

“Sunshine”, “Angels” and “Rainbows” – The importance of language developed by mothers bereaved by perinatal loss

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Abstract

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 were 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 “Finding the words: Language, labels and legitimate distress” three themes were developed that captured the ways in which participants used language to challenge societal silence and 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 researchers recommend the adoption of labels developed by rather than for bereaved parents in order to provide empathic care.

Keywords: *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 end in miscarriage, resulting in up to 45,000 hospital admissions annually in England (NHS Digital 2019). In England and Wales, almost 2500 stillbirths were recorded in 2020 and over 1700 neonatal deaths recorded in 2018 (ONS 2022, 2021).

Despite the prevalence, western societies often fail to recognise the significance of such losses and the psychological impact on those who experience them (Farren et al. 2020; 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 et al. 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 an 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 midwifery practice (SANDS 2016) refer to the need for better training and support for these healthcare professionals. Existing literature focuses specifically on either perinatal loss or the subsequent pregnancy, rather than the whole experience and is predominantly quantitative (for example Farren et al. 2020; Hunter et al., 2017; Hutti et al., 2018). This results in a fragmented approach in existing evidence, and means distress is often measured

through psychometric scores which fails to represent the experiences of those who do not meet psychiatric thresholds.

Aims and Study Design

This qualitative study aimed to explore the subjective experiences of women who had lived through a perinatal loss and a subsequent pregnancy, and particularly what support made a meaningful difference to their experiences. The research was undertaken as part of a counselling psychology doctoral thesis, and identified the importance of language in shaping individuals' experiences. The developed 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 et al. 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 participants had a recent healthcare experience. As postnatal depression can occur any time in the first twelve months after birth (NHS 2018), 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 than relating to the way in which losses are experienced (O'Leary and Warland 2016).

Table 1: Participant Demographics		
Ages of participants	26-42 years	(mean 34.55)
Racial/ethnic background	White	39 (95%)
	Another racial/ethnic background	2 (5%)
Sexuality	Heterosexual	39 (95%)
	Another sexuality	2 (5%)
Class	Lower/working class	19 (46 %)
	Middle class	16 (39%)
	No class category	6 (15%)
Employment	Full-time employed	14 (34%)
	Part-time employed	17 (41%)
	Full-time student	1 (2%)
	Another employment status	9 (22%)
Disability	Yes	3 (7%)
	No	38 (93%)

Relationship status	Married/partnered	38 (93%)
	Divorced/separated/single	3 (7%)

There was 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 for all participants are summarised in Table 1. Participants had experienced losses throughout pregnancy, with many having experienced more than one loss. The perinatal loss experiences of participants are summarised in Table 2.

Table 2: Participants' Living Children and Perinatal Loss History		
Number of living children	1	17 (41%)
	2	18 (44%)
	3	6 (15%)
	(Mean 1.7)	
Ages of living children	0 -14 years	(mean 3.7)
Loss and living children	Living children before first loss	15 (37%)
	Loss in first pregnancy	26 (63%)
Gestation of losses	Less than 12 weeks	48 (60%)
	12 to 23 weeks	20 (25%)
	24 to 42 weeks	8 (10%)

	Neonatal loss	4 (5%)
	(Total losses	80)
Number of perinatal losses experienced	1	20 (49%)
	2	11 (27%)
	3	3 (7%)
	4	5 (12%)
	5	2 (5%)

Ethics

This project received ethical approval from the Health and Applied Sciences Faculty Research Ethics Committee at Authors' University, 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. Surveys were completed anonymously, and interview data anonymised during transcription.

Analysis

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

of Braun and Clarke’s (2006, 2020) reflexive thematic analysis were used through an iterative process, as seen in Table 3.

Table 3: The Six Phases of Thematic Analysis (Braun and Clarke, 2006, 2020)	
Phase 1: Data familiarisation and writing familiarisation notes	The primary researcher carried out all data collection and transcription, followed by further familiarisation by multiple readings of the data. A reflective journal was used throughout to make notes and personal reflections.
Phase 2: Systematic data coding	Coding of the interview and then survey data was done line by line, paying equal attention to each part of the data. The research team provided an auditing process by checking the data and code development throughout and discussing ideas and personal reflections. Initial coding was mainly semantic, with later development of latent codes to look below the surface level meaning of participants. Codes were collated separately from the data and rough diagrams were developed of ideas.
Phase 3: Generating initial themes from coded and collated data	Codes were collated from both sources of data and organised to reflect some of the commonality in what participants had expressed. Ideas about patterns in the data were developed through early thematic

	maps, constantly returning to the data, codes and reflective notes, as well as discussion with the research team.
Phase 4: Developing and reviewing themes	Patterns were identified through an iterative process of reviewing collated codes and returning to the raw data. Further thematic maps were developed to illustrate developing ideas, highlighting areas of overlap, contradiction and bringing clarity to theme formation.
Phase 5: Refining, defining and naming themes	Themes were refined to ensure that any areas of overlap were addressed and that the themes created a cohesive story about participants' experiences. Theme names used participant quotations where possible to keep close links between the original data and developed themes.
Phase 6: Writing the report	Themes were initially written up as part of a doctoral thesis, a process that brought further clarity to each theme idea. Findings were then further disseminated through presentations to practitioners and then through seeking relevant publications.

Results

The overarching theme “Finding the words: language, labels and legitimate distress” was developed to represent the way in which participants used language to challenge societal silence, legitimise the personhood of their loss, whilst creating a community of support. This overarching theme encompassed three themes. 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 minimised the legitimacy of the baby’s personhood, with a significant impact on the experience:

¹ ‘S#’ represents quotes from survey data, with interview data denoted by ‘Int. #’

“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.

“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 common of these labels was *“rainbow baby”*, a term for a living child after loss. This was 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.

The women also reported that “*rainbow*” was also a term adopted by specialist services that catered for the pregnancy after loss, including NHS clinics, 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).

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. 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 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.

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. Participants suggested that the medical language used to refer to their losses denied both death and personhood, and most referred to their losses as babies, with a sense of their continued existence either in memories or life after death.

The labels used by the women reflected not only the different identities of their children, but also their changing motherhood identity. There seemed to be an attempt to develop social norms through common language, and also provide 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 seemed 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' use of 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 with 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, 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 are evolving processes, and the narratives around this develop and are 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 suggest 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, and requires empathic sensitivity to the subjective experience of those being treated.

Limitations and Future Research Opportunities

As the participant group was predominantly White British heterosexual women with partners, recruitment of a more diverse participant group 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 researchers are 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 were 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 show 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.

Reflective Questions

- What key things do you take away from this research with mothers?
- How will this impact on your practice?
- What labels are used for perinatal loss in your workplace and how might these be understood by parents?
- Would you consider losses early in pregnancy as bereavements?

- Considering your experience working with perinatal loss, is there anything you would do or say differently?

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