student Other	14 (34%) 17 (41%) 1 (2%) 9 (22%)
Disability	Yes No	3 (7%) 38 (93%)
Relationship status	Married/partnered Divorced/separated/single	38 (93%) 3 (7%)

There were a total of 41 participants, 40 of whom completed the survey, and 5 interviews (4 of whom had also completed the survey). The demographic details of all participants are summarised in Table 1.

Ethics

This project received ethical approval from the Health and Applied Sciences Faculty Research Ethics Committee at The University of the West of England, and adhered to the British Psychological Society's Code of Human Research Ethics (BPS, 2014). Informed consent was obtained before participation in either survey or interview.

Analysis

All data was analysed using reflexive thematic analysis, as this allows the flexibility of combining multiple sources of data (Braun & Clarke, 2006; 2020). An inductive approach was taken to analysis, working with the data from the bottom-up (Braun & Clarke, 2013), exploring the perspectives of the participants, whilst also examining the contexts from which the data was produced. The analysis sought to identify patterns across the data in order to tell a story about the journey through loss and the next pregnancy. The six stages of Braun and Clarke's (2006; 2020) reflexive thematic analysis were used through an iterative process.

Results

The overarching theme "Losing a baby shaped who I am today" was developed to represent the personal developmental journeys apparent in the data. This development was evident across three themes. For the scope of this article, the theme "Finding the words: language, labels and legitimate distress" will be reported, with three subthemes. These were: (1) silence and denial of death; (2) "sunshine", "angels" and "rainbows" – developing a language for loss and (3) "we haven't got a word" – the precarious identity of bereaved mothers.

Silence and denial of death

Participants reported silence around their losses and grief, through the lack of words from those around them who did not know what to say, exacerbating the felt isolation:

> *"I think no one knew what to say so it was a very lonely time" (S11)* [1]

> *"Family and friends generally didn't know what to say... I felt quite alone most of the time" (S15)*

Participants also highlighted the way in which labels used by others could minimise their experiences, such as medical terminology:

> *"they call it 'products of conception'... it's very sterile and very clinical... not very caring" (Int. 4)*

The labels used within the hospital were often distressing. This included the use of "*spontaneous abortion*" (S21) and "*foetal remains*" (S30) to describe miscarriage, as well as the use of "*miscarriage*" (S30) for losses that required giving birth.

The labels linked to gestation impacted the legitimacy of the baby's personhood, with a significant impact on the experience:

> "*I think there is very little Information regarding loss in the middle months. Before 12 weeks it's classed as miscarriage after 24 weeks it's a stillbirth but what was I? The term used was a late miscarriage yet I gave birth I had full labour, my breasts produced milk for a baby that wasn't there*" (S21)

For this participant, the label of "*late miscarriage*" did not acknowledge the experience of giving birth and the postnatal period. For those with earlier losses, there can be a perceived hierarchy to loss labels that can be dismissive of the grief and distress experienced:

> "*It would be nicer if early miscarriage could be acknowledged. There's a lot of focus on stillbirth... but early loss is just considered "one of those things" when really it can be devastating*" (S11)

These experiences led to an effort to develop terminology that might help break the societal taboos around perinatal losses.

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[1] 'S#' represents quotes from survey data, with interview data denoted by 'Int. #'

"Sunshine", "Angels" and "Rainbows" – Developing a Language for Loss

Specific language was used as a way to legitimise the loss or distress, including labels attributed to both living and lost children. The most commonly used term was "*rainbow baby*" used without explanation, highlighting how normalised this was within the baby loss community:

> "*Our rainbow baby boy… was born*" (S21)
>
> "*I… finally got my rainbow baby*" (S36)

The term rainbow seemed symbolic of this new life fitting into a wider family narrative, one where hope was only found after suffering. While not referring directly to the lost infant, the label of "*rainbow baby*" provided symbolism of the relationship between the lost and living children.

Living children were referred to differently depending on whether they came before or after loss:

> "*My sunshine baby, she's my life saver... My rainbow baby, she healed me in ways I never knew possible*" (S20)

The different terms for living children highlights the significance of a loss event, that for these mothers there is a before and after, there is a difference between "*sunshine*" babies and "*rainbow*" babies. For this participant, her "*sunshine*" baby was considered protective, a child that predated her loss, giving her a reason to continue to live. Her "*rainbow*" baby, coming after the distress of loss, has a different role in bringing healing. This term "*sunshine*" is only applied retrospectively, once a following sibling is lost. This shows the way in which experiences are developed and reframed based on the fertility journey.

For the loss itself, there was more ambiguity about how to refer to it, which seems to partly reflect a lack of social norms. Some used the term "*angel baby*", which seemed to suggest a continued heavenly existence for these babies:

> "*I've got living children as well as my angel*" (Int. 1)
>
> "*I had to be sedated to have my angel girl removed*" (S19)

These representations imply a spiritual or supernatural aspect to the experience, bringing both comfort and connection to the deceased. While participants suggested that the medical language used to refer to their losses denied both death and personhood, most mothers referred to their losses as babies, with a sense of their continued existence either in memories or life after death.

These labels reflected not only the different identities of their children, but also their changing motherhood identity. It seemed to be an attempt to develop social norms through common language, and also provided rich symbolism that represented the experience in terms that were socially acceptable. The development of common terms seemed to be both a result of and contribute to the creation of communities of others with similar experiences. The importance of collective symbolism was apparent in the data, with many participants accessing online support to connect with other parents with shared understanding, for example:

> *"[supported by] baby loss groups on Facebook angel mums*" (S19)

Shared language seems to be a way of establishing a supportive community, as well as communicate to outsiders of that community in terms that hold meaning.

"We haven't got a word" – The Precarious Identity of Bereaved Mothers

Despite a developing common language for babies in relation to perinatal loss, the lack of a word to describe a grieving parent was considered significant:

> *"I always wanted, that was my long term goal, was to get a word that meant the equivalent of orphan or widow, that you could use in society to explain that you have got a loss… that is something that's quite important is that, we haven't got a word*" (Int. 5)

The lack of a word meant that there was a perceived failure by people to acknowledge the position of bereaved parents in society.

Participants also questioned the ambiguity of the term "*mother*", at what point this label applied, and when women could include this as part of their identity. In the face of uncertainty after multiple losses this participant asks:

"*would I ever be a mother?*" (Int. 2), but experienced the miscarriages after her daughter was born differently:

> "*having a healthy baby… there was just a lot of pressure taken off, 'cause I was like now I have a child, I am a mother*" (Int. 2)

It seemed that "*mother*" was a term that was unavailable to women experiencing loss, but could be used in reflecting on their experience, as this in part gave validity to the personhood of the lost child. When asked if she considered herself a mother after the loss of her daughter, the participant responded:

> "*Then I wouldn't, now I would… I was a mother the whole time*" (Int. 1)

Although unable to consider herself a mother until she had a healthy baby, she was able to give herself this identity retrospectively for her first pregnancy. Not owning the identity of mother could impact on the child's identity, but was a difficult title to claim without the ability to carry out what was perceived to be the actions of a mother:

> "*when I ordered the head stone, that really started to hit me because it was the first time I wrote 'mother' when it said 'relation to deceased'… well how can I be a mummy when I've not had chance to bath her and dress her and change her*" (Int. 5)

However, despite her own struggles with her motherhood identity, this participant was inclusive in her definition of a mother in her desire to support others.

Discussion

In exploring the experience of perinatal loss and the subsequent pregnancy it was apparent that terminology could be both validating and dismissive of the mother's distress. The participants using new language to represent their experiences seems to be a form of symbolism, both as important expressions of meaning making through grief (Nadeau, 2006), but also a way to develop a community through others who share in the language and identity that this gives (Sawicka, 2017). Society has established rituals; expected behaviour by both the bereaved and those who interact with them, with bereaved status achieved through the recognised death of a loved one (Corless et al., 2014).

Where perinatal loss is not acknowledged as such a death, the mother may therefore be denied the status of 'bereaved' and not treated as such by either professionals or others within their social sphere.

Despite grief responses being recognised in all forms of loss, this grief is often invalidated by medical and social silence (Martel, 2014). This sense of hierarchy can be exacerbated by the assumptions of healthcare workers who consider later losses as more traumatic than early loss (Murphy, 2019). The way in which labels can legitimise or dismiss not only the distress but also the personhood of the lost raises questions about what is 'counted' as a baby, and how this differs between individuals, professionals and society more generally. The mother can attribute personhood from the earliest stages of pregnancy, despite this being "revoked" by cultural taboos in the face of a loss (Layne, 2000, p.323).

Language around early losses has developed in line with advancements in medical technology and societal expectations, with 'miscarriage' being favoured over the medical term 'spontaneous abortion' since the mid 1980s (Moscrop, 2013). For those whose losses sit on the margins between legal definitions of miscarriage and stillbirth, the distinctions made can exacerbate distress by failing to prepare women for the process of giving birth and invalidating their experience through lack of recognition (Smith et al., 2020).

Grief and the relationship with the lost is an evolving process, and the narrative develops and is shaped by the language available (Hedtke, 2002). Symbolism provides important cultural tools for understanding experience, and for prescribing emotional reactions to situations (Sawicka, 2017). However, such symbols do not exist for miscarriages and stillbirths, leading to ambiguous emotional experiences (Sawicka, 2017). The data suggests that mothers were able to develop their own symbols and therefore support themselves and each other in the emotional processing of their losses.

The way in which participants used labels to legitimise their losses, and the significance of their experiences, whilst rejecting the labels used by medical professionals, highlights the emotive nature of language. The inadequacy of language to provide a label for parents who lose a child can make their role in society and identity as parents precarious (Seigal, 2017). Healthcare professionals can make a meaningful difference to the experiences of women by an increased awareness about the terminology used when caring for those who have experienced perinatal loss. Avoiding medicalised terms whilst choosing language that validates the mother and the identity of their loss may significantly improve women's healthcare experience, but requires empathic sensitivity to the subjective experience of those being treated.

Limitations and Future Research Opportunities

As the sample was predominantly white British heterosexual women with partners, recruitment of a more diverse sample would help develop the findings further. Whilst this study was focused on the lived experiences of mothers, understanding the role of both social and professional support could be further developed by future qualitative research with those surrounding the mother, including partners and healthcare professionals.

With terminology playing such a key role in the findings, the researcher is aware of how the language of the questions will have limited responses. Whilst aiming to provide an opportunity for women to share their stories in their own words, no terms are neutral and there were examples of individual differences amongst participants in what language they embraced or rejected, as well as how they framed their experience. Further research that specifically seeks to explore the language of loss in more depth could help provide more nuanced understanding of these important issues for healthcare professionals.

Conclusion

Qualitative survey and interview data was used to explore the experiences of mothers who had been bereaved by perinatal loss and gone on to have a living child. The need for developing a common language seems to be an important part of breaking the silence and taboos around baby loss. However, the experiences of these participants shows the importance of this language being developed by rather than for bereaved parents, and the need for healthcare professionals to be aware of the power of the labels they use, and to be inclusive of the subjective experiences of those who they care for. Empathic care requires sensitivity to the way in which terminology can both validate and dismiss distress experienced by bereaved mothers.

Key Points

- Societal silence and medical terminology can exacerbate the distress of perinatal loss, both during the loss and in subsequent pregnancies
- Bereaved parents develop symbolic labels for their lost and living children that acknowledge the personhood of the lost and their lasting legacy within the family
- Shared terminology provides socially acceptable language and leads to the development of a community of support with others with shared experience
- The terminology used by midwives was identified as an important way in which care can make a meaningful difference to the experience of bereaved mothers

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