

Reflective evaluations of perinatal bereavement care provision in the US and UK: An exploratory qualitative comparative study

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Keywords: *care provision, comparison, miscarriage, perinatal bereavement, stillbirth, United Kingdom, United States, culture*

Implications for practice

- In both the US and UK, perinatal bereavement pathways have been constructed in response to culture, education, and healthcare payment systems – we suggest flexibility is required to accommodate individual needs.
- Regardless of nation, the meaning of loss for parents does not relate to gestational age, but instead to when ‘fetal personhood’ is ascribed; this should be considered when activating a perinatal bereavement pathway (eg, miscarriage, stillbirth, neonatal etc).
- Regardless of what perinatal bereavement pathway maternity professionals activate, bereaved parents’ psychological needs should be explored and attended to.

- In neither the US or UK are there follow-up guidelines that direct routine screening for PND, complicated grief syndrome, PTSD, or Complex-PTSD post perinatal bereavement – we recommend these should be available to all women internationally.

Abstract

There is increased recognition of the need to improve standards of perinatal bereavement care, due to its frequency and potential sequelae. As part of a Fulbright Scholar award, United States (US) and United Kingdom (UK) researchers collaborated to explore similarities and differences in perinatal bereavement care between two nations. Using an explorative qualitative comparative method, key categories within perinatal bereavement provision were identified and analysed. Themed findings include: (1) Differences in definitions of miscarriage and stillbirth impact care pathways; (2) For the experienter grief is the same regardless of legal lines drawn; (3) The meaning of loss is personal and ‘fetal personhood’ needs to be acknowledged during care; (4) Appropriate psychological care is required whether miscarriage or

stillbirth is experienced. We conclude that perinatal bereavement care should include screening for Postnatal Depression (PND) and Post-Traumatic-Stress-Disorder (PTSD), and support should be equally available to all women who experience perinatal bereavement, irrespective of type of loss. Acknowledging that cultures react to loss in different ways, we recommend that strategies are developed to build human resilience. For example, Compassionate-Mind-Training (CMT), which helps people cope with trauma through cultivating compassion and teaching self-care strategies to build resilience, reduce self-criticism, and decrease threat-based emotions.

Introduction

The loss of a wished-for child during pregnancy or shortly post-birth often leads to grief, bereavement, and recognition that this experience is a life-changing event (Wright, 2016). While most parents work through their grief without complications, many develop traumatic grief. In the UK around 3,500 women experience trauma post perinatal bereavement every year (ONS, 2017), with a systematic review by Christiansen *et al* (2017) finding that up to 39% develop Post-Traumatic-Stress-Disorder (PTSD) or Complex-PTSD (ICD-11) (WHO, 2018; Karatzias *et al*, 2019), which can have devastating effects upon well-being and relationships (Hollins Martin *et al*, 2021a; Brockington *et al*, 2017). Extracting data, US-based studies indicate that up to 50% of women post-stillbirth develop PTSD (Cacciatore, 2013; Cacciatore *et al*, 2014). Together this evidence overwhelmingly supports the importance of implementing interventions that are helpful towards improving psychological outcomes for women who have experienced perinatal bereavement (Akard *et al*, 2018; Burden *et al* 2016; Côté-Arsenault *et al*, 2014; Hollins Martin *et al*, 2014, 2021a; Hutti & Limbo, 2019; Pueyo *et al*, 2021). In response, recommendations support the improvement of standards of perinatal bereavement care (Steen, 2015). Recognising the importance of studying and improving perinatal bereavement care, this study grew out of the

researchers' unique opportunity to collaborate through a Fulbright Scholarship that facilitated them to compare perinatal bereavement care provision between the US and UK.

In this exploratory qualitative comparative study, 'perinatal' refers to the time from pregnancy to the months following birth, and 'perinatal death' is defined as loss of a pregnancy any time before or during birth, including death of a neonate in the first month of life (Limbo & Kobler, 2010). The country-unique terms of miscarriage, stillbirth, perinatal death, and neonatal death, and their associated gestational age or days of life were reviewed. Recognition of US and UK differences in definitions of these terms became a useful starting point to examine how definitions impact upon perinatal bereavement care provision (see Table 1). The apparent differences between US and UK definitions refer to the period of 20 to 24 weeks gestation, which are calculated from date of conception. From a foetal development perspective, this is generally the perivable stage of foetal maturity when there is a questionable chance of foetal viability, which is the point at which a foetus can survive outside of the maternal uterus, with likely need for medical support.

To date, no literature has compared perinatal bereavement care provision between the US and UK. There are innumerable research studies undertaken in the US and UK, which are accompanied by those from other developed countries. In fact, the new knowledge gained from other countries and cultures is commonly used to move science forward and to inform best care in one's own country. What has received little attention is recognition of the unique country-specific context of perinatal loss, including the cultural milieu and elements that shape that context. However, the many differences between cultures that likely influence study results have not been examined, such as accepted definitions, fundamental philosophy, structure, and funding of health care systems, etc. Cross-cultural explorations provide opportunities to see beyond our own viewpoint, which enables us to learn from others and consider new ideas and ways of thinking. Thus, gaining some understanding of the context within which research studies were conducted could provide new insights and enhancement of healthcare and support. Therefore, to address this gap, our team of experts worked to make

Table 1: Differences in terms used to define perinatal bereavement between the US and the UK

Definitions	US	UK
Miscarriage	Naturally occurring death of a nonviable fetus and placenta from the uterus before the 20th week of gestation (ASRM: American Society for reproductive medicine, 2012 & CDC, 2023). Early loss of a pregnancy during 1st 13 weeks of pregnancy is miscarriage or spontaneous abortion (ACOG, 2023).	Baby (or fetus or embryo) dies in the uterus during pregnancy from conception up to 23 weeks and 6 days (Miscarriage Association, 2023).
Stillbirth	Death of fetus at or after 20 weeks of pregnancy, before or during delivery with no evidence of life; classified as early (20–27 weeks), late (28 and 36 weeks), or term (37 or more completed weeks) stillbirth (CDC, 2023).	Child issued forth from its mother after the 24th week of pregnancy and which did not, at any time after being completely expelled from its mother, breathe, or show any other signs of life (NHS Perinatal Institute, 2021).
Perinatal death	Infant death under age 7 days and fetal death at 28 or more completed week of gestation. (CDC, 2023).	Fetal deaths after 24 completed weeks of gestation and death before 7 completed days (NHS Perinatal Institute, 2021).
Neonatal death	Live birth of newborn that dies prior to 28 days of age. Early neonatal death occurs <7 days expressed per 1000 live birth, and further subdivided into early (<7 days), late (7–27 days) (American Academy of Pediatrics, 2016)	If the baby is born alive, even before 24 weeks, and lives even for a matter of minutes, that is considered a live birth and a neonatal death. Death before the age of 28 completed days following live birth (NHS perinatal Institute, 2021): <ul style="list-style-type: none"> • Early neonatal is up to 7 days. • Late neonatal is from 7 and up to 28 days.

this comparison. The purpose was to learn from one-another’s expertise and experience, and through an exploratory study of the literature and public documents, we began to recognise that each country has its own history of health care provision, varying structure for financing and delivering care, and cultural values that influence differences in perinatal bereavement care provision.

Culture is defined as patterns of learned behaviour that are underpinned by values that have evolved over generations (Ayebare *et al*, 2021). Within this context, it is also important to recognise that values and beliefs influence social norms in terms of spirituality, gender, and social attitudes (Ayebare *et al*, 2021), which influence reactions, decision-making, coping styles, and

support provided when perinatal bereavement occurs (Gire, 2014). With these definitions in mind, we sought to compare and contrast aspects of delivery of perinatal bereavement care between the US and UK through a cultural lens.

Methods

An exploratory qualitative comparative method was used to reflectively evaluate differences in perinatal bereavement care between the US and UK. This study was funded by a Fulbright scholarship, which enabled a well-published US Professor to travel to the UK for the months of June, July, and August 2021. Her concurrent research study was an ethnography of perinatal bereavement care provided in the Edinburgh/Lothian region of Scotland. The UK authors

served as the Fulbrighter's sponsors and mentors. Ethical approval was gained through the sponsor university, which involved planned interviews with bereaved parents, midwives, and charity organisation personnel; all authors were included in the study approval. The second author (DCA) sought guidance of co-researchers of UK norms from the beginning of data collection, which led this expert group to seek and discuss UK healthcare, public policies and the literature. It became apparent that there were no existing sources that had compared UK and US guidelines and approaches. Thus, this exploratory study began. A comparative approach was taken to explain and gain improved understanding of related processes involved in the creation of an event, feature, or relationship (Pickvance, 2005). In this instance, the event was perinatal bereavement, the feature was care provided, and the relationship was between the US and UK. To date, the comparative approach is an underdeveloped research method, which has gained more attention recently due to globalisation and technological advances on cross-national platforms. We used explicit contrasting of two cases (US & UK) to explore parallels and differences, as suggested by Azarian (2011).

Research team

Three perinatal bereavement experts met weekly for 2-hour discussions over the 3-month period (12 in total), to examine similarities and differences in perinatal bereavement care provision between the US and UK. Topics of inquiry arose from US researcher questions of the UK researchers. This led to expert discussion, followed by literature and public document searches, and then our qualitative analysis of all combined data. Detailed and dated memos were taken by two of the co-researchers that were shared and consolidated over time, with noted topical issues and areas for further exploration. These discussions were followed by searches for nation-specific documents and related literature. Two of the authors are well-published in the area of perinatal bereavement, with the first UK based (Hollins Martin & Forrest, 2013; Hollins Martin *et al.*, 2013; 2014; 2016; 2021b) and the second US placed (Blackmore *et al.*, 2011; Côté-Arsenault, 2003, 2007; Côté-Arsenault & Denney-Keolsch, 2016; Côté-Arsenault & Donato, 2011; Côté-Arsenault & Dombek, 2001; Côté-Arsenault *et*

al., 2014, 2021). During the process, conversations were informed by considerable knowledge and expertise, and published literature. The third author is an academic with extensive experience in delivering education to student midwives in the UK. As such, she contributed to discussion and played a validation role.

Data collection

Due to the Covid-19 pandemic and its restrictions, 4 meetings were accommodated on Teams and 8 face-to-face (Total 12), with all three team members present. First, areas categorised as important for critical discussion were recorded. These organically emerged from early questions asked by the second author, as she began ethnographic work and queried language used for types of perinatal loss, experience of bereavement for parents, meaning of loss, and cultural elements that likely inform care, and bereavement including meaning of lost. Second, similarities and differences between the US and UK were critically discussed. Third, data gathered from the literature, internet websites, and professional organisations were recorded by the first two authors, shared with the team along with key data identified, such as sources of definitions of perinatal loss, legal documents, care provider standards (eg midwives, nurses, physicians) and research studies that addressed these issues. Fourth, implications for clinical practice were identified and critically analysed. Fifth, recommendations for future practice were generated.

Data analysis

Sense-making and critical appraisal of categories took place concurrently with data-collection. Significant elements were ranked in order of origin, and in full recognition that legal and definitional differences reflect contextualised culture. In turn, the impact of care that women, partners, and families receive during loss and subsequent support provided were critically analysed, and additional sources sought when more information was needed. Identification that the organisation of psychological care is often based on legal definitions, rather than on parents' needs, broadened data collection to examine immediate psychological support and later community-based support.

Interviews

Semi structured interviews were carried out by the US member of the team (DCA) to gather a broader picture of bereavement care provision in Scotland (UK). Sequential data-collection permitted viewing of this from multiple perspectives, which in this study included the views of parents who have experienced perinatal bereavement and the midwives who teach the topic and provide care.

Participants

Parents (8 mothers; 2 fathers) who had experienced perinatal bereavement were recruited via Held in Our Hearts charity (<https://heldinourhearts.org.uk/>) and through snowball sampling. Inclusion criteria for participation were (1) bereaved parent, (2) pregnancy (miscarriage or stillbirth) or infant loss in Scotland, to understand the general picture of views about bereavement care provided in Scotland being sought. Participants who opted to be interviewed were provided with informed choice prior to providing verbal consent. Ethical approval was granted via the university ethics committee (US and UK).

Interview data collection

The semi-structured interview schedule addressed participants' individual stories of perinatal bereavement and their experiences of support and care provided by both voluntary and statutory services. Interviews were carried out face-to-face in public places or via video conference and lasted between 45-90 minutes.

Interview data analysis

Interviews were transcribed verbatim, and read and re-read to identify preliminary codes. Short descriptive labels were allocated to sections of text, following which labels expressing similar concepts were grouped together to form themes (to be reported elsewhere). Three of the quotes have been selected to elaborate reportings in this paper.

Findings and discussion

Themed findings include:

1. Differences in definitions of miscarriage and stillbirth impact care pathways.

2. For the experiencer, grief is the same regardless of legal lines drawn.
3. The meaning of loss is personal and 'foetal personhood' needs to be acknowledged during care.
4. Appropriate psychological care is required whether miscarriage, stillbirth, or neonatal death is experienced.

What follows is a discussion of each of these themes in terms of comparison between the US and the UK.

1. Differences in definitions of miscarriage and stillbirth impact care pathways

There is a fundamental difference in the US and UK health care systems that we noted. US healthcare is paid for through either private insurance for those who can afford it, and government programs for those who qualify due to low income levels or other socioeconomic need. Thus, healthcare accessibility and equity are highly variable from private and public institutions; many lack access to adequate care (Schneider *et al*, 2021). In comparison, the UK has a universal healthcare system (National Health Service; NHS) with access for all.

In the US, a miscarriage is defined as loss of a baby before the 20th week of pregnancy, and stillbirth refers to loss of a baby at or after 20 weeks of pregnancy (CDC, 2023), with these definitions unlegislated. Due to inconsistency of terminology in the US, the American Academy of Pediatrics (AAP, 2016) suggested consistent definitions. It is noteworthy that this effort includes reporting requirements, which include state specified differences (Barfield *et al*, 2016 & AAP, 2016). Each US state has its own pregnancy and stillbirth reporting requirements, with management of care standards determined by major professional academies (eg the American College of Obstetricians and Gynecologists (ACOG, 2023) and American College of Nurse Midwives (ACNM, 2023). These differences reflect individual US culture of independent states, with all recognising the need for setting professional standards.

On the contrary, in the UK, there is a legal line drawn between miscarriage and stillbirth at 24-weeks that is then carried over to care provided. In contrast, in other countries, the

gestational line that separates miscarriage from stillbirth is drawn elsewhere. For example, Norway classifies this boundary at 16 weeks, Italy and Spain 26 weeks, and Australia 20 weeks. Also, it is challenging for maternity care experts to provide an accurate date of conception, with an Expected Date of Delivery (EDD) useful for informing what management pathway should be followed. Within the UK, the demarcation line between miscarriage and stillbirth is legislated in law by the Registration of Births, Deaths and Marriages Act (1965), which is a parliament act that altered pre-existing legislation to redefine stillbirth at 24 completed weeks in 1992. This legal line dictates that miscarriages are not registered in the UK¹, which then affects differing care provision between miscarriage and stillbirth. For example, the UK legal limit for Termination of Pregnancy (TOP) (Abortion Act, 1967) lies at 24 completed weeks gestation, consistent with the legislated line between miscarriage and stillbirth. Post this timeline, TOP is illegal except in the case of foetal anomalies, which has implications for management, treatment, and where care is provided. To assist decision-making, the Royal College of Obstetricians and Gynaecologists (RCOG, 2010) produced guidance that responded to medical advancements (eg 3D ultrasound and magnetic resonance imaging), which permit earlier diagnosis of congenital abnormality. In response, medical terminations are legal beyond the 24-week TOP limit.

The US legal story differs quite dramatically. For example, there is no national TOP law (referred to as abortion). Recent US Supreme Court decisions about abortion rights (Dobbs v Jackson; Constitution Center, 2022) has led to a mosaic of the 50-states legislating legal availability (or restrictions) of abortion services. As such, provision of care in the instance of incomplete abortion (spontaneous) or foetal anomalies varies state-by-state. Thus and at present, there is no guarantee of abortion rights for women and no national legislation that addresses this right at a whole US level.

A point of consistency between the US and UK relates to neonatal death, which is defined in both countries as the death of live born infant within 28 completed days of life. In addition, a live birth is defined as the infant taking a breath post-birth or having a heartbeat at any gestational age. In response, neonatal care is provided to support any live birth in both the US and UK (Table 1).

Now, returning to the effects that legal definitions have upon decision making. In the UK, obstetricians work alongside midwives who specialise in normal pregnancy and birth (NMC, 2019) while gynaecologists (also obstetricians) work alongside Registered General Nurses (RGN) (NMC, 2018), who care for female reproductive organs and are not qualified to participate in childbirth. Registered Midwives (RM) (NMC, 2019) care for women experiencing stillbirth, with miscarriage care usually carried out in an Early Pregnancy Assessment Service (EPAS), which specialises also in managing women with ectopic pregnancy, and monitoring women undergoing medical management. Differences between RMs (NMC, 2019) and RGNs (NMC, 2018) are fundamental, with different proficiencies underpinning each role. These variations in competency also effect distinctions in terminology used. For example, in the UK, RGNs (NMC, 2018) are not qualified to care for labouring or postnatal women. Also, in the UK, gynaecological wards are ordinarily situated in general hospitals, which geographically ordinarily sit separate to maternity units. Notably, and to match this situation, there are separate management pathways that direct care provided to women experiencing miscarriage, stillbirth, or neonatal death (National bereavement care pathway for pregnancy and loss, 2021).

In contrast, in the US, the majority of maternity care is provided by obstetricians, with very few Certified Nurse Midwives (CNM) or lay midwives (Institute of Medicine, 1989). CNMs hold academic degrees (Masters or Doctor of Nursing Practice) beyond their foundation nursing degree. Consistent with UK midwives, CNMs view pregnancy as a normal healthy state, and they provide holistic bio-psycho-social care for women across their childbearing journey. A small minority of women receive care from family physicians who elect to provide obstetric care, with their presence more common in rural, as opposed to urban, areas. When a woman's pregnancy status becomes high risk, care is either managed collaboratively or transferred to an obstetrician or Maternal Foetal Medicine (MFM) physician. In the US, obstetricians are also gynecologists and surgeons, and they provide health care across womens' lifespans. There are also gynecology wards in hospitals that care for women with female reproductive medical issues, and high-risk antepartum units in urban centers for women who need in-hospital care during

Table 2: UK Nursing and Midwifery Council (NMC) standards of proficiency for midwives that relate to perinatal bereavement (NMC, 2019)

6.80	Work in partnership with the woman, her partner and family as appropriate, and in collaboration with the interdisciplinary and/or multiagency team, to plan and implement compassionate, respectful, empathetic, dignified midwifery care for women and/or partners and families experiencing perinatal loss or maternal death, and demonstrate the ability to:
6.80.1	Provide care and follow up after discharge to women and/or families experiencing miscarriage, stillbirth, or newborn infant death, and understand the care needed by partners and families who experience maternal death.
6.80.2	Provide end of life care for a woman or for a newborn infant the woman's, father's/partner's, and family's wishes and religious/spiritual beliefs and faith.
6.80.3	Arrange provision of pastoral and spiritual care according to the woman's, father's/partner's, and family's wishes and religious/spiritual beliefs and faith.
6.80.4	Support and assist with palliative care for the woman or newborn infant.
6.80.5	Offer opportunities for parents and/or family to spend as much private time as they wish with the dying or dead infant or woman.
6.80.6	Support the parents of more than one newborn infant when a newborn infant survives while another dies, recognising the psychological challenges of dealing with loss and bereavement and adapting to parenthood at the same time.
6.80.7	Provide care for the deceased woman or newborn infant and the bereaved, respecting cultural requirements and protocols.
6.80.8	Support the bereaved woman with lactation suppression and/or donating her breastmilk if wished.
6.80.9	Provide clear information and support regarding any possible post-mortem examinations, registration of death and options for funeral arrangements and/or a memorial service.

pregnancy. In-hospital bedside care is provided primarily by Registered Nurses (RNs) within antepartum, labour and delivery, neonatal, and postpartum wards in conjunction with medical doctors (National Academies, 2020).

The research team recognised that legal and policy statements are very much culturally constructed. For example, the UK has liberal abortion and termination laws, which are accepted by much of the population (Aiken *et al*, 2021). In contrast, within the US, there are wide legal differences, with currently 18 of the 50 states having limits <22 weeks gestation. In addition, 6 states and the District of Columbia have no gestational age limit for abortion. However, the majority (61-80%) of the US adult population favour women's access to abortion (Gallup poll, 2022). To compare, in the UK, the 24-week line makes a clear statement that losses prior to this line are less significant than perinatal loss beyond 24-weeks. Support for this assessment includes maternity leave policy and certificate of remembrance being issued after 24-week loss, with neither available to mothers who experience a miscarriage.

The contrast between the US and the UK is two-fold. The UK distinct line at 24-weeks gestation (Abortion Act, 1967) and its accompanying guidelines (National bereavement care pathway for pregnancy and loss, 2021), do not exist in the US at a national level. Instead, some states and some employers provide brief work leave, and the national Family and Medical Leave Act (FMLA, 1993) can sometimes apply to couples with no national guarantee (US Department of Labor, 2022). The FMLA (1993) offers up to 12-weeks unpaid leave, and ensures return to work job security. US guidelines that effect care delivery provided by nurses or midwives' do not exist. Alternatively, several sources of standards exist, with no US national source. In contrast, the UK Nursing and Midwifery Council (NMC) have published standards of proficiency for midwives that relate to perinatal bereavement (NMC, 2019) (see Table 2). Midwives are expected to follow these guidelines.

In the UK, midwives deliver stillborn babies, and follow processes directed by guidelines (National bereavement care pathway for pregnancy and loss, 2021), which are underpinned by research evidence (NICE, 2020). When perinatal loss occurs prior

Table 3. Organisations and websites for US perinatal bereavement training

Organisation	Website
Resolve through Sharing	www.resolvethroughsharing.org/
National Share	Nationalshare.org
Star Legacy	Starlegacyfoundation.org
The American College of Obstetricians and Gynecologists (ACOG)	acog.org
Association of Women’s Health, Obstetric & Neonatal Nurses: Perinatal Orientation and Education Program (POEP4) Module 14: Perinatal Loss	www.awhonn.org/education/perinatal-orientation-and-education-program-fourth-edition-poep4/
Return to Zero HOPE	https://rtzhope.org/

to 24-weeks gestation, care is directed by separate guidelines (NICE, 2019) that lead care depending upon diagnosis (eg early miscarriage, ectopic gestation, missed abortion etc).

In contrast, in the US, medical management depends upon condition of mother and foetus, and is not dictated explicitly by gestational age. Instead, the management approach of an intrauterine demise (ie foetal death without full expulsion of products of conception) depends upon the size of the foetus. In the case of preterm labour involving periviable foetuses (22-23 weeks), treatment with tocolytic medications to slow or stop uterine contractions and maternal hospitalisation is often prescribed, in hopes of continuing the pregnancy until the foetus reaches viability. In such cases, practice guidelines are provided by care provider’s respective professional organisation (eg ACOG, 2023; ACNM, 2023). In addition, nursing guidelines for physical and bereavement care are often defined by place of employment and underpinned by professional organisations’ recommendations (eg AWHONN, 2022; PLIDA, 2022) (see Table 3). Although there is no single agency that has agreed upon guidelines for physicians, nurses, and midwives in the US, there is overall agreement about what care should look like for women, partners, and families experiencing early and late pregnancy loss and infant death.

2. For the experiencer grief is the same regardless of legal lines drawn

It quickly became obvious that regardless of where legal gestational lines are drawn, the

social identity of the foetus is formed by parents anytime post conception (van den Akker, 2011). Parents, most particularly women, often form early emotional bonds to their unborn child irrespective of gestational age. Hence and regardless of where the line is drawn, a grief process will begin in most parents, which is accompanied by a sense of loss, profound sadness, and other related emotions. A mother’s words illustrate her experience: *‘This might shock you, but because [baby] was before 24 weeks I was only entitled to 3 days paid off work. Bereavement policy is all wrong’.*

A responsive grief process has been confirmed through neuroimaging, which has revealed higher inflammation and cortisol dysregulation amongst those who experience greater psychological grief (O’Connor, 2019). The reason for greater grief may be due to the magnitude of ‘foetal personhood’ ascribed to the lost baby.

3. The meaning of loss is personal and ‘foetal personhood’ needs to be acknowledged during care

Acknowledging that grief is a natural journey, it is important to personalise every foetal loss in line with the experiencer’s assignment of ‘foetal personhood’ (Côté-Arsenault & Dombeck, 2001). Each woman and her partner’s personal sense of what has been lost (eg a pregnancy, a baby, or a baby with a name), should be assessed whilst care is given. The parents often have differing views of ‘foetal personhood’, which may occur for a variety of reasons, but most obviously due to the fact that the woman physically carries the foetus. Assignment of ‘foetal personhood’ may

also change over time, as the impact of the loss is acknowledged. For parents, the meaning of loss is more often related to assignment of 'foetal personhood', and not gestational age (Côté-Arsenault & Dombek, 2001). A woman's sense of 'being pregnant' customarily evolves overtime into 'having a baby', as foetal movements increase. Naming of the baby and having a memorial or funeral service also designates even greater personhood. To provide high-quality psychosocial care, it is important to recognise how each parent refers to their baby. If a name has been given, it should be recorded in the case-notes and used by the care provider. This action will psychosocially remove the outward facing impersonal label of miscarriage or stillbirth, which is used to direct physical management down its appropriate clinical pathway.

One major finding of this study, is that regardless of what guideline is activated in either the US or UK, the bereaved parents' psychological needs are more similar than different. As such, legal definitions of losses should not dictate parental needs. Also, in the instance of impending loss (eg threatened abortion), women may be seen in the emergency department, where nurses and physicians may not be prepared to provide informed and sensitive care. In addition, the reporting requirements for pregnancy loss vary by US state, with no formal certificates provided to acknowledge miscarriage, with some states issuing stillbirth certificates. In terms of funeral arrangements, cremation and group burial is commonly offered across the US, with private burial an option provided by some funeral homes free of charge. In addition, postnatal follow-up and bereavement support is usually available from hospital nurses with specialised training (eg Resolve Through Sharing or Share). There are also many perinatal loss support charities across the US that offer support groups for all types of loss (Table 3).

It should be noted that it is important to ensure that language used is sensitive to personalising the 'foetal person' in both miscarriage and stillbirth care pathways. Communication must be sensitive and clear, along with providing adequate opportunity for parents to ask questions (Aiyelaagbe *et al*, 2017), with high quality psychological care shown to reduce emergent pathological grief (Kersting & Wagner, 2012). One interviewed midwife stated: *'I think there is a rank disregard of women's experiences and what they*

mean. And the loss and bereavement are still a death, you know, they're still not widely acknowledged.'

Whether spoken or written, the term 'miscarriage' trivialises status of 'foetal personhood', with grief endured often as intense as that experienced post-stillbirth. In the UK, legal documentation prior to 24-weeks does not acknowledge the 'foetal person' as a registered birth, which seems to have resulted in stillbirth research excluding discussions about psychosocial impact of miscarriage (Burden *et al*, 2016). Yet in the modern context and to maintain a permanent connection, regardless of gestational age of foetal death, it has become commonplace for women to have their baby's name tattooed on their body (Davidson, 2017). Hence, referring to the miscarried baby by the parents' chosen name shows understanding that continued identity of their child is important. Parents in the US have reported feeling that their grief is disenfranchised, post either miscarriage or stillbirth (Cacciatore, 2013). This disenfranchised grief is often ascribed to lack of recognition of the loss by society, family, friends, and sometimes health care providers. As such, acknowledgment of all perinatal losses should be directed in clinical care standards.

4. Appropriate psychological care is required whether miscarriage, stillbirth or neonatal death is experienced

There is an apparent social differentiation between perinatal loss through miscarriage, stillbirth, or neonatal death in both the US and UK (Mergl *et al*, 2022). Reasons for this may be the presence of a formed baby later in pregnancy contributing to increased recognition and the legal and medical line of 24 weeks gestation. Along with this, another reason may be the common silence that often accompanies hidden death, with miscarriages often occurring at home and in isolation. In contrast, later losses usually entail labour and birth and its accompanying provision of psychological care in a hospital setting.

The legal demarcation of 24 weeks in the UK clearly dictates the line between miscarriage and stillbirth, and this has implications regarding the perceived value of the pregnancy/baby. In addition, it demarks the line when motherhood (and thus maternity leave benefits) start, the limit where abortion is no longer allowed, and the

standard of care to be used by midwives. In the UK, a miscarriage is not formally registered, with most hospitals providing a certificate to mark the loss upon request.

As shared by a UK mother: *'She was 23 weeks, 4 days;...because she wasn't 24 weeks, they couldn't register her birth. I mean, she was born...[but lacks] the recognition that she was born, because she doesn't exist on any paper. I think that was what upset me, because they she wouldn't be recorded to be born...That was a tough time.'*

In the UK, such parents may be offered the option of having a memorial, burial service, or cremation. In contrast, when a stillbirth occurs, a specialist midwife will discuss whether parents want to hold their baby, take photographs, and explain tests designed to identify why their baby died (Hollins Martin & Forrest, 2013). In contrast to miscarriage, in the UK, stillborn babies must be registered. In England and Wales, registration must be completed within 42 days of the baby's birth and within 21-days in Scotland. In Northern Ireland, stillbirths do not require to be registered, but can be if parents request this within 1 year of birth. Also post stillbirth, a follow-up appointment is issued around 6 weeks post-loss, to check women's health, give post-mortem and test results, and discuss possibilities for future pregnancy. Dependent upon the UK NHS Health Board, a bereavement support officer, midwife, or health visitor may act as a point of contact.

Level of psychological support provided is a significant predictor of women coping and adjusting post-perinatal bereavement (Murphy & Cacciato, 2017). A systematic review and meta-analysis by Burden *et al* (2016) analysed 144 international studies that reported on grief experienced post miscarriage, stillbirth, termination of pregnancy due to foetal anomaly, and neonatal death, and associated guilt, disenfranchisement, and envy of others. Currently in the UK, there is no direct pathway for detecting and treating women who are experiencing depression, complicated grief syndrome, PTSD, or Complex-PTSD after any type of perinatal bereavement (Bromley *et al*, 2017; Hollins Martin *et al*, 2021a). Although bereavement pathways have been developed in the majority of maternity units in the UK, care provided is 'patchy' and does not routinely screen for PTSD/CPTSD using scales such as

the International-Trauma-Questionnaire (ITQ) (Cloitre *et al*, 2018). In the UK and in relation to care provided, In the UK and in relation to care provided, the National Bereavement Care Pathway (NBCP) (2018) endorses that 9-standards be charted:

- (1) A parent-led bereavement care plan is in place for all families, providing continuity between settings and into any subsequent pregnancies.
- (2) Bereavement care training is offered to staff who come into contact with bereaved parents, and staff are supported to access this training.
- (3) All bereaved parents are informed about and, if requested, referred for emotional support and for specialist mental health support when needed.
- (4) There is a bereavement lead in every healthcare setting where a pregnancy or baby loss may occur.
- (5) Bereavement rooms are available and accessible in all hospitals.
- (6) The preferences of all bereaved families are sought and all bereaved parents are offered informed choices about decisions relating to their care and the care of their babies.
- (7) All bereaved parents are offered opportunities to make memories.
- (8) A system is in place to clearly signal to all health care professionals and staff that a parent has experienced a bereavement to enable continuity of care.
- (9) Healthcare staff are provided with, and can access, support and resources to deliver high quality bereavement care.

To compare, in the US, care provided is primarily dependent upon whether-or-not the woman is admitted to hospital. Outpatient psychological care lacks consistency and standards between states. Postpartum depression is often assessed using a self-report validated scale (Thombs *et al*, 2014), and PTSD screening is not done post loss or otherwise. On this point, there is consistency between the UK and the US, with lack of attention paid to screening for mental health problems post perinatal loss. However, in full recognition of differences represented in guidelines, regardless of where gestational lines are drawn and what country a woman resides in (O'Conner, 2019), a grief process will likely

be activated, which may or may not become complicated grief (Hollins Martin *et al*, 2021a).

Theme 2 acknowledges that grief experienced is similar regardless of where the legal gestational line is drawn (van den Akker, 2011), which has implications for provision of perinatal bereavement care. At present care is organised in pathways, which are defined in the UK as before or after 24 completed weeks gestation (Registration of Births, Deaths & Marriages Act, 1965). Physical care pre and post this line often differs, yet psychological management could perhaps be similar. Regardless of where the line is drawn, which differs between countries (see Theme 1), the Perinatal Bereavement Grief Scale (PBGS) (Ritsher & Neugebauer, 2002) could be used as part of routine care. The PBGS has been designed to measure grief following reproductive loss in terms of yearning for the baby regardless of gestational age at time of loss. The PBGS has high internal consistency and test-retest reliability and can distinguish between grief and depression (Ritsher & Neugebauer, 2002). Also, the PBGS could enable study of the epidemiology and prognostic value between defined pathways and care provision and could be routinely used to detect psychological maladaptation to perinatal loss.

Irrespective of the US, UK, and all other countries around the world, what we know is that women grieve, and that the grief process is neuro-physiologically wired (Silva, 2014), with the entirety of written works about grief and individual experience informed by cultural values (Rosenblatt, 2008). Given that we know all humans have these neuro-physically wired grief pathways (Silva *et al*, 2014) and in relation to the identified Theme 4 which recognises that appropriate psychological care is required whether miscarriage or stillbirth is experienced, this supports the idea that carers could build flexible cultural embedded psychological toolkits that promote self-care. Just one example is Compassionate-Mind-Training (CMT) (Hollins Martin *et al*, 2021b), which cultivates compassion, teaches self-care strategies, builds resilience, and reduces self-criticism and threat-based emotions. CMT develops understanding of cognitive biases and unhelpful thinking patterns that are directed by genetics and the environment (Gilbert, 2014; Gilbert *et al*, 2017). CMT teaches balance between psychological threat, drive, and the soothing systems, through a 3-way flow of

compassion: (1) delivering compassion to others, (2) accepting compassion from others, and (3) developing compassion towards self. To stabilise emotions and create self-soothing, CMT improves ability to cope and lessens perceptions of threat and danger (Beaumont & Hollins Martin, 2016; Durkin *et al*, 2016; Hollins Martin *et al*, 2021a&b; Gilbert, 2014). Whilst many bereaved parents experience trauma through perinatal bereavement, there are some who experience posttraumatic growth. This idea acknowledges that personal growth can occur following a life crisis and can help build resilience for future living (Tedeschi & Calhoun, 2004; Tedeschi *et al*, 2007).

Implications and conclusions

This exploratory qualitative comparative study has shown that perinatal bereavement care provided in both the US and UK is more similar than different, with both cultures recognising that strategies are needed to encourage women and their partners to be open about their grief. In both countries there are bereaved families who feel isolated and lack support due to geographic distance or lack of sensitive care provision. Also, some variables are inhibiting progress of psychosocial care provided. For example, differences in gestational lines drawn between miscarriage and stillbirth are reflected in health care organisations, with this division echoed by support charities. For example, in the UK, the Stillbirth and Neonatal Death Society (Sands, 2022) attend to those who have experienced perinatal death post 24-weeks, and the Miscarriage Association (2023) offer psychosocial care to women prior to this 24-week demarcation line.

Comparatively, in the US, there is usually no differentiation between miscarriage and stillbirth support groups. However, in larger organisations, early loss and late loss groups might be offered when there are different parental needs. For example, parents may be most comfortable amongst others who have had more similar experiences.

The purpose of this comparative paper was for experts in psychosocial delivery of perinatal bereavement care in the US and UK to learn from one-another's expertise, which was the focal event of our study. Since many maternity care experts feel ill-equipped to deliver psychosocial

elements of perinatal bereavement care (Steen, 2015; Stolberg, 2011), it is important to continue to improve standards and consistency of care provided. The first identified key area relates to arbitrary gestational lines drawn between miscarriage and stillbirth, which vary between the US (20 weeks) and UK (24 weeks), which for the experiencer holds little meaning. Acknowledging that the woman, partner, and family have lost 'someone' and not 'something' is important, with recommendation made that the 'foetal person' is acknowledged by a chosen name, which is recorded in the clinical notes. A second key area noted, is that while physical care varies by gestational age along with management, psycho-social care should be driven by woman, partner, and family needs. Hence, regardless of whether the miscarriage or stillbirth pathway is followed, language used must be sensitive towards individualising the 'foetal person', if that is what the parents are doing. Whilst there may be sound reasons to have separate miscarriage and stillbirth support groups due to individual experiences of loss (eg passing tissue versus holding a still baby), this division should not be solely based upon strict gestational lines. The grief experienced is likely to be similar, with the commonality of stories and memories shared in support groups potentially driving group differences.

In response to our discussions, we recommend that all carers who encounter grieving couples engage in basic training on the unique aspects of perinatal bereavement, communication that conveys caring and not minimalising, and sharing of resources about bereavement support from charities (Leitaoa *et al*, 2021; Wool & Catlin, 2019).

To summarise, perinatal bereavement interventions vary and are used inconsistently across countries and cultures. Reasons for this include culture, education, healthcare payment systems and sponsorship, content, and level of training of health care professionals, and what evidence is used to inform hospital guidelines, protocols, and standards. Regardless of what type of perinatal loss has been experienced (ie, miscarriage, stillbirth, neonatal death), there can be profound long-term injurious psychological, physical, and social impacts for the experiencer. Hence, it is important to advance research in this area at both a national and international level.

Limitations

The authors recognise limitations of their study. The first limitation being that only three perinatal bereavement experts took part in the study, all three of whom are published scholars. Nonetheless, it is important to note that findings were informed by literature and other data sources. Second, although the study was time-limited, the researchers spending three months together has generated some inspirational concepts, with generation of new recognitions of multiple influences that effect perinatal bereavement care. Recognising that culture fashions, influences, shapes, and restricts how systems of care develop (Rosenblatt, 2008), comparisons in perinatal bereavement care between the US and UK have been informed by individual experts' learning, experience, and personal research into systems of delivery in their country of origin. Also, theorising about processes and developing pathways for delivering perinatal bereavement care must be guided by research. In this instance, research specifically designed to develop care provided to grieving women, partners, and families at a holistic level (ie, physically, psychologically, and socially). Beyond this, it is theoretically important to understand cultural variances, with disparities between the US and UK informing ideas that have potential to improve standards of care in both places. In addition, terminology definition differences should be noted and taken into account when reviewing reported research from various countries.

Note

1. In England, from February 2024, if a woman's pregnancy ends before 24-weeks' gestation, an optional free certificate can be applied for at: <https://www.gov.uk/request-baby-loss-certificate>.

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