Parental Bereavement Following Perinatal Loss: A Qualitative Exploration of Support Experiences and the Role of Milk Donation

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Dedication

This thesis is dedicated to the memory of the Poppy, Aris, Rebecca*, Naiomi, Artemis, Angus, Layla, and Giai, whose lives are honoured within these pages, and to their mothers who shared their experiences with courage and generosity. Without their trust, insights, and voices, this research would not have been possible.

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And to my Mum: thank you for a lifetime of encouragement and support for every academic and professional goal I’ve ever set. Your constant presence in my life, your help with keeping my home running, and your quiet pride (even if you’re not always sure exactly what I’m doing!) have carried me through more than you know. The hard work, resilience, and determination you demonstrated throughout my childhood was an example to me, and has made this achievement possible. I hope I’ve made you proud in return.

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This work is dedicated to my Mum and to my son, Alex, two of the greatest influences in my life. To my Mum, whose hard work and love made this achievement possible. To Alex, who gives me the reason, strength, and purpose to keep going. You are both at the heart of everything I do.

Some lessons in life come disguised as endings. Others become the ashes from which new stories begin.

Chapter 1

Parental Experiences of Psychological and Psychosocial Support Following Perinatal Bereavement: A Systematic Review of Qualitative Research

Prepared in accordance with the author requirements for Death Studies; https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=udst20

Abstract

Parents who experience perinatal bereavement are at increased risk of psychological distress. While psychological and psychosocial support can help, the most beneficial aspects remain unclear. This review synthesised qualitative research on parents' experiences of support following perinatal loss to identify what aids recovery. A systematic search across seven databases (PubMed, PsycINFO, ScienceDirect, PsycARTICLES, ProQuest, CINAHL, and SCOPUS) identified ten qualitative studies. Studies were appraised using the CASP checklist, and thematic synthesis (Thomas & Harden, 2008) was applied. Seven descriptive themes were organised into three analytical themes: (1) Experiencing Support: Relational and Emotional Containment, (2) The Form and Function of Intervention: What Makes Support Work, and (3) When Systems Fail: Barriers, Silences, and Structural Exclusion. Parents valued compassionate, validating care that acknowledged their loss and identity. Symbolic practices and personalised, timely support were also important. Barriers included institutional insensitivity, inconsistent access, and marginalisation of fathers' grief. Findings underscore the importance of inclusive, flexible, and emotionally attuned approaches that validate parents' grief and affirm the baby's identity.

Key Words: Perinatal Bereavement, Psychosocial Support, Psychological Intervention, Qualitative Research, Parental Grief, Systematic Review

Introduction

Perinatal bereavement, defined as the loss of a child during pregnancy through to the first year after birth, including stillbirth, neonatal death, and pregnancy loss, is a deeply traumatic and multifaceted experience for many parents. Globally, it is estimated that perinatal loss affects up to 30% of pregnancies, equating to over 6.3 million perinatal deaths annually (Blackmore et al., 2011; Gaudet et al., 2010;). These losses represent not only the death of a baby but also the loss of anticipated roles, hopes for the future, and a coherent family narrative. The loss can dismantle a parent's sense of identity and sever psychological ties to a longed-for future, often accompanied by feelings of bodily failure or disconnection (Garrod & Pascal, 2019).

This loss often encompasses not only the physical but also the symbolic and social dimensions of becoming a mother or father, which are deeply connected to personal identity, bodily experience, and cultural validation (Rossen, Opie & O'Dea, 2023). This lack of recognition can hinder the grieving process, as parents struggle to find meaning and validation for their loss within their cultural and social contexts (Norwood & Boulton, 2021). Rates of depression are four times higher among bereaved mothers than non-bereaved peers (Gold et al., 2016), with around 20% experiencing clinically significant symptoms a year later (Badenhorst & Hughes, 2007).

Complicated grief is often misunderstood and under-recognised in the context of perinatal loss. Disenfranchised grief, where the grief is not openly acknowledged or socially validated, can exacerbate these feelings. Lang et al. (2011) conducted interviews with 13 bereaved couples in Canada and identified several sources of ambiguity and disenfranchised grief, including societal minimisation of the loss and lack of support from healthcare professionals. This lack of societal validation can reinforce feelings of isolation, guilt, and psychological anguish.

In response to the complex and far-reaching impacts of perinatal bereavement, a variety of psychological and psychosocial interventions have been developed to support parents. These include cognitive-behavioural therapy (CBT), grief counselling, mindfulness-based therapies, peer and support groups, midwife-led bereavement care, and trauma-informed interventions. The rationale for these interventions is rooted in psychological models of grief, trauma recovery, cognitive reframing, and relational healing. A systematic review and meta-analysis by Li et al. (2024) assessed 21 randomised controlled trials and found that nonpharmacological interventions significantly improved grief, posttraumatic stress disorder, depression, anxiety, and perceived social support among parents who experienced perinatal loss. The study highlighted that cognitive-based interventions, face-to-face delivery modalities, and individual-based formats with four or fewer sessions were particularly effective. Mindfulness-based interventions (MBIs) have also shown promise, in a systematic review by Dolan et al. (2022) comparing MBIs and CBT in reducing symptoms of complicated perinatal grief. The findings indicated that both interventions produced favourable reductions in perinatal grief symptoms, depression, and posttraumatic stress.

Shaohua and Shorey (2021) found that online peer-support groups following perinatal bereavement are effective and accessible modalities for parents facing geographic, economic, or cultural barriers to in-person care, demonstrating feasibility, acceptability, and reductions in grief intensity, stress-related outcomes, and depression. Interventions embedded within maternity and neonatal care, delivered by nurses, midwives, or specialist bereavement teams, can provide continuity and validation at critical moments of vulnerability. A further review by Xie et al. (2024) demonstrated that midwife/nurse-led psychosocial interventions have the potential to improve grief, anxiety, depression, posttraumatic stress disorder symptoms, and other psychosocial outcomes for parents experiencing perinatal loss.

Despite growing evidence for the efficacy of these interventions, existing research is disproportionately weighted toward quantitative studies, such as randomised controlled trials and outcome-based evaluations. While these studies are indispensable for measuring intervention effectiveness, they frequently lack the depth to capture the emotional, relational, and existential dimensions of bereaved parents' experiences. While essential for measuring effectiveness, quantitative studies often overlook the emotional and relational dimensions of grief. As such, many of the most human aspects of care, such as being heard, feeling safe, or experiencing compassion, are under-explored or entirely omitted. Additionally, quantitative studies often neglect to investigate why some parents disengage or decline support altogether, thereby failing to illuminate barriers to engagement such as stigma, mistrust, previous trauma, timing, or perceived irrelevance of services.

Qualitative studies offer vital insights into how bereaved parents interpret therapeutic encounters and which aspects of care feel meaningful or harmful. These insights are vital for developing interventions that are person-centred, culturally competent, and adaptable to varied grieving trajectories. For example, Jones, Albanese, and Boles (2023) explored bereaved parents’ perceptions of legacy and remembrance, highlighting that emotional connection and being genuinely acknowledged in grief were key contributors to healing, elements often absent in structured or overly medicalised support. Understanding how parents experience psychological and psychosocial interventions allows clinicians and service designers to refine not only the content of interventions but also their delivery, tone, and context.

A further limitation of the current literature lies in its demographic focus. Research on perinatal bereavement support has historically centred mothers, with comparatively little exploration of the experiences of fathers, same-sex parents, trans or non-binary individuals, and people from racially minoritised or low-income communities (Salgado et al., 2021). This skewed focus risks marginalising those whose grief may already be unrecognised or unsupported, and may reinforce systemic inequities in access to care. Furthermore, qualitative insights into barriers to engagement are lacking, despite evidence that many parents do not access formal support even when available.

Some prior reviews of interventions for perinatal bereavement date back decades and lack relevance to current clinical practice or service configurations (Lasker & Toedter, 1994). Importantly, the relational and emotional dimensions that underpin effective bereavement care remain under-theorised and under-synthesised at the review level. For example, Jonas-Simpson et al. (2013), in a qualitative study exploring nurses' experiences of grief following perinatal death, emphasised how emotional and relational dynamics are central to the care experience but often go unacknowledged in formal service design. There is therefore an urgent need to integrate contemporary, high-quality qualitative evidence to inform therapeutic approaches that are effective, acceptable, and meaningful to parents bereaved in the perinatal period.

This systematic review aims to synthesise qualitative literature exploring parents' experiences of psychological and psychosocial interventions and support following perinatal bereavement. By centring parental voices, it will highlight the emotional, relational, and contextual dimensions of support that are often absent in quantitative evaluations. The review will contribute to clinical knowledge by illuminating how parents engage with support, what they find beneficial or detrimental, and how these experiences can inform the design, and delivery of future interventions. By synthesising qualitative evidence, this review aims to bridge the gap between clinical efficacy and personal experience, ultimately informing therapeutic practices that are both evidence-based and empathetically grounded.

Aims and Research Questions

The primary aim of this review is to synthesise qualitative evidence on how parents experience psychological or psychosocial interventions and supports following perinatal bereavement. The two central research questions guiding this review are:

1. What are the experiences of psychological or psychosocial intervention or supports for parents who have experienced perinatal bereavement? (RQ1)
2. What do parents perceive as the most beneficial aspects of psychological or psychosocial support in their recovery, healing, and grief process? (RQ2)

Given the increasing number of qualitative studies exploring parents' lived experiences, a systematic review of qualitative literature is both timely and necessary.

Methods

Registration

This review will follow ENTREQ (Tong, et al., 2012). reporting guidelines to ensure methodological rigour. In accordance with reporting guidelines, this systematic review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO) on 29th May 2025.

Search strategy

Following an initial scoping search a full search strategy was developed, discussed and agreed with a university librarian. Search terms using SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, and Research type) criteria can be found in Table 1 (Cooke, Smith, & Booth, 2012). An example of a complete search strategy can be found in Appendix 1.3 (p80). The search strategy was adapted to contain relevant syntax for each database searched. Seven electronic databases were searched on 14th April 2025, and were as follows:

- Pubmed
- ScienceDirect
- PsychINFO (EBSCOhost)
- CINAHL
- ProQuest
- PsychARTICLES
- Scopus

Table 1. SPIDER Search Terms

SPIDER Criteria	Example Term Used
Sample: Parents who have lost a child from pregnancy – 1 year post birth; Adults aged 18-99	Antenatal loss; Perinatal loss; Baby loss; Fetal loss (foetal); Fetal death (foetal); Prenatal loss; Still-birth (stillbirth, still birth); perinatal death; Women (woman); men (man); mother; father; maternal; paternal; parents
Phenomena of Interest: Psychological or Psychosocial interventions and supports	Psychology (psychological) intervention; Psychological support; Psychosocial intervention; Psychosocial support; Group intervention; Group; Support; Intervention
Design: Published literature of any qualitative design	Grounded theory (analysis); Case study; Ethnography; Narrative analysis; Focus group; Interpretative phenomenological analysis; Content analysis; Interviews; Thematic analysis; Discourse analysis; Qualitative; Hermeneutic analysis; Qualitative interviews
Evaluation: Experiences of interventions; Important aspects of interventions; Beneficial aspects of interventions; Aspects that cause reduction in negative grief related symptoms; Aspects that caused improved coping mechanisms/psychological wellbeing/ grief recovery	Attitude; View; Perception; Perspective; Feeling; Thought; Experience; Lived experience

Limits were added to searches in terms of population (“Human”), language (“English”), and print type (“Excluding books”). Forwards and backward citation searching was carried out on included papers to reveal any additional relevant papers. Reference lists of relevant systematic reviews were also screened for further papers. Results of the searches were exported to Rayyan reference management software (Ouzzani et al., 2016).

Inclusion/Exclusion Criteria

Eligibility criteria is listed below.

Table 2. Systematic Review Inclusions and Exclusion Criteria

	Inclusion	**Exclusion**
Participants	Parents (mothers/fathers) of any age who have experienced the loss of a child from pregnancy through to 1 year post-birth who have engaged in or received some form of psychological or psychosocial intervention or support for their grief.	Those who have experienced perinatal loss but have not engaged in or received any type of psychological or psychosocial support for their grief
Study Focus	Studies focused on experiences of support and interventions for perinatal grief	Studies solely focused on the experiences of health professionals or those of extended family members of perinatal grief
Outcome	Experiences of psychological or psychosocial interventions and supports, narratives of therapeutic processes, views on helpful and unhelpful aspects in grief support	Experiences solely of the death and grief outside of the context of the intervention / support experienced
Language & Article Type	Articles in English.	Articles in languages other than English. Systematic reviews.
Publication Type	Journal articles, grey literature, industry reports, dissertations	Book chapters
Methodology	Qualitative studies	Quantitative studies or mixed-method studies.

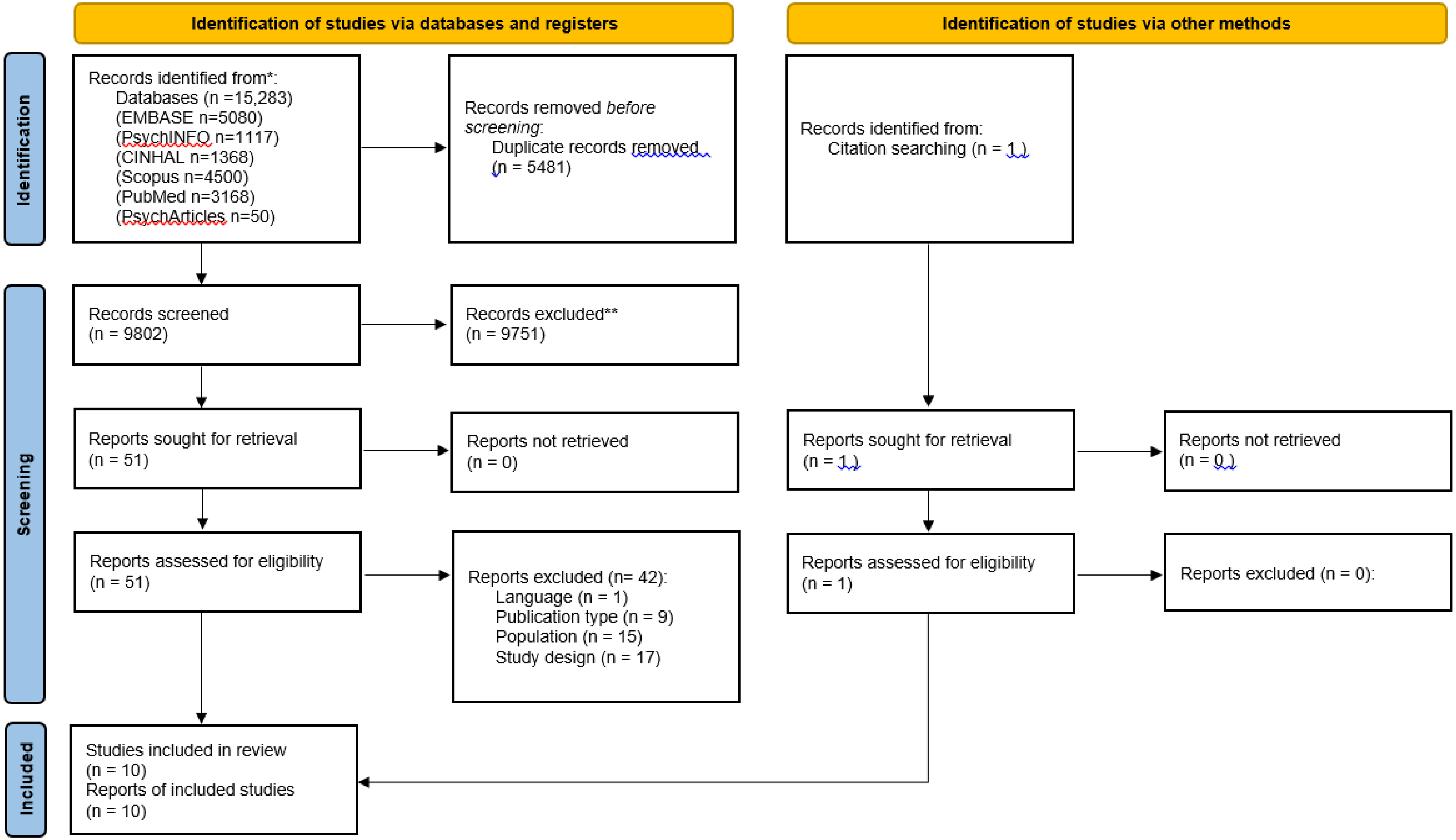
Review Process

Following the collation of 15,283 articles 5481 duplicate articles were removed prior to screening for eligibility. This was firstly performed automatically by the reference management software, and manually checked by the reviewer. The first phase of screening involved reviewing titles and abstracts of all identified articles (N=9802) and was carried out by the primary author. Eligible articles and those of uncertain relevance were included for second stage screening which involved a full text review (N=51). Of the 51 articles eligible for full text screening 8 were initially unavailable. The primary author requested these be sourced via the university library's inter-library loan service. All 8 papers were sourced on loan from partner universities.

The primary author then read the full articles of all 51 papers and identified those meeting criteria for data extraction. A second reviewer (Trainee Clinical Psychologist) was involved in screening a sample of papers at each stage of the screening process, screening a sample of titles and abstracts (980/9802), and a sample of full text papers (5/51). Initial interrater concordance was 96% (940/980) at title and abstract stage. Differences occurred regarding ambiguity of the papers relevance to the review, analysis methods, and participant ages. These discrepancies were discussed and resolved to reach 100% consensus. Interrater concordance was 100% (5/5) at full text screening stage.

Backwards and forwards citation searching was carried out on the nine included papers, and one additional paper was found to be suitable for inclusion. The final results of the screening process can be found in a PRISMA diagram in Figure 1.

Figure 1. PRISMA Study Identification and Screening Process



Data Extraction and Quality Appraisal

A data extraction tool was developed by the primary author (Appendix 1.4, p,82) which was used to extract key characteristics and results from each paper individually. The Critical Appraisal Skills Programme (CASP) Qualitative Checklist (Appendix 1.2, p79) was used to assess the methodological quality of included studies. This tool consists of ten questions designed to evaluate key aspects of qualitative research, including clarity of aims, appropriateness of methodology, ethical considerations, rigour of data analysis, and the value of the findings. CASP is particularly suited to this review due to its focus on interpretive depth, reflexivity, and methodological coherence, which are essential for appraising studies exploring lived experiences. Its use ensures consistency and rigour in assessing the quality of the included qualitative literature. The outcome of this appraisal process can be found in the results section of the paper.

Reflexivity

The primary author is a Trainee Clinical Psychologist who is currently carrying out separate research in the area of perinatal bereavement. It has therefore been important to maintain awareness of not over identifying any narratives from that research within these papers and this review.

The primary author is a mother of one living child and has previously accessed hospital based maternity care services. She has not experienced baby loss either directly or indirectly in her personal life. It has been important throughout this research to engage in continual reflective and supportive supervision when dealing with the subject matter of this review. The primary author received regular non-academic supervision from her field supervisor (Consultant Clinical Psychologist in Maternity and Neonatal Psychological Interventions) to support with processing the emotional impact of this research. An example of the primary authors' reflective diary can be found in Appendix 1.6 (p86).

In addition, this dataset is examined through the lens of an early-thirties white female with no experience of baby loss. This is important to consider given that a number of the papers were exploring the experiences of fathers, black mothers, or young teenage mothers. All of the above factors in relation to the primary author were explored through the use of reflective diaries and supervision.

Thematic Synthesis

The results of the studies were synthesised using thematic synthesis, following the approach outlined by Thomas and Harden (2008), which is particularly suited to integrating findings from diverse qualitative studies. This method was chosen due to the heterogeneity across the included literature in terms of research questions, populations, and analytical focus. The synthesis process involved three key stages. First, all text labelled as 'results' or 'findings' in the primary studies was coded line-by-line, generating initial descriptive codes that remained closely grounded in the original data. These codes were then organised into related areas to develop descriptive themes that captured patterns across studies. Analytical themes were developed firstly within papers, providing a summary of analytical themes across all 10 included papers for review. Finally, a process of interpretive synthesis was undertaken to construct higher-order analytical themes across studies, which went beyond the content of the original studies to generate new insights and hypotheses. This process was undertaken by the primary author and checked and discussed in supervision.

This approach allowed for the systematic identification of both recurring and contrasting experiences, while maintaining transparency in how interpretations were developed. Relationships within and across studies were explored, including variations in findings by type of loss, demographic factors such as parental age, and the nature or format of the interventions. Particular attention was paid to identifying which elements of support were experienced as helpful or unhelpful. To support transparency and coherence in the synthesis process, the final analytical themes were reviewed against the included studies to determine the breadth of support across the dataset. Finally, the robustness of the synthesis was considered by reflecting on the quality and depth of the included studies, potential biases, and the consistency of findings. Reflexivity was maintained throughout the process, with ongoing consideration of the role of the researcher in shaping interpretations.

Results

Study and Participant Characteristics

The 10 studies included in this synthesis were published between 2004 and 2021.A summary of the study characteristics can be found in Table 3 below. Three studies were conducted in the United States of America, two in Australia, one in Sweden, one in Finland, one in the UK, one in Spain, and one across both Brazil and Canada. The studies involved diverse sample sizes ranging from 4 to 131 participants. There were a total of 292 participants across all 10 studies, of this, 178 were male (60.9%).

The studies explored a range of interventions and support mechanisms, including healthcare provisions, peer support, psychosocial support, grief counselling, and bereavement care services. The length of engagement with support services varied across studies, ranging from a few months to several years. Support was provided through a combination of healthcare professionals, peer groups, and community organisations, with some studies focusing on online support and others on face-to-face interactions.

Participant ages varied from 18 to 48 years old (mean: 35.2 years). A few studies provided detailed information on participant education levels, which ranged from secondary school to graduate degrees, while others did not report this detail. Ethnicity was predominantly Caucasian, with only a few studies providing specific ethnic breakdowns, such as African American, Brazilian, or New Zealanders. In some studies, ethnicity was not reported. The data collection methods used across the studies included various qualitative approaches, with semi-structured interviews being the most common. Other methods included open text questionnaires, focus groups, and repeated time-point interviews. Analysis methods varied from thematic analysis and content analysis to inductive manifest content analysis and phenomenology.

Table 3. Summary of Study Characteristics

Study #	**Authors (Year & Country)**	**Sample Characteristics**	**Intervention / Support Characteristics**	**Data Collection, Method & Analysis**	Author assigned **Themes** Sub-themes
S1	Cacciatore, Erlandsson & Radestod (2013) Sweden	Total = 131 Gender = 100% male Age = Not reported Ethnicity = Not reported	Healthcare provisions & third sector support service Timeframe: Not reported Facilitators: Healthcare professionals	Open text questionnaire Inductive manifest content analysis	**Gratitude** Providers supported fatherhood Consideration of the child Preservation of the memory **Sad, Hurt or Angry** Nonchalance or coldness Unsympathetic or insensitive Disrespect towards the baby
S2	Aho, Paavilainen & Kaunonen (2012) Finland	Total = 4 Gender = 100% female Age = Not report Ethnicity = Not reported	Online peer support Timeframe: Weekly for 5 years. Facilitators: Peers and group administrators	Online peer group messages Inductive content analysis	**Emotional Support** Sharing oppressive feelings Supportive well-being Displays of Sympathy **Informational Support** Referring to sources of help Information sharing **Support Through Community** Admitting as a member Sharing ones story Support in community Supporting a pleasant environment
S3	Fenstermacher & Hupcey (2019) USA	Total = 8 Gender = 100% female Age = 18-21 years old Education = Not reported	Psychosocial supports & bereavement counselling Timeframe: 0-12 weeks following perinatal loss.	Repeated time-point interviews. 3 across 12 weeks. Constant comparative analysis	*6 time-points / focuses* **During Loss** Compassionate information **Immediately Following Loss** Guidance and respect **During Hospital Stay** Consistency and experience **Hospital Discharge** Anticipatory guidance

		Ethnicity = African American			Isolation **During Follow-up** Relating to others Variety of options **What Didn't Help** Othering Unsympathetic community
S4	Silverio et al (2021) United Kingdom	Total = 24 Gender = 91.6% female Age = Not reported Ethnicity = Not reported	Psychosocial support & bereavement support services	Semi-structured interviews Template Analysis	**Fragmented Care** Confusion and uncertainty **Away From Support Systems** **Impersonal Care and Support Through a Screen**
S5	Paris, Montigny & Pelloso (2021) Brazil & Canada	Total = 44 Gender = 100% female Age = 20-34 years old Education level reported. Greater or equal to 12 years old (Brazilian = 62%, Canadian =100%) Ethnicity = Brazilian & Canadian (40.9%)	Healthcare provisions & grief support group	Semi-structured interviews Content Analysis	**Assistance Received Postpartum** Hospital environment Outpatient care **Professional Support in Coping with Maternal Grief** With contact and memories Without contact and memories Impossibilities of contact with the babies
S6	Azeez et al (2021) Australia	Total = 10 Gender = 100% male Age = 31-42 (M35) Education = High school (10%), Tradesmen (20%),	Psychosocial supports, bereavement counselling & peer support groups	Semi-structured interviews Thematic Analysis	**From Hospital to Home: Continuity of care** Hospital support experiences are critical to fathers support needs Inconsistences with discharge and follow up services Referral/continuity of services: the key facilitator to

		Undergraduate (30%) Postgraduate (30%), Not provided (10%). Ethnicity = Australia/ European/ New Zealand			engagement in formal support options **Self and Community barriers to support** Informal supports: social recognition and acknowledgement masculine norms can impede engagement in support for fathers support options must be varied to meet father’s needs
S7	Avila et al (2020) Spain	Total = 21 Gender = 61.9% female Age = 26-43 (M = 35.6) Education = Some college (33%), College degree (43%), Advanced college (24%) Ethnicity = not reported	Healthcare provisions bereavement support services, peer support groups & psychosocial supports.	Semi-structured interviews Gadamer Hermeneutic Phenomenology	**Professional care in dealing with parents grief** Important aspects of professional care Continuing pathways of care **Effects of social support in parental grief** The silence that surrounds grieving parents Family and other children: a key element Perinatal loss support groups: a reciprocal help
S8	Obst & Due (2019) Australia	Total = 8 Gender = 100% male Age = 33-48 years old Education level reported. 1/8 = secondary education, 7/8 = tertiary education Ethnicity = 8/8 Caucasian	Support group, bereavement counselling, psychosocial supports, healthcare support	Semi-structured interviews Thematic Analysis	**Nature of grief for men** Individual experiences Lack of recognition for men’s grief **Support experiences** Varying needs Support requires social recognition **Facilitators and future supports** Male specific informal supports Reframing the language of support

S9	Diamond & Roose (2016) USA	Total = 11 Gender = 100% female Age = Not reported Ethnicity = 9 whites, 2 African American	Peer support programme	Focus groups & semi-structured interview Thematic Analysis	**Contact** **Positive aspects of PSP** **Difficult with PSP** **Suggestions for PSP**
S10	Kavanaugh, Trier & Korzec (2004) USA	Total = 31 Gender = 70.9% female Age = 19-34 Education levels reported. Range = 11-17 years in education.	Psychosocial supports	Semi-structured interviews Descriptive Phenomenological Methods	**Emotional Supports** **Advice & Guidance** **Financial & Material** **Practical Supports** **Socialising**

Quality Appraisal

All included studies had clearly defined aims, and the use of qualitative designs was appropriate for exploring bereavement and grief in the context of support. Interviews, focus groups, and online peer support messages were used across studies, all methods well-suited to investigating sensitive, personal experiences. Most adhered closely to their design aims, with Aho, Paavilainen & Kaunonen (2012), Silverio et al. (2021), and Azeez et al. (2021) standing out for clearly aligning their research questions with robust qualitative methodologies.

Ethical procedures were reported in all studies. Most provided clear evidence of ethical approval and addressed informed consent and confidentiality. Azeez et al. (2021) and Paris, Montigny & Pelloso (2021) offered detailed accounts of their ethical protocols, including participant protections. In contrast, Cacciatore, Erlandsson & Rådestad (2012) mentioned ethics approval only briefly at the article's end, with limited detail on procedures. Reflexivity was addressed inconsistently. Aho et al. (2012), Silverio et al. (2021), and Obst & Due (2019) acknowledged the researcher's role, though with varying depth. Azeez et al. (2021) offered explicit reflection, which scored positively on the CASP tool. In contrast, Cacciatore et al. (2012) and Fenstermacher & Hupcey (2019) gave little consideration to reflexivity, affecting their ratings in this domain.

Data collection methods were generally well-described. Most used semi-structured interviews, with some incorporating focus groups or online messages. Data analysis approaches included thematic and content analysis, which were appropriate for qualitative aims. Aho et al. (2012) and Obst & Due (2019) were particularly clear in detailing procedures. However, Cacciatore et al. (2012) lacked sufficient clarity on their analysis, resulting in a lower rating. Findings across studies were generally clear and contributed valuable insights into bereavement support. Azeez et al. (2021), Silverio et al. (2021), and Obst & Due (2019) provided particularly rich, well-substantiated findings. Fenstermacher & Hupcey (2019), while still valuable, offered less comprehensive reporting on the impact of grief support systems.

Table 4. Critical Appraisal Skills Programme Checklist Results

Paper #	**Authors**	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**
1	Cacciatore, Erlandsson & Radestod (2012)	Y	?	N	?	?	N	N	Y	N	Y
2	Aho, Paavilainen & KauNnen (2012)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
3	Fenstermacher &Hupcey (2019)	Y	Y	Y	?	N	N	N	Y	Y	Y
4	Silverio et al (2021)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
5	Paris, Montigny & Pelloso (2021)	Y	Y	Y	?	Y	N	?	Y	Y	Y
6	Azeez et al (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
7	Aliva et al (2020)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

8	Obst & Due (2019)*	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
9	Diamond & Roose (2016)	Y	Y	N	Y	Y	N	Y	N	Y	Y
10	Kavanaugh, Trier & Korzec (2004)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Abbreviations: Y = Yes, N = No, ? = Unclear. Domains: **Q1** = Clear statement of aims; **Q2** = Suitable qualitative methodology; **Q3** = Appropriateness of research design; **Q4** = Appropriateness of recruitment strategy; **Q5** = Adequacy of data collection; **Q6** = Relationship between researcher and participant; **Q7** = Ethical consideration; **Q8** = Rigor of data analysis; **Q9** = Clear statement of findings; **Q10** = Value of research.

**Indicates studies that have been co-rated by an independent second reviewer.*

Thematic Synthesis

Inductive thematic analysis initially generated 29 descriptive codes, capturing key features of parents' accounts of psychological and psychosocial support. These codes were clustered into seven descriptive themes, which reflected patterns in how support was experienced, the factors that shaped its impact, and the barriers parents encountered (Table 5). From these descriptive themes, three overarching analytical themes were developed to represent broader constructs grounded in the original data. These analytical themes synthesise cross-cutting processes within parents' experiences, illuminating what made support meaningful, and how systemic gaps contributed to unmet needs. Each analytical theme is further divided into sub-themes to reflect distinct but interconnected aspects of experience. An example of this can be found in Appendix 1.5 (p84).

Analytical Theme Coverage Across Included Studies

Experiencing Support: Relational and Emotional Containment

This theme was present in **9 of 10 studies** (S1, S2, S3, S4, S6, S7, S8, S9, S10), highlighting the core role of relational and emotional support in how interventions were received. Participants described feeling emotionally held by professionals, peers, or loved ones as vital to their grief and recovery, regardless of intervention type or setting. This theme cut across intervention type, setting, and population.

The Form and Function of Intervention: What Makes Support Work

Grounded in **8 of 10 studies** (S1, S2, S3, S5, S6, S7, S9, S10), this theme reflects what made support helpful: humanising the baby and loss, flexible and personalised care, and tools for coping and meaning-making. These findings have clear implications for grief intervention design.

When Systems Fail: Barriers, Silences, and Structural Exclusion

Supported by **5 of 10 studies** (S1, S4, S6, S7, S8), this theme highlights systemic shortcomings, fragmented care, gendered assumptions, and institutional insensitivity that, while not universal, deeply shaped parents’ grief.

Together, these themes describe parent’s experiences of support, what made support effective, and where systems failed them.

Table 5. Final Analytical Themes, Descriptive Themes, and Supporting Codes from Thematic Synthesis

Analytical Theme	**Descriptive Themes**	**Codes**
Experiencing Support: Relational and Emotional Containment	Relational Validation and Professional Support	• Supportive vs. Dismissive Professional Conduct • The Critical Role of Presence, Acknowledgment, and Validation • Importance of Peer Connection and Emotional Support • Social Support, Solidarity & Connection • Role of Relationships in Coping
	Experiences of Isolation and Emotional Disconnection	• Isolation and Social Withdrawal
The Form and Function of Intervention: What Makes Support Work	Recognition, Symbolism, and Memory-Making	• Recognition and Validation of Parental Grief • Humanisation of the Baby and the Loss • Facilitation of Memory-Making and Symbolic Keepsakes
	Accessibility, Fit, and Responsiveness of Support	• Flexibility and Personalisation in Support Delivery • Timing and Emotional Readiness • Ambivalence and Mismatch in Available Support • Continuity and Accessibility of Support • Importance of Consistent and Compassionate Care • Professional Support: Interventions, Information & Fit
	Psychological Recovery and Meaning-Making	• Tools for Meaning-Making and Grief Integration • Alternative Coping Strategies and Meaning-Making • Hope and Through Time and Support • Disrupted Identity and the Search for Meaning • Coping Mechanisms • Grief Processing & Pathways to Closure • Informal and Indirect Pathways to Support
When Systems Fail: Barriers, Silences, and Structural Exclusion	Institutional and Structural Barriers to Care	• Constraints on Parental Agency and Institutional Insensitivity • System-Level Disruption and Institutional Control • When Support Harms: The Impact of Insensitive or Misattuned Responses • Inconsistencies and Failures in Psychosocial Support
	Gendered Silences and the Marginalisation of Fathers	• Barriers to Engagement and Paternal Invisibility • Marginalisation of Fathers’ Grief • Masculine Identity and Help-Seeking Conflict

The themes capture parents' experiences of support services and their reflections on what aspects of care were most meaningful in their healing and grief processes. The themes span both affirming and challenging encounters, encompassing emotional, relational, practical, and systemic dimensions of care (Table 5). The final analytical themes are:

1. *Experiencing Support: Relational and Emotional Containment*
2. *The Form and Function of Intervention: What Makes Support Work*
3. *When Systems Fail: Barriers, Silences, and Structural Exclusion*

Theme 1: Experiencing Support: Relational and Emotional Containment

This theme examines the emotional and relational dimensions of bereavement support following perinatal loss. Parents' experiences were shaped by whether care was emotionally attuned and acknowledged their grief and their baby's identity. Such support was described as containing and validating, while insensitive or absent responses left many feeling isolated or dismissed. Two sub-themes emerged: *Relational Validation and Professional Support* and *Experiences of Isolation and Emotional Disconnection*.

1.1 Relational Validation and Professional Support

Many parents reflected positively on interactions where professionals conveyed emotional presence, compassion, and validation. These moments helped create a sense of safety, recognition, and support during an otherwise disorienting and painful time. One parent recalled that "the staff made us feel as though we were exactly like all the other couples having a baby" (Cacciatore, Erlandsson, & Rådestad, 2012, p667), emphasising how inclusive and respectful care helped affirm their identity as parents despite the loss. Another described how professionals "spoke clearly and, um, presented our options in the most professional manner they could" (Azeez et al., 2021, p2737), highlighting the importance of sensitive communication and clarity in distressing circumstances. When professionals took time to make parents feel understood, as one parent recalled," I didn't expect to be treated with such respect and empathy. I felt that they understood that it was a painful ordeal for me and my husband" (Paris, 2021, p4), underscoring how humanising language conveyed emotional presence.

Validation also emerged in peer support interactions, where emotionally attuned expressions mirrored the kind of relational support parents valued from professionals. One bereaved mother recalled a message she received in an online support space: "Don't be too hard on yourself, let yourself grieve, it takes time" (Aho, Paavilainen, & Kaunonen, 2012, p420), highlighting the comfort found in compassionate, non-fixing presence. Practical and emotional guidance was also significant; one parent noted that "they talked with us and guided us through difficult questions" (Cacciatore, Erlandsson, & Rådestad, 2012, p668), pointing to the value of support that was both emotionally attuned and practically helpful.

Other forms of connection emerged through less formal intervention routes, such as support phone calls that initially felt intrusive but ultimately became supportive: “At first I thought it [telephone call] was weird, and then I thought oh, they actually care and are trying to understand what is going on and they want to know how I’m doing” (Fenstermacher & Hupcey, 2019, p16).

Peer support was another vital element of relational containment. For some, connection with other bereaved parents offered unique emotional validation: “Talking with couples who have gone through the same thing made me feel less alone” (Ávila et al., 2020, p156) and “Having a peer parent helped normalize my feelings, such as anger, when others were telling me to move on and that I was stuck” (Diamond & Roose, 2016, p152). These relationships helped alleviate isolation and provided a sense of solidarity and shared understanding that professional support alone could not always offer.

1.2 Experiences of Isolation and Emotional Disconnection in Support

Despite the presence of psychological and psychosocial interventions, some parents described feeling emotionally disconnected from the support offered to them. These experiences often reflected missed opportunities for validation, empathy, or inclusion, factors essential to feeling genuinely supported during bereavement.

For some bereaved parents, professional interactions felt impersonal, dismissive, or emotionally disconnected. One parent recalled, “The first [professional] was totally cold and said to my wife that she should stop acting like a baby” (Cacciatore et al., 2012, p668). Even in more structured support contexts, such as group meetings, a lack of perceived fit could leave parents feeling excluded or unsupported. As one participant explained, “Yeah, we went to the support group and they were really good about everything but they were all married and so I kind of felt left out” (Fenstermacher & Hupcey, 2019, p17). Others described the frustration of inconsistent follow-up and difficulty accessing key professionals: “...but I also remember after that they were really hard to get hold of. The social worker we had was um ((pauses)) probably a very busy person, but trying to get hold of her to book in meetings or just have a chat, seemed really difficult.” (Azeez et al., 2021, p2725). Across these experiences, a lack of emotional attunement, perceived exclusion, or reduced accessibility diminished the supportive value of services and created barriers to connection.

In some cases, emotional disconnection arose not from what was said, but from what was absent. As one parent explained, “In the hospital nobody told me about any book or something to see or read. We later looked for associations to be able to talk, but nobody told us about them” (Ávila et al., 2020, p155), highlighting how the absence of information or proactive support offerings left parents feeling isolated and unsupported. Together, these narratives demonstrate that meaningful psychosocial support requires more than procedural access. For support to be effective, it must feel emotionally safe, inclusive, and genuinely responsive to the needs and identities of all parents navigating perinatal grief.

Theme 2: The Form and Function of Intervention: What Makes Support Work

This theme examines what bereaved parents found effective and meaningful in the structure, delivery, and responsiveness of support. Participants described how emotionally attuned, symbolically rich care helped them process grief, make sense of their experience, and access support that felt personally relevant. Three sub-themes reflect how support worked best: *Recognition, Symbolism, and Memory-Making*; *Accessibility, Fit, and Responsiveness of Support*; and *Psychological Recovery and Meaning-Making*.

2.1 Recognition, Symbolism, and Memory-Making

Participants described the value of support that humanised their baby and acknowledged the significance of their loss. This often came through symbolic gestures and emotionally present interactions. Expressions of reverence and respect were particularly meaningful. One parent stated, “They took him rather soon to the photographer so we got a life-long pictorial memory” (Cacciatore et al., 2012, p668), highlighting the emotional significance of tangible remembrance. Another recalled, “I took all the souvenirs offered by the hospital staff: baptism, fingerprints, the identification bracelet and the service of a photographer. We spent about six hours with our daughter” (Paris, Montigny, & Pelloso, 2021, p4), demonstrating how symbolic acts of recognition created meaningful time and connection amidst loss. These gestures helped to create tangible legacies, offering comfort and a continuing bond with the baby.

2.2 Accessibility, Fit, and Responsiveness of Support

Support was most effective when it aligned with the identity, preferences, and emotional state of the bereaved parent. Some fathers expressed a need for gender-congruent support: “Sometimes it’s easier to talk to a stranger […] it couldn’t have been a woman though, for me at least, I’d want to speak to another bloke because […] even though there’s no difference or whatever, there is in my head” (Obst & Due, 2109, p4). Others emphasised that language around support needed to reflect how men process and seek help: “I think personally the way to reach out to men and make them connect with [support] is to frame the proposition completely differently. And not make it about support. I think it honestly would be better to tap into what they’re probably thinking themselves, and that’s about supporting other people. And through that you actually support them.” (Obst & Due, 2019, p4).

Continuity of care also emerged as a key factor in feeling supported and secure: “I just want the same person to check on me every time” (Fenstermacher & Hupcey, 2019, p15). This points to the need for services to prioritise consistency and relational continuity to foster trust and emotional safety over time.

The structure and setting of support services also influenced how safe and accessible they felt. One participant reflected on the discomfort evoked by conventional group formats: “Seeing people sitting in a circle can be a little bit confronting because it then makes you feel like you’re going to have to stand up and talk to people about something that’s incredibly personal” (Obst & Due, 2019, p3). This highlights how emotional readiness and the design of interventions must be considered to ensure support environments are inclusive, non-threatening, and adaptable to the vulnerability of grieving parents.

2.3 Psychological Recovery and Meaning-Making

Parents found healing through opportunities for reflection and expression, whether individually or in connection with others. One mother shared, “Like I wrote to myself and just reading online blogs. Blogs that other females have wrote and talked about their miscarriages and stuff about their losses. So just reading and writing to myself every day helped me out a lot” (Fenstermacher & Hupcey, 2019, p16), highlighting the therapeutic value of writing and peer narratives.

The transformative impact of grief was also acknowledged: “You just get an understanding of how it can change your life. Like this has really changed me” (Fenstermacher & Hupcey, 2019, p16). Support that enabled such self-understanding was especially valued. In-person support, especially from peers, was helpful when it promoted trust and mutual recognition: “It would be helpful to have peer parents make the effort to go to group with parents the first time together so you have the face-to-face connection. That is important” (Diamond & Roose, 2016, p152). Another parent reflected “And we didn’t really talk specifically about that, I sort of raised it over a few things and they were pretty good about it […] the appropriate response to anything that they say is, yeah that sucks man […] And that’s all I wanted to hear.”” (Obst & Due, 2019, p4).

When discussing interventions one participant reflected on the evolving nature of grief, offering a sense of hope while acknowledging its persistence: “The road of grief is long and winding, and sometimes it takes you to deep waters. It gets easier over time, you will never forget it but it changes shape so that you can live with it” (Aho, Paavilainen, & Kaunonen, 2012, p422). This highlights how interventions that foster meaning-making and can support long-term psychological adjustment should be considered. Together, these accounts demonstrate that effective support is not just about availability, but about resonance, support that is emotionally attuned, identity-aware, symbolically meaningful, and capable of nurturing the long arc of healing.

Theme 3: When Systems Fail: Barriers, Silences, and Structural Exclusion

This theme captures the systemic and structural barriers bereaved parents faced when accessing psychological or psychosocial support. Although some professionals acted with compassion, broader failures in care delivery, referral pathways, and institutional attitudes often left parents feeling abandoned, dismissed, or excluded. These experiences are reflected in two sub-themes: *Institutional and Structural Barriers to Care* and *Gendered Silences and the Marginalisation of Fathers*.

3.1 Institutional and Structural Barriers to Care

Parents frequently described how systems failed them at critical moments, often during or immediately after their loss. Institutional insensitivity and fragmented follow-up were common themes. One parent recalled, “The staff member was… incredibly clumsy and did not give us any information or guidance. You can go home now and come back tomorrow morning. Goodbye!'” (Cacciatore et al., 2012, p668), reflecting how the absence of communication or guidance heightened distress and disorientation in an already traumatic moment.

Receiving support in hospital environments was sometimes experienced as actively distressing. One mother recalled, “It causes you great grief and sadness to hear other infants cry in your room… all the mothers with their infants, and I had just lost mine… An unbearable experience that you want to run away from” (Ávila et al., 2020, p155). Others spoke of an abrupt and unsupported transition home: “When you leave the hospital, the health professionals ignore you and do not perceive that support or care you have at a first moment. We were very hurt, lost and needed a guide…” (Ávila et al., 2020, p155).

Even when psychological support had been promised, it often failed to materialise. One participant shared, “I was hospitalized several days after delivery, they said that a psychologist would visit me but she did not come” (Paris, Montigny, & Pelloso, 2021, p4). These absences left many feeling unsupported at a time of acute vulnerability.

In some cases, parents described the emotional toll of inadequate communication and the absence of meaningful support from professionals. One mother expressed, “If they can't say anything that would encourage me or anything, then don't say anything to me at all” (Kavanaugh, Trier, & Korzec, 2004, p82). This statement reflects how harmful thoughtless or empty interactions can feel in moments of acute vulnerability. Rather than provide comfort, poorly handled communication left parents feeling dismissed or even further distressed, adding to the emotional burden they were already carrying.

Together, these narratives reveal how institutional shortcomings, whether due to understaffing, lack of training, or poor continuity, created lasting harm. Bereaved parents needed timely, informed, and compassionate care but were too often met with silence, absence, or confusion.

3.2 Gendered Silences and the Marginalisation of Fathers

Fathers often experienced bereavement support services as implicitly or explicitly excluding them. Although some services claimed to prioritise father involvement, their actual practices did not reflect this. One father observed that, “In contrast with the midwife, the physician we overall had the most contact with did not listen to me. Feels typical, they (caregivers) say that they think it is really important that the fathers take part, but then they completely fail to show any interest, except when they respond with sarcastic remarks or humiliate us” (Cacciatore et al., 2012, p668).

Fathers were also subjected to assumptions about their emotional responses. A further participant recalled, “A female physician met me with the attitude that the loss was not as sorrowful for me as for my wife” (Cacciatore et al., 2012, p668). These assumptions fed into the marginalisation of men within both the clinical and social context of grieving.

The imbalance was reflected in the way professionals engaged with couples. One father explained, "…there was a definite focus on [my wife] rather than myself as the dad […] they would more often talk to her about what was going on rather than specifically approaching me" (Azeez et al., 2021, p2725). Socially, fathers were also overlooked. As another participant shared, "Every time I'd get a text from my friends the text was like how's [partner]? […] but you know, the father is just as upset even though he doesn't necessarily show it in the same way" (Obst & Due, 2019, p3).

These gendered gaps in support also extended to access. One parent stated, "We would have liked the hospital to tell us that there were support groups instead of our looking for them. When you have so much pain it becomes even harder" (Ávila et al., 2020, p155). Another reflected, "Expressing our feelings with a psychologist who had more knowledge of the subject would have helped us a lot. It would not have taken away the pain, but it would have guided us and gave advice. I don't understand why we were not offered psychological help at times when you are so lost" (Ávila et al., 2020, p156).

These accounts show that fathers' grief is often minimised or rendered invisible within systems still shaped by assumptions about gender roles and emotional expression. Addressing these silences requires not only individual attunement but also structural changes to how services are designed and delivered.

Discussion

This review synthesised parents' experiences of psychological and psychosocial support following perinatal bereavement, identifying how such support is experienced and which aspects are most helpful, mapped across three core thematic dimensions of parental experience. Theme 1, *Experiencing Support: Relational and Emotional Containment*, primarily addresses how parents experience support in relational and emotional terms (RQ1). Theme 2, *The Form and Function of Intervention: What Makes Support Work*, identifies specific aspects of support that parents found beneficial in their healing and grief process (RQ2). Theme 3, *When Systems Fail: Barriers, Silences, and Structural Exclusion*, serves as a critical counterpoint to both questions by highlighting when and how systems fall short, shaping negative or absent experiences of care.

Together, these findings directly address both review questions. Across studies, parents described how compassionate relational validation was central to meaningful care. Support was valued when it acknowledged the parent's grief, offered symbolic practices such as memory-making, and allowed for autonomy and emotional readiness. Conversely, support that was absent, impersonal, or poorly timed was often experienced as alienating or even harmful. These themes suggest that the emotional tone**,** relational quality**,** and flexibility of care are as crucial as the intervention itself.

Integration with Existing Literature

These findings align with and deepen existing qualitative and quantitative literature. The relational and symbolic elements emphasised by parents echo previous qualitative work highlighting the centrality of emotional connection, remembrance, and legacy in grief (Jones, Albanese, & Boles, 2023; Jonas-Simpson et al., 2013). Rather than seeking closure, parents described grief as a process of sustaining connection and integrating loss into their parenting identity and broader life narrative. Memory objects, rituals, and emotional language featured prominently in this process, both in therapeutic and informal contexts.

Quantitative studies have established the psychological toll of perinatal bereavement, including increased rates of depression, anxiety, and PTSD (Gold et al., 2016; Badenhorst & Hughes, 2007). This review adds experiential insight into how inadequate or misattuned support may contribute to distress, while validating, relational care may offer emotional protection. Several quantitative reviews (Li et al., 2024; Dolan et al., 2022; Shaohua & Shorey, 2021; Xie et al., 2024) have identified effective interventions such as psychological and peer support, but tend to focus on symptom reduction. This review complements those findings by showing *why* such interventions may or may not be helpful. Factors such as emotional readiness, relational tone, and continuity of care shaped how support was received. These results also support earlier work by Jonas-Simpson et al. (2013) on the importance of empathy and therapeutic presence. Even brief, emotionally attuned interactions, such as using the baby's name, were remembered years later with clarity and gratitude. At the same time, participants described disenfranchised grief and institutional silence, echoing Lang et al. (2011) and Norwood & Boulton (2021). Professionals who minimised or ignored the baby's existence contributed to feelings of erasure and abandonment. This review reinforces Rossen, Opie & O'Dea's (2023) argument that systemic disregard can compound grief and highlights the exclusion of fathers in particular. While earlier work identified paternal invisibility, this review offers concrete examples of how such exclusion was enacted, being left out of consultations, discouraged from emotional expression, or assumed to be unaffected.

Theoretical Implications

These findings extend conceptual understandings of grief, identity, and care following perinatal loss. Parents' emphasis on symbolic continuity and memory-making supports previous qualitative research suggesting that remembrance and legacy help parents preserve their identity as caregivers (Jonas-Simpson et al., 2013; Jones, Albanese, & Boles, 2023). Rather than seeking detachment, parents described an ongoing effort to sustain the parenting role and integrate the loss into daily life. The review also reinforces theories of identity disruption, especially those centred on embodied grief. Mothers reported a fragmented sense of self following the loss, consistent with Garrod & Pascal (2019), who explored the reconstruction of maternal identity. Bodily experiences such as lactation and hormonal changes were often overlooked by services focused narrowly on psychological symptoms, supporting Rossen, Opie & O'Dea's (2023) call to recognise the embodied and socially situated nature of perinatal grief.

The exclusion of fathers and other marginalised parents also maps onto theories of social invisibility and disenfranchised grief (Lang et al., 2011; Salgado et al., 2021). Participants described being overlooked or discouraged from expressing grief, reinforcing the need for inclusive bereavement frameworks that accommodate diverse expressions of identity and emotion. Finally, the findings support a shift from standardised models toward relational and intersubjective approaches to care. Empathy and human connection were often described as more meaningful than structured interventions. The review challenges dominant paradigms that prioritise technique over presence, and argues for trauma-informed, person-centred care. Structural issues such as fragmented services and cultural assumptions shaped the experience of grief, indicating that psychological models must move beyond the individual to account for systemic and societal influences.

Clinical and Policy Implications

The findings have important implications for clinical practice and service design. First, healthcare professionals must recognise the importance of emotional presence, relational validation, and personalisation. Support that explicitly acknowledges the baby and validates the parent's grief can improve engagement and emotional outcomes. Second, services should be flexible and responsive to individual needs. Parents must be offered options such as memory-making, peer support, and psychological care, and the autonomy to engage when emotionally ready. Greater continuity across care settings is also essential to avoid fragmented or re-traumatising experiences. Third, systemic and cultural assumptions must be addressed. Fathers and marginalised parents face specific challenges that must be recognised through inclusive training, diverse representation, and co-designed interventions. Services should actively create space for all grieving parents to be seen, supported, and validated.

Strengths and Limitations

This is the first known systematic review to focus specifically on parents' lived experiences of psychological and psychosocial support following perinatal bereavement. Drawing on ten studies, the review offers a nuanced synthesis of valued support features. A key strength is its inclusion of both maternal and paternal perspectives, helping to address the historically mother-focused lens of perinatal grief research. This review is strengthened by its use of established quality appraisal tools to ensure methodological rigor, alongside a transparent and in-depth thematic synthesis grounded in verbatim data. The inclusion of documented reflexivity, a participant-centred focus, and attention to the clinical relevance of findings enhances both the trustworthiness and applied value of the review.

However, the quality and richness of included studies varied. Some, such as Cacciatore et al. (2012), Silverio et al. (2021), and Azeez et al. (2021), provided extensive quotes and clear interpretive links; others offered less analytic depth. This reflects variation in reporting styles more than conceptual significance. Support types also differed, ranging from formal interventions to informal peer care, limiting direct comparisons. Inconsistent demographic reporting further restricted exploration of how identity factors, such as ethnicity or socioeconomic status, shape experiences. Longitudinal impacts were underexplored, limiting insight into how needs evolve over time. Nonetheless, the emergence of consistent experiential themes across diverse forms of support suggests that certain relational and emotional elements, such as compassion, continuity, and validation, are valued regardless of delivery format. This reinforces the idea that *how* support is provided may matter as much as *what* is provided. Finally, as with all qualitative syntheses, the review is shaped by interpretive decisions. Care was taken to preserve nuance, but thematic grouping always involves a degree of subjectivity.

Future Research Directions

Future research should explore how specific aspects of support, such as timing, relational dynamics, and symbolic practices, facilitate healing and adjustment. Longitudinal studies are especially needed to understand how needs and experiences shift over time. More inclusive research is also essential. The experiences of same-sex couples, non-biological parents, and racially minoritised families remain underrepresented, despite potential barriers unique to these groups. Improved demographic reporting is necessary to examine how intersecting identities shape support experiences. Finally, future syntheses may consider including qualitative components from mixed-methods studies, which were excluded here due to methodological categorisation, to broaden the evidence base without sacrificing depth.

Conclusion

This review underscores that psychological and psychosocial support after perinatal bereavement is most effective when it honours the relational, symbolic, and embodied nature of grief. Across diverse contexts, parents valued care that was compassionate, validating, and responsive to their individual needs. Support that recognised their baby and role as parents helped facilitate meaning-making and emotional integration. In contrast, systemic gaps and exclusionary practices risked compounding distress and disenfranchising grief. By centring the voices of bereaved parents, this review highlights the need for trauma-informed, person-centred support models that address both emotional and structural dimensions of care. Meaningful progress will require not only improved interventions but cultural and systemic change in how perinatal loss is understood and supported within healthcare systems.

References

References in bold indicate papers included in the review.

Aho, A. L., Paavilainen, E., & Kaunonen, M. (2012). Mothers' experiences of peer support via an Internet discussion forum after the death of a child. Scandinavian journal of caring sciences, 26(3), 417-426. https://doi.org/10.1111/j.1471-6712.2011.00929.x

Ávila, M. C., Medina, I. M. F., Jiménez-López, F. R., Granero-Molina, J., Hernández-Padilla, J. M., Sánchez, E. H., & Fernández-Sola, C. (2020). Parents' experiences about support following stillbirth and neonatal death. Advances in Neonatal Care, 20(2), 151-160. DOI: 10.1097/ANC.0000000000000703

Azeez, S., Obst, K. L., Oxlad, M., Due, C., & Middleton, P. (2021). Australian fathers' experiences of support following neonatal death: a need for better access to diverse support options. Journal of Perinatology, 41(12), 2722-2729. https://doi.org/10.1038/s41372-021-01210-7

Badenhorst, W., & Hughes, P. (2007). Psychological aspects of perinatal loss. Best Practice & Research Clinical Obstetrics & Gynaecology, 21(2), 249-259. https://doi.org/10.1016/j.bpobgyn.2006.11.004

Blackmore, E. R., Côté-Arsenault, D., Tang, W., Glover, V., Evans, J., Golding, J., & O'Connor, T. G. (2011). Previous prenatal loss as a predictor of perinatal depression and anxiety. The British Journal of Psychiatry, 198(5), 373-378. DOI: https://doi.org/10.1192/bjp.bp.110.083105

Cacciatore, J., Erlandsson, K., & Rådestad, I. (2013). Fatherhood and suffering: a qualitative exploration of Swedish men's experiences of care after the death of a baby. International journal of nursing studies, 50(5), 664-670. https://doi.org/10.1016/j.ijnurstu.2012.10.014

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qualitative health research*, *22*(10), 1435-1443.

Diamond, R. M., & Roose, R. E. (2016). Development and evaluation of a peer support program for parents facing perinatal loss. Nursing for women's health, 20(2), 146-156. https://doi.org/10.1016/j.nwh.2016.02.001

Dolan, N., Grealish, A., Tuohy, T., & Bright, A. M. (2022). Are mindfulness-based interventions as effective as cognitive behavioral therapy in reducing symptoms of complicated perinatal grief? A systematic review. *Journal of midwifery & women's health*, *67*(2), 209-225. https://doi.org/10.1111/jmwh.13335

Fenstermacher, K. H., & Hupcey, J. E. (2019). Support for young black urban women after perinatal loss. MCN: The American Journal of Maternal/Child Nursing, 44(1), 13-19. DOI:10.1097/NMC.0000000000000485

Gaudet, C., Séjourné, N., Camborieux, L., Rogers, R., & Chabrol, H. (2010). Pregnancy after perinatal loss: association of grief, anxiety and attachment. Journal of reproductive and infant psychology, 28(3), 240-251. https://doi.org/10.1080/02646830903487342

Garrod, T., & Pascal, J. (2019). Women's lived experience of embodied disenfranchised grief: Loss, betrayal, and the double jeopardy. Illness, Crisis & Loss, 27(1), 6-18. https://doi.org/10.1177/1054137318780582

Gold, K. J., Leon, I., Boggs, M. E., & Sen, A. (2016). Depression and posttraumatic stress symptoms after perinatal loss in a population-based sample. Journal of women's health, 25(3), 263-269. https://doi.org/10.1089/jwh.2015.5284

Jonas-Simpson, C., Pilkington, F. B., MacDonald, C., & McMahon, E. (2013). Nurses' experiences of grieving when there is a perinatal death. Sage Open, 3(2), 2158244013486116. https://doi.org/10.1177/2158244013486116

Jones, M. T., Albanese, E., & Boles, J. C. (2023). "They were here, and they still matter": A qualitative study of bereaved parents legacy experiences and perceptions. Palliative Medicine, 37(8), 1222-1231. https://doi.org/10.1177/02692163231180926

Kavanaugh, K., Trier, D., & Korzec, M. (2004). Social support following perinatal loss. Journal of family nursing, 10(1), 70-92. https://doi.org/10.1177/1074840703260905

Lang, A., Fleiszer, A. R., Duhamel, F., Sword, W., Gilbert, K. R., & Corsini-Munt, S. (2011). Perinatal loss and parental grief: The challenge of ambiguity and disenfranchised grief. OMEGA-Journal of Death and Dying, 63(2), 183-196. https://doi.org/10.2190/OM.63.2.e

Lasker, J. N., & Toedter, L. J. (1994). Satisfaction with hospital care and interventions after pregnancy loss. Death studies, 18(1), 41-64. https://doi.org/10.1080/07481189408252642

Li, X., Li, Y., Qian, L., Han, P., Feng, H., & Jiang, H. (2024). Mothers' experiences of breast milk expression during separation from their hospitalized infants: a systematic review of qualitative evidence. BMC Pregnancy and Childbirth, 24(1), 124. https://doi.org/10.1186/s12884-024-06323-3

Norwood, T., & Boulton, J. (2021). Reconciling the uniquely embodied grief of perinatal death: a narrative approach. Religions, 12(11), 976. https://doi.org/10.3390/rel12110976

Obst, K. L., & Due, C. (2019). Australian men's experiences of support following pregnancy loss: A qualitative study. Midwifery, 70, 1-6. https://doi.org/10.1016/j.midw.2018.11.013

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—a web and mobile app for systematic reviews. *Systematic reviews*, *5*(1), 210. DOI 10.1186/s13643-016-0384-4

Paris, G. F., Montigny, F. D., & Pelloso, S. M. (2021). Professional practice in caring for maternal grief in the face of stillbirth in two countries. Revista brasileira de enfermagem, 74(3), e20200253. https://doi.org/10.1590/0034-7167-2020-0253

Rossen, L., Opie, J. E., & O'Dea, G. (2023). A mother's voice: The construction of maternal identity following perinatal loss. OMEGA-Journal of Death and Dying, 00302228231209769. https://doi.org/10.1177/0030222823120976

Salgado, H. D. O., Andreucci, C. B., Gomes, A. C. R., & Souza, J. P. (2021). The perinatal bereavement project: development and evaluation of supportive guidelines for families experiencing stillbirth and neonatal death in Southeast Brazil—a quasi-experimental before-and-after study. Reproductive health, 18(1), 5. https://doi.org/10.1186/s12978-020-01040-4

Shaohua, L., & Shorey, S. (2021). Psychosocial interventions on psychological outcomes of parents with perinatal loss: A systematic review and meta-analysis. International journal of nursing studies, 117, 103871. https://doi.org/10.1016/j.ijnurstu.2021.103871

Silverio, S. A., Easter, A., Storey, C., Jurković, D., Sandall, J., & PUDDLES Global Collaboration. (2021). Preliminary findings on the experiences of care for parents who suffered perinatal bereavement during the COVID-19 pandemic. BMC Pregnancy and Childbirth, 21(1), 840. https://doi.org/10.1186/s12884-021-04292-5

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*, *8*(1), 45. DOI: 10.1186/1471-2288-8-45

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC medical research methodology*, *12*(1), 181.

Xie, J., Hunter, A., Biesty, L., & Grealish, A. (2024). The impact of midwife/nurse-led psychosocial interventions on parents experiencing perinatal bereavement: An integrative review. International journal of nursing studies, 157, 104814. https://doi.org/10.1016/j.ijnurstu.2024.104814

Chapter 2

Bereaved Mothers' Lived Experiences of Donating Breast Milk Following Perinatal Loss: An Interpretative Phenomenological Analysis

Prepared in accordance with the author requirements for Death Studies; https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=udst20

Plain Language Summary

Title: Understanding the experiences of mothers who donate their breast milk after baby loss.

Background: When a baby dies during pregnancy or shortly after birth, the grieving process can be complex and deeply painful. Some mothers begin producing breast milk even after their baby has died. While this can be distressing, a small number of bereaved mothers choose to express and donate this milk (Waldby, Noble-Carr & Carroll, 2023). We know very little about how this experience affects grieving mothers, or what donating milk means to them emotionally. This study aimed to explore how bereaved mothers make sense of milk donation after loss and what shapes their experiences.

Aims and Questions:

The study explored the following:

1. What emotional and psychological impact does milk donation have for bereaved mothers?
2. How do relationships with partners and families influence this experience?
3. How do the circumstances of the baby's death affect mothers' experiences of donation?
4. How do healthcare professionals and services support or hinder the donation process?

Methods: Eight mothers who had donated breast milk after the death of their baby took part in the study. All were recruited through the Memory Milk Gift service in Scotland. The women had experienced a range of pregnancy or infant losses. All participants took part in an individual interview with the researcher. The study used a qualitative approach called Interpretative Phenomenological Analysis (IPA), which focuses on understanding how people make sense of important life experiences in their own words (Smith & Nizza, 2022).

Main Findings and Conclusions: Mothers described milk donation as a meaningful part of their grief. While it did not remove their pain, it gave them purpose, pride, and a continued connection to their baby. Many said it helped them regain a sense of control after a traumatic loss. For some, donation was a way to express care and help others. Others faced emotional or physical challenges, including exhaustion, discomfort, or lack of support. Having even one supportive person, often a partner, made a difference, though some family members were unsure or disapproving.

Symbolic items like memory pebbles or trees helped mothers feel their baby was recognised. However, support from professionals varied. Some felt well cared for, while others described silence, limited information, or insensitive conversations about milk and grief. This study shows that milk donation after baby loss can be emotionally powerful and symbolically important, reinforcing theories of meaning reconstruction following bereavement (Neimeyer, 2001). Services should offer timely, compassionate support and recognise donation as both generous and personally meaningful. Improved awareness among professionals may help bereaved mothers feel better supported and less isolated.

References:

Neimeyer, R. A. (2001). *Meaning reconstruction & the experience of loss*. American Psychological Association

Smith, J. A., & Nizza, I. E. (2022). *Essentials of interpretative phenomenological analysis*. American Psychological Association

Waldby, C., Noble-Carr, D., & Carroll, K. (2023). Mothers, milk and mourning: The meanings of breast milk after loss of an infant. *Sociology of Health & Illness*, *45*(1), 109-127.

Abstract

The death of a baby during pregnancy or the perinatal period presents profound psychological and emotional challenges for bereaved mothers. Some choose to express and donate breast milk after loss, yet little is known about how this shapes grief, identity, and recovery. This study explored the lived experiences of bereaved mothers who donated milk, focusing on psychological meaning-making, relational dynamics, and systemic support. Eight bereaved mothers in Scotland took part in semi-structured interviews following neonatal or gestational loss. Transcripts were analysed idiographically using Interpretative Phenomenological Analysis (IPA), with reflexive engagement throughout. Five Group Experiential Themes were developed: (1) Making Meaning and Rebuilding After Loss, (2) Milk as a Symbolic Link to the Baby, (3) Emotional Complexity and the Psychological Labour of Donation, (4) Lived and Embodied Experiences of Lactation After Loss, and (5) Relational and Systemic Support: Facilitators and Barriers to Donation. Milk donation was described as a reparative and affirming act, allowing mothers to express care, maintain connection, and reclaim agency. Emotional experiences included pride, guilt, ambivalence, and vulnerability. The timing and context of loss shaped decisions and meaning-making. Partner support and symbolic memory items were valued. Inconsistent communication and service provision influenced negatively experiences. Findings inform bereavement care, clinical practice, and staff training.

Key Words: Perinatal Loss, Breast Milk Donation, Bereavement, Maternal Identity, Grief, Meaning-Making, IPA, Clinical Psychology

Introduction

Perinatal Loss

Perinatal loss is a unique and devastating event involving both the loss of a child and the anticipated parental role (Carroll et al., 2014). This dual grief can profoundly affect parents, particularly mothers, who often feel isolated in the immediate aftermath as their expected identity abruptly disappears (Oreg, 2019). Significant grief may persist for up to a year (Badenhorst & Hughes, 2007), with around 20% of mothers experiencing symptoms beyond this period.

The psychological impact is substantial. Armstrong (2002) found that mothers who had lost a baby showed higher rates of anxiety, depression, and grief in subsequent pregnancies compared to those without such a history. Herbert et al. (2022) conducted a systematic review and meta-analysis of 29 studies across 17 countries, including 31,072 bereaved women and 1,261,517 controls. Their findings indicated that mothers who experienced perinatal loss were significantly more likely to develop depression and anxiety than those in control groups, highlighting the need for targeted mental health assessment and interventions. These findings underscore the lasting impact of perinatal bereavement on maternal mental health and the importance of proactive, sensitive psychological care.

Post-loss Lactation and Purpose

Bereaved mothers often lactate following infant loss, whether due to premature birth, stillbirth, or neonatal death. Lactation is a natural postpartum process, and when an infant survives, breastfeeding has been shown to reduce maternal stress and improve mood (Krol & Grossman, 2018). Psychological benefits include enhanced attachment, improved emotional wellbeing, and physiological regulation (Gibbs, Forste, & Lybbert, 2018; Xu et al., 2014).

Recent research highlights the sentimental and psychological meaning lactation and milk donation can hold after loss. For some mothers, expressing and donating milk becomes a way to reclaim a lost maternal role. Welborn (2012), in semi-structured interviews with 21 bereaved mothers, found that donation helped them form a new identity as donors, allowing grief to be channelled into altruistic action. Similarly, Ward et al. (2022), using IPA with seven bereaved mothers in Northern Ireland, found that milk donation fulfilled the maternal role, fostered empowerment, and transformed loss into generosity. In Australia, Waldby, Noble-Carr, and Carroll (2023) conducted in-depth interviews with 17 bereaved mothers and seven fathers, revealing both the emotional and physical demands of lactation after loss. Their findings emphasised the positive impact of tailored support, with themes of meaning-making, maternal identity, and reaffirmed maternal capacity.

While historical literature focused on coercive wet nursing, voluntary milk donation after perinatal loss remains underexplored. Yet emerging studies suggest it offers bereaved mothers a meaningful path to reclaim agency, express care, and reassert identity.

Meaning-making

The process of meaning-making following a bereavement is a key concept in both perinatal and maternity psychology. Meaning-making is viewed as the reconstruction of a person's world following a loss, allowing them to organise their changed reality and conceptualise a new future (Neimeyer, 2001; Neimeyer & Thompson, 2014). In many cultures, grief rituals serve as structured processes that facilitate meaning-making, particularly in the context of child loss (Markin & Zilcha-Mano, 2018).

Research suggests that bereaved mothers similarly engage in meaning-making following perinatal loss (Alvarez-Calle & Chaves, 2023). Some mothers form personal rituals, while others find meaning in actions that extend beyond their immediate loss, such as breast milk donation (Oreg, 2020). Oreg (2019) conducted a content analysis of 80 bereaved mothers' personal accounts of milk donation, and posits that for certain mothers, lactation and breast milk donation represent a way to integrate loss into a meaningful framework, providing a sense of purpose amidst grief.

The desire to make sense of perinatal loss aligns with Uren and Wastell's (2002) findings that seeking meaning in bereavement can aid in psychological adjustment. This is particularly relevant in the context of breast milk donation, as it enables bereaved mothers to engage in an act of care and connection, even in the absence of their own child. By donating milk, these mothers not only provide nourishment for other infants but also find solace in the continuation of their child's legacy in a tangible and life-affirming manner.

Theoretical Perspectives on Perinatal Grief

Contemporary grief theories offer further insight into how bereaved mothers may navigate the complex psychological terrain following perinatal loss. The Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999, 2010) conceptualises grief as a dynamic oscillation between *loss-oriented* experiences, such as yearning, sadness, and emotional pain, and *restoration-oriented* processes that involve adapting to new roles and engaging in purposeful activities. Within this framework, breast milk donation may be understood as a restorative act that enables mothers to re-engage with aspects of a disrupted maternal identity and find meaningful ways to move forward, even in the shadow of profound loss. Additionally, the Continuing Bonds Theory (Klass, Silverman & Nickman, 1996) challenges the notion that healthy grieving requires detachment from the deceased, suggesting instead that maintaining an ongoing emotional connection can be both adaptive and comforting. For bereaved mothers, donating milk may serve as a tangible expression of this continuing bond, an act that honours the baby's existence and embeds their legacy into a life-sustaining contribution for others. These frameworks enrich understandings of how seemingly physical acts, like lactation and milk donation, may carry deep symbolic and psychological meaning in the wake of perinatal bereavement.

Scottish Context

Although the psychological benefits of breast milk donation after perinatal bereavement are growing in recognition, discussions about this option remain rare in many countries, with lactation suppression often recommended instead (Carroll et al., 2020). In Scotland, such conversations with newly bereaved parents are still uncommon in neonatal and maternity care. While the Glasgow Milk Bank, established in 2013, provides donor milk for premature and medically vulnerable infants (Alyahya et al., 2019), the Memory Milk Gift (MMG) service, dedicated to milk donation following perinatal loss, was only introduced in 2021.

The recent establishment of MMG offers a unique opportunity to explore the experiences of bereaved mothers in Scotland who have donated milk after loss. Understanding the psychological impact of this may offer insights into bereavement and inform more supportive care for mothers. This research could also help increase post-loss milk donations, improving donor milk access for vulnerable infants.

Research Aims

By interviewing bereaved mothers who have donated milk, the study seeks to illuminate their motivations, emotional responses, and reflections on the process. The aim of this study is to investigate the experiences of bereaved mothers who donate breast milk after baby loss, and will seek to gain further understanding by addressing the following research questions:

- Do mothers benefit psychologically from donating milk after baby loss and, if so, what are these benefits?
- Do mothers feel supported by their partner and wider families to donate milk after baby loss, and how does this impact decisions to donate and/or cease lactation?
- Do the circumstances around the baby loss affect the mother’s decision to donate milk or what meaning they make from donation?
- How did bereaved mothers experience staff when having conversations about lactation and milk donation after loss, did they feel supported and what if any improvements could be made to these interactions and conversations?

Methods

Ethics

This study was reviewed by the South East Scotland Research Ethics Committee 02 and a favourable opinion was given by the committee (IRAS 339661) on the 20th December 2024, and the NHS Greater Glasgow and Clyde Research and Innovation Department (UGN24MH396) provided approval on the 20th January 2025. Correspondence in relation to ethical approval is provided in Appendix 2.3 (p90), 2.4 (p95), and 2.5 (p97). Informed consent was obtained from participants verbally and on a consent form, as shown in Appendix 2.8 (p102).

Design

A qualitative design was employed to explore the experiences of mothers who had donated their breast milk following the loss of their baby. Considering the deeply personal and emotional nature of the study, along with the small and specific population available with these experiences, Interpretative Phenomenological Analysis (IPA) was chosen as an appropriate method for addressing the research question and providing rich insights. IPA is a powerful qualitative analysis approach that provides an in-depth understanding of an individual's personal experience, particularly in emotionally complex or transformative contexts (Smith & Nizza, 2022). It is particularly well suited to exploring how individuals interpret and derive meaning from complex or emotionally challenging topics (Tuffour, 2017).

Recruitment

The study was conducted within NHS Greater Glasgow & Clyde's Memory Milk Gift service, based at the Queen Elizabeth University Hospital, in collaboration with the University of Glasgow's School of Health and Wellbeing. Participants were eight unrelated mothers who had experienced infant loss and subsequently donated breast milk to the Glasgow service. Although recruitment approval had also been obtained for Chester Milk Bank, this was ultimately unnecessary due to successful recruitment at the Glasgow site.

At the time, 38 mothers had donated to the Memory Milk Gift service and met eligibility criteria (see Table 1). All had expressed interest in future research via donor forms and provided consent to be contacted. In consultation with supervisors and clinicians, a batch recruitment strategy was agreed upon to ensure a manageable sample size and avoid having to decline willing participants. Ten eligible donors were contacted initially, followed by six more the following week. Once the target sample was reached, no further contact was made.

The principal investigator (PI) had no access to donor lists or identifying information. Donor selection was managed by clinical staff within the Memory Milk Gift team, with input from the lead nurse and service manager. Consideration was given to the recency of each participant's loss to minimise potential distress. Clinical staff emailed eligible donors with the study invitation, including the information sheet and consent materials. Interested participants contacted the PI directly or via the service. All were offered an initial phone call with the PI prior to providing written consent. Verbal consent was also re-confirmed at the start of recorded interviews. Study documents are included in Appendices 2.6 (p98), 2.7 (p99), 2.8 (p100), 2.9 (p101) and 2.10 (p102).

Table 1. Inclusions and Exclusion Criteria

Inclusion Criteria
Participants must all be over 18 years old
Experience perinatal loss of a baby >16 weeks gestation
Expressed and donated breast milk to Memory Milk Gift service in Glasgow
Participants should be resident in the United Kingdom

Participant Characteristics

Eight bereaved mothers, aged 25-36 years (M=31 years) took part in the study, each of whom had donated breast milk following the loss of a baby. All participants identified as women and mothers. At the time of loss, five participants were experiencing their first pregnancy, while three had experienced a previous loss, birth, or living child. Losses ranged from second trimester to infancy, with babies dying between 16 weeks gestation and 15 months of age. Types of loss included stillbirth (n=1), termination for medical reasons (n=1), post-natal medical complications, or clinical error (n=6). For some, the loss was sudden and traumatic; for others, it followed a difficult neonatal period.

Lactation emerged at different points in the participants' experiences. Most mothers (n=6) began expressing milk after the birth of the baby they lost; one participant expressed antenatally following a subsequent pregnancy, and one expressed following their baby's birth and following a subsequent pregnancy. The duration of expression varied, ranging from a one-time colostrum donation to several weeks, months, or ongoing expression. For some, donation ended when their baby died; others expressed for longer, or during a subsequent pregnancy. Full details of participant characteristics can be found within Table 2.

Table 2. Participant Baby Loss Characteristics

Participant number	**Mother's Name**	**Pregnancy number (and other context)**	**Baby's Name**	**Age of Loss**	**Reason/Type of Loss**	**Stage of Expression**	**Reason or Time of Stopping**
1	Emilia*	2nd pregnancy (one older child & one younger)	Poppy	16w	TFMR (Malformation)	Subsequent Pregnancy	Subsequent child weaned
2	Clara*	First pregnancy (8 years of IVF)	Aris	23w 2d	Pre-term birth complications and infection.	Following live birth	When baby passed away
3	Elizabeth*	2nd pregnancy (one previous miscarriage)	Rebecca*	(born at 32w5d) Died 10w 2 days old	Pre-term birth, malformation, organ failure	Following live birth	When baby passed away
4	Bethany*	First Pregnancy	Naiomi	(born at 40w) Died 24 days old	Malformation, oxygen deprivation, organ failure	Following live birth	When baby passed away
5	Selene*	First Pregnancy	Artemis	29w	Malformation, pre-term birth and complications	Following live birth	7 full bottles / 4 weeks
6	Imogen*	First Pregnancy	Angus	41w2 days (stillbirth)	Stillbirth. Group B strep.	Following stillbirth	6 months after death of baby
7	Hazel*	First pregnancy (twin pregnancy & one subsequent daughter)	Layla	(born at 34 weeks) Died 15 months	Medical mistake	Post-birth and subsequent pregnancy	Ongoing
8	Diana*	Second pregnancy (previous miscarriage & one living child now)	Giai	2 days old	Born not breathing, period without oxygen, life support switched off	Following live birth	When baby passed away

*Indicates where a Pseudonym has been used.

Sample Size

There is no universally agreed sample size for Interpretative Phenomenological Analysis (IPA), and researchers prioritise the depth of individual experience and adherence to IPA principles over fixed numbers (Eatough & Smith, 2017). While some guidance suggests a range of up to ten participants, and even single-participant studies can be justified (Robson, 2002), recent recommendations for doctoral-level IPA research propose six to eight participants to allow detailed idiographic analysis (Smith & Nizza, 2022).

Given the specific nature of this study, bereaved mothers who donate breast milk following loss, and the small pool of potential participants via the Memory Milk Gift service, a target sample of 4–8 participants was both realistic and methodologically appropriate. Ultimately, eight participants were recruited. Unlike thematic saturation approaches, IPA does not aim for saturation; instead, richness and complexity in data are the guiding standards (Braun & Clarke, 2021). This study's eight in-depth interviews provided sufficient interpretive material to meet the test of data sufficiency (Braun & Clarke, 2021), supporting robust idiographic analysis. Given the specific context and small participant pool, eight participants were both realistic and sufficient.

Data Collection

A semi-structured interview schedule was developed by the PI after reviewing existing literature and consulting with the Chief Investigator and Field Supervisor. Further input was sought from experts by lived experience. Feedback on the draft schedule was obtained from four mothers in an online group matching the target population, two with experience of late-term baby loss and two who had expressed and donated breast milk. Feedback was positive, with suggestions on wording and question order incorporated into the final schedule (Appendix 2.11, p103).

The interview guide explored key areas: pregnancy and circumstances of the baby's death; motivations and experiences of milk donation; emotional and psychological impacts; family and social support; decisions about stopping donation; healthcare interactions; and experiences with the Memory Milk Gift service. Interviews were conducted by the PI at the Queen Elizabeth University Hospital maternity psychology department or online via Microsoft Teams, lasting 24 to 132 minutes. Consent was obtained to record interviews, either via Dictaphone (in person) or Teams (online). Recordings were stored securely on the University of Glasgow's password-protected, two-factor authenticated OneDrive and deleted after transcription.

Participants received a £20 online voucher and a debrief document following completion of the interview. The PI transcribed all interviews, with transcripts pseudonymised before analysis. Many participants requested their babies' real names be used, which was respected. All were offered the chance to review their transcripts, though none chose to do so.

Analysis

Interpretative Phenomenological Analysis (IPA) was used to explore participants' lived experiences, following Smith and Nizza's (2022) updated approach. The principal investigator (PI) conducted the analysis, adhering to IPA's idiographic, inductive, and interpretative principles. Each transcript was read and re-read for immersion, with exploratory notes made on descriptive, linguistic, and conceptual aspects of meaning-making. From these, Personal Experiential Themes (PETs) were developed to capture significant psychological aspects of each participant's experience. Superordinate and subordinate themes were then organised within each case before cross-case analysis identified patterns of convergence and divergence. An example of this process for Participant 5 can be found in Appendix 2.16 (p108). This informed the development of Group Experiential Themes (GETs), reflecting shared experiential meaning while respecting individual variation. One transcript was independently reviewed by the research and field supervisors to enhance rigour. Quotations were selected to illustrate themes and prioritise participant voice. IPA's focus on sense-making of complex, emotionally charged experiences made it well suited to this study. Further details of the analysis process are provided in Appendix 2.13 (p105).

Reflexivity

The PI had no previous relationship with any of the study participants. The PI is a female with one child, has previously accessed NHS GGC maternity services, and has personal experience of breastfeeding and expressing breast milk. However, the PI has not experienced baby loss and has never donated breast milk. The PI holds an undergraduate degree and a masters degree in Psychology, and is currently working towards her doctorate in clinical psychology. The PI was working as a trainee clinical psychologist within forensic child and adolescent mental health services at the time of the study, and had no clinical involvement in maternity psychology services. The study participants knew about the researchers' participation on clinical training and motivations for research, but were not aware of her personal circumstances of having a child herself. The PI utilised a reflective diary throughout the analysis process in order to facilitate discussions within supervision and support transparency in data analysis. An example of this can be found in Appendix 2.14 (p106).

Results

Through close, idiographic engagement with the data, five Group Experiential Themes (GETs) were developed to reflect shared patterns of meaning across participants, while preserving the nuanced and personal accounts of each mother. An example of GET development can be found in Appendix 2.15 (p107). Each GET contains sub-themes that capture specific aspects of experience and meaning-making. These are presented in Table 3.

Table 3. Group Experiential Themes and Subthemes

Group Experiential Themes	Subthemes
(1) Making Meaning and Rebuilding After Loss	Turning tragedy into something good
	Reclaiming agency through action
	Pride and legacy
(2) Milk as a Symbolic Link to the Baby	Tangible connection and continuity
	Letting Go: Grief and Readiness
(3) Emotional Complexity and the Psychological Labour of Donation	Grief, guilt, and ambivalence
	Protection through avoidance or suppression
(4) Lived and Embodied Experiences of Lactation After Loss	Emotional and physical demands of donation
	The presence or absence of milk
	Lactation as evidence of motherhood
(5) Relational and Systemic Support: Facilitators and Barriers to Donation	Tangible acknowledgment: how memory items matter
	Gaps, silences, and harmful communication
	Partner and family support: present or peripheral

Making Meaning and Rebuilding After Loss

This theme captures the ways in which mothers sought to make meaning from their baby's death by engaging in actions that fostered a sense of purpose, legacy, or agency. Milk donation was experienced not only as a practical act, but as an emotionally and symbolically rich avenue through which participants could continue mothering, honour their baby, and reclaim some control in an otherwise powerless situation.

1.1 Turning Tragedy Into Something Good

For many bereaved mothers, milk donation was a way to transform grief into meaning, not just helping others, but honouring their baby's legacy. It offered purpose, value, and a sense that their baby's life left a lasting imprint.

> "I think it was to do something in like Rebecca's name. Like, you know, to have that… to know that out of something tragic and hurtful and whatever it was to us, there was still good coming from it."
> *— Participant 3*

> "I just didn't want it to go to waste. I kind of didn't want it to just like, like, sit in the freezer… I wanted it to go to some kind of good use."
> *— Participant 8*

Across these accounts, donation was experienced as both a symbolic act and a practical solution, a way to give meaning to unused milk, to honour the child who could not be fed, and to find a small sense of redemption or pride in a situation defined by loss. Donation often offered a form of emotional redirection and a way to derive benefit from absence.

1.2 Reclaiming Agency Through Action

For many participants, milk donation was a rare act of agency after traumatic loss, a choice rooted in autonomy, self-determination, and emotional resilience. Several mothers described feeling confident in their decision, regardless of others' views or expectations.

> "No, I'd kinda made my mind up that that's what I was gonna do anyway. If everyone had said don't do it and stuff, I still would have for my own gratification then."
> *— Participant 1*

For others, donation helped re-establish a connection with their body after feeling disempowered by the clinical or traumatic nature of the birth and loss. Lactating became a way to reassert physical and emotional agency, and to reclaim a relationship with themselves that had been disrupted.

> "As I told you before it [lactating] was the only natural thing that was happening to me during all these interventions... all the control… or some of it, not all of it, came back through that. From that point on, I started to have a relationship with myself, through the milk… with my body."
> *— Participant 5*

Even when donation was not framed in explicitly physical terms, participants often described it as a meaningful act they chose to undertake and something that aligned with their values and instincts.

> "I didn't have to. It was just something, I feel quite strongly that I wanted to be able to try and do."
> — *Participant 7*

For these mothers, donation was positioned not as something imposed or passively accepted, but as a deliberate and empowered decision and a way to reassert selfhood in the face of loss.

1.3 Pride and Legacy

For some mothers, milk donation was a way to honour their baby's life and ensure their memory held meaning beyond death. Giving to other infants carried deep emotional significance, affirming their identity as mothers and offering pride in creating a legacy of care.

> "I was so grateful that Artemis's legacy was going to continue, with her milk some other children are going to be fed."
> — *Participant 5*

> "But somehow his name there maybe… I don't know, be a bit positive and thinking that, oh, I've done something and he won't be forgotten, you know."
> — *Participant 2*

These mothers described donation as both a tribute to their child and a continuation of the maternal role, providing a sense of emotional solace through symbolic impact. Pride also emerged from the personal effort involved in expressing milk, especially in the face of physical and emotional hardship.

> "So it then became a thing, I think… breastfeeding almost became… I had to work so hard for that in the start. And the importance of I felt really proud of myself for being able to express…"
>
> — *Participant 7*

For this participant, pride was not only in helping others, but also in her own perseverance, reclaiming of maternal function, and emotional strength during a time of profound disruption.

Milk as a Symbolic Link to the Baby

This theme explores how milk became both a physical product and a symbolic link to the baby. For grieving mothers, continuing to lactate and donate provided emotional connection, supported healing, and formed a meaningful part of their ongoing maternal journey.

2.1 Tangible Connection and Continuity

For some mothers, expressing and donating milk became a tangible expression of their continued connection to their baby. In the absence of their child, lactation offered a way to sustain a maternal role and maintain a sense of closeness. The milk itself, and the act of producing it, carried emotional meaning that extended beyond its practical function.

> “Almost like… Like you were feeding your own baby, but it's helping someone else's.”
> — *Participant 1*

> “The continuing to pump is that again it's that continuing that connection to Layla.”
> — *Participant 7*

Donation could also reflect a broader sense of maternal solidarity. For some, helping other babies was an extension of their own mothering and a way to honour their child through the act of care.

> “I think that, that it's a connection. It's like we mums, we need to help each other, you know.”
> — *Participant 2*

In these accounts, milk became more than a substance, it symbolised the ongoing presence of the baby and a continued identity as a mother, even in the midst of loss.

2.2 Letting Go: Grief and Readiness

The decision to stop expressing milk was not always immediate or straightforward. For some participants, ending lactation marked a natural point of closure. This was sometimes seen as a reclaiming of identity or a quiet resolution that the donation journey had fulfilled its purpose. For others, the act of stopping brought renewed pain, symbolising another layer of loss.

> “Gradually I did it less and less, until one day there were only some drops coming out… For me it was such a healing process to come back to where I started.”
> — *Participant 5*

While for some the process of letting go was gradual and therapeutic, others described the psychological strain of recognising that donation could not continue indefinitely. This awareness brought with it a complex emotional reckoning, shaped by individual readiness and the symbolic meaning attached to milk.

> “I think it's that hard psychological bit because… I think what I'm very acutely aware of as well is that you can't donate forever.”
> — *Participant 7*

> "Yeah, there was [reservations]… there was a little bit of like almost letting go of another part of her…"
> — *Participant 8*

For some, stopping was experienced not just as a physical shift, but as a return to self or a necessary end to something emotionally sacred. Whether it brought healing or renewed sorrow, the moment of letting go marked a significant psychological and symbolic transition.

Emotional Complexity and the Psychological Labour of Donation

This theme explores the emotional complexity of lactation and milk donation after baby loss. Mothers described navigating grief, guilt, ambivalence, and avoidance. While donation offered meaning and purpose for some, it also brought challenging emotions that had to be processed alongside the drive to give back.

3.1 Grief, Guilt, and Emotional Cost

For some mothers, the emotional experience of milk donation after baby loss was marked by ambivalence. While donation offered a form of emotional release or comfort, it also invoked difficult feelings such as guilt, grief, and self-blame. The decision to donate did not erase pain but existed alongside it becoming a source of meaning that could sometimes lighten the weight of loss.

> "And also there's probably some days where, like nothing helps. But... in an overall picture, yeah, for me anyway, it has helped to know that I've done it."
> — *Participant 3*

> "Yeah, it's a, it's a little of positivity in all this negativity that you're going through, you know…"
> — *Participant 4*

These reflections illustrate how donation functioned as a complex emotional coping strategy. It could offer solace, a sense of purpose, or symbolic restitution. However, it also stirred feelings of inadequacy or regret. For these mothers, the act of giving milk was not simple or purely comforting, but emotionally charged and deeply entwined with their ongoing grief.

3.2 Protection Through Avoidance or Suppression

For some mothers, the emotional burden of lactation after loss led to protective strategies such as suppressing milk or emotionally distancing from the process. Continuing to express milk was often too painful, so donation involved giving what had already been expressed, offering purpose without prolonging the experience. These actions served as a form of emotional self-preservation, creating space between their grief and the physical act of giving milk.

> "I took tablets to stop my milk when I was in hospital because it came in and yeah, that was really difficult… I was just like, yes, I'll take that [medication] because I just don't want this feeling."
> *— Participant 8*

These accounts reflect how some mothers chose to limit their emotional or physical engagement with lactation to avoid further distress. Whether through stress, emotional overwhelm, or a desire to avoid prolonged grief, these decisions represented protective responses to an already devastating experience.

Lived and Embodied Experiences of Lactation After Loss

Lactation and milk donation were central to many mothers' experiences after loss, intertwining physical demands with emotional grief. For some, donation offered connection to their baby's memory; for others, it was a complex and sometimes painful process of endurance and healing.

4.1 Emotional and Physical Demands of Donation

Lactation and milk donation after baby loss placed significant emotional and physical demands on mothers. For some, it was draining and logistically challenging; for others, it offered a quiet space for reflection amid grief, despite its taxing nature.

> "It does get time consuming at some point… having to rely on making sure you have a pump."
> *— Participant 6*

These quotes highlight the practical and physical burdens of ongoing milk expression. Participants described the emotional and logistical strain of managing grief alongside the routines of lactation, often driven by a strong internal motivation despite the toll.

> "So at the beginning having that eight times a day of like 15 minutes of just quiet and peace was really good to just gather my thoughts and think… It was really good to just have that moment of quiet to just think about what was happening."
> *— Participant 6*

For this mother, the repetitive nature of pumping became a quiet space for emotional processing, suggesting that amidst the effort and exhaustion, donation could also serve as a grounding and reflective practice.

4.2 The Presence or Absence of Milk

The presence or absence of breast milk after loss became a powerful emotional marker for many mothers. For some, milk production offered reassurance, a physical confirmation of their maternal identity, while for others, it acted as a painful reminder of the child who could no longer feed from them. The emotional significance of lactation in this context raised complex questions about motherhood, caregiving, and bodily meaning after loss.

> “My worry was because I was only 32 weeks… Would like… would I be able to express that early?”
> — *Participant 3*

> “…it was amazing to be able to see that I did have milk… it was such a relief to know that I could do it.”
> — *Participant 6*

These participants expressed both anxiety and relief around the emergence of milk, illustrating how lactation was experienced not only as a physical process but as a deeply emotional milestone. For some, being able to produce milk brought comfort and a sense of validation in an otherwise uncertain time.

> “It’s really psychologically hard to be trying to donate for a baby that isn’t feeding from you. In some ways by having twins… I had somebody to keep up my supply.”
> — *Participant 7*

Here, the emotional difficulty of producing milk for a baby who had died is acknowledged directly. The presence of a surviving twin created a bittersweet tension, helping sustain milk supply, but also highlighting the absence of the baby who could not feed.

4.3 Lactation as Evidence of Motherhood

For many mothers, lactation and donation powerfully affirmed their maternal identity after loss. Producing milk became a tangible reminder they were still mothers, helping them reclaim purpose and stay connected to a caregiving role despite their baby’s absence.

> “Like I there’s probably meaning in it [lactating & donating] for me as a mother. Yeah, because it's like I feel like all mothers want to help each other in some sort of way.”
> — *Participant 4*

> “I wish you'd have a section where you talked about milk donation and how useful it can be in dealing with grief, because I really felt like being productive was helping me with my grief journey and like giving me stuff to do it makes me feel useful and making me feel like I was still being a mother.”
> — *Participant 6*

These mothers articulated how donation offered not only emotional meaning, but also a way to enact motherhood in the absence of their baby. Through practical, purposeful action, they found relief from grief and maintained a sense of maternal identity.

> “I told her, I don’t have milk. In my head I was thinking, ‘am I even a mother, is this even a child, how can my body have milk?’”
> *— Participant 5*

In contrast, this participant reveals the deep emotional turmoil that can accompany the absence of milk. For her, lactation was closely tied to identity, and the body’s inability to produce milk amplified feelings of confusion and loss. This quote underscores how closely the physical and psychological dimensions of motherhood were entangled in the donation experience.

Relational and Systemic Support: Facilitators and Barriers to Donation

Recognition and remembrance played a vital role in the milk donation process for many mothers, offering a way to honour their child’s memory. Acts like having their child’s name placed on a tree or receiving a commemorative pebble served as powerful symbols of their child’s legacy. These gestures of acknowledgment helped mothers navigate their grief, reinforcing their maternal identity and providing emotional validation in the face of loss.

5.1 Tangible Acknowledgement: How Memory Items Matter

Memory items such as commemorative pebbles and plaques were meaningful forms of tangible recognition for milk-donating mothers. These objects offered a lasting connection to their baby, symbolising their child’s existence and legacy. For many, these small but significant gestures brought comfort, validated their grief, and affirmed their identity as mothers. Often provided by hospital or milk bank staff, the care taken to offer these items was itself impactful, reflecting sensitive support and visible acknowledgment of both their loss and their donation.

> “’Cause I know that when you donate in like the name of a baby and that, you can get like the little pictures and the wee kind of thing, and that really just made everything a lot better.”
> *— Participant 1*

This quote highlights how simple, tangible items such as photographs and keepsakes helped the participant feel more connected to her child’s memory. These items provided comfort and enhanced the emotional significance of the donation process.

> “I still have the Pebble with his name… so it's always it's always a reminder that he exists and he's on the hospital wall as well... So yeah, it helps. I know it's it sounds very small, you know, he's just his name on the wall, but it's very big for a person who lost

> the baby, you know.”
> — *Participant 2*

For this participant, the pebble with her child’s name served as an essential reminder of the child’s existence. Despite the simplicity of the gesture, it provided an important emotional anchor during her grieving process.

> “I think it was very important for me, like extremely important, that I got something for this donation. They gave me this bit of wood, and it said in loving memory or Artemis on the back. I think this actual thing that I could hold in my hand, that I could take with me in my bag, or have it next to my bed side.”
> — *Participant 5*

This quote illustrates the deep emotional value of holding a physical memento, something that could be kept close. For this participant, the memorial item provided ongoing comfort and connection, reinforcing the significance of the donation.

> “Whereas actually having, just even the little token gestures… they then sent the photos of the tree that they put Layla's name on to and the Pebble with… with Layla's name… it's having little bits of Layla everywhere. So I like the fact that Layla's name is part of the milk tree and we have that. It's just, it's proof of Layla having existed. That Layla was relevant and she, she mattered.”
> — *Participant 7*

For this participant, the visual reminders of her child, such as the pebble and the tree with her child’s name, provided proof of her child's existence and significance. These tokens gave her a sense of ongoing connection to her child and validation for her grief.

5.2 Gaps, Silences, and Harmful Communication

Mothers who donated breast milk after loss often encountered communication gaps, silences, or insensitive responses from healthcare professionals. These experiences added to the emotional complexity of donation, leaving some feeling unsupported or misunderstood. In some cases, their efforts were overlooked or dismissed, compounding their grief and highlighting the need for more sensitive, informed communication around milk donation.

> “So nobody spoke when, when she passed away, nobody spoke to me about it [breastmilk].”
> — *Participant 3*

This quote underscores the silence surrounding milk donation after a baby’s death. The participant felt that there was no guidance or conversation about the next steps, leaving her to navigate the experience alone.

> “This midwife, to be honest, dismissed me wanting to continue pumping and taking the milk. I was like… who are you?”
> — *Participant 5*

Here, the participant describes feeling dismissed by a healthcare professional when she expressed a desire to continue pumping and donating milk. This response made her feel unsupported and invalidated in her decision.

> “There wasn’t even kind of a like, ‘Oh, you’ve got a lot that you’re juggling… thank you so much, that you’ve managed to do that.’ It was more just kind of treated a little bit as an expressing number.”
> — *Participant 7*

This quote reflects the lack of recognition and acknowledgment for the participant’s efforts. Rather than receiving emotional support for her donation, she felt her efforts were reduced to a mere task, further reinforcing the emotional challenges she faced.

5.3 Partner and Family Support: Present or Peripheral

The role of family and partners in the milk donation process varied considerably among participants. While some felt actively supported and emotionally held by those around them, others experienced a lack of engagement or even subtle resistance, leaving them to navigate the experience more independently. Regardless of the level of support, participants often described the decision to donate as deeply personal and something they were ultimately determined to do for themselves.

> “It was just my husband who knew about it and he never said anything. Actually, he let me take all the decisions.”
> — *Participant 1*

This participant describes a quiet but respectful form of support. Her husband did not actively engage in the process, but his silence was not interpreted negatively, rather, it was perceived as trust in her autonomy and emotional authority to make the right decision for herself.

> “Yeah, so like my mum and my partner's mum knew I was going to breastfeed, and knew I was pumping and all that… they were all being really supportive with it.”
> — *Participant 4*

Here, active emotional and practical support from family members offered comfort during a highly emotional time. Having this backing helped the participant feel that her choice was valid and recognised, adding a layer of collective care to what was otherwise a solitary grieving process.

> “Nobody's opinion would have been able to put… nobody has been negative about it. But I think if they had been negative, I feel so strong about my own beliefs…”
> — *Participant 7*

This quote illustrates the strength of personal conviction. Even in the hypothetical absence of support, this mother’s decision to donate was anchored in her own values. Family support was appreciated, but not essential and her determination to act in accordance with what felt right to her was primary.

> “So the way my mum was made me feel very down about it, but otherwise others didn't have a big impact and my partner was very supportive about it. Which was good. But ultimately I was just happy that I was doing it. I would have done it, I think, regardless.”
> — *Participant 6*

This participant described her mother’s lack of support as emotionally difficult. Her mother appeared to disapprove of breastfeeding, frequently questioning when she would stop and suggesting that formula was just as good. Although this undermined her confidence, the support of her partner helped offset the impact. Ultimately, her strong personal motivation carried her through, reinforcing the importance of even limited emotional backing

Discussion

This study explored the lived experiences of bereaved mothers who donated breast milk following the death of their baby, using Interpretative Phenomenological Analysis (IPA) to examine the psychological, relational, and contextual processes surrounding lactation and donation after loss. In response to the overall aim, to explore how bereaved mothers make sense of their experiences of milk donation and the factors that shape this process, five Group Experiential Themes (GETs) were developed, offering insight into the symbolic meaning, emotional complexity, and support systems associated with donation.

In response to the first research question regarding benefits of milk donation after baby loss**,** the findings suggest that milk donation often served as a psychologically reparative act. Mothers described donation as a way to "turn tragedy into something good," reframe their grief, and maintain a symbolic connection to their child (GETs 1, 2 and 3). The act of expressing and giving milk provided continuity with mothering, supported identity reconstruction, and helped restore a sense of agency and purpose following traumatic loss. Although donation did not erase grief, it offered emotional comfort and a way to reclaim control in a situation defined by helplessness. These findings echo previous research suggesting that milk can be both a painful reminder and a source of meaning-making in grief (Waldby, Noble-Carr & Carroll, 2023; Oreg, 2019, 2020). They also support earlier observations that donation may serve a reparative function for bereaved mothers (Welborn, 2012; Ward et al., 2022).

These findings complement Waldby, Noble-Carr and Carroll (2023), who described milk as both a painful reminder of loss and a powerful medium for memorialising the baby. While their work emphasised the embodied and social dimensions of milk as a biological resource, the present study extends this by foregrounding mothers' psychological meaning-making. Here, milk was not only biologically significant but emotionally transformative with its meaning shifting over time as mothers moved through grief, identity, and connection. Additionally, Ward et al. (2022) emphasised how perinatal loss disrupts narrative coherence and identity continuity, often leaving parents searching for ways to make sense of their experience. The current study extends this insight by illustrating how milk donation can serve as one such narrative anchor, helping mothers to bridge the gap between the trauma of loss and the ongoing project of living as a parent to a baby who is no longer present.

In response to the second research question on partner and family support, participants described varied relational dynamics (GET 5). Some received quiet encouragement from partners or family, while others encountered ambivalence or subtle disapproval, particularly from older generations. Yet across accounts, mothers emphasised their autonomy in donation decisions. The presence of at least one supportive figure, often a partner, appeared to buffer the emotional impact of less supportive family dynamics. This supports earlier findings on the importance of relational recognition in parental grief, particularly how emotional validation from close others can help reinforce maternal identity (Ward et al., 2022; Oreg, 2020). The emotional, cultural, and relational significance of lactation after loss also aligns with recent literature on motherhood and grief. Welborn (2021) highlighted how maternal identity is socially enacted and emotionally negotiated, especially post-loss. Participants in this study reaffirmed their maternal role through donation, remembrance, and continued caregiving. The current findings extend Welborn's work, illustrating how maternal identity may be reasserted through embodied acts, such as lactation, even when social recognition is limited.

In response to the third research question regarding the circumstances of the loss and meaning-making processes**,** the findings indicate that the timing, context, and nature of the loss played a significant role in shaping participants' decisions and emotional readiness to donate (GETs 2, 3 and 4). Mothers who lost their baby at later gestational stages or who had living children often experienced milk donation as a more integrated part of their grieving process. In contrast, those whose loss occurred earlier or under traumatic circumstances sometimes described a more conflicted or physically distressing experience. Emotional readiness and bodily responses (e.g. presence or absence of milk) were key factors influencing donation decisions, and the act of stopping donation was often described as another layer of loss. These findings reflect previous observations that embodied experiences, such as lactation, can shape how mothers navigate both grief and maternal identity after perinatal loss (Waldby et al., 2023; Welborn, 2012; Ward et al., 2022).

In response to the final research question with regards to communication, staff and service supports**,** participants reflected on both positive and distressing encounters with healthcare professionals. Symbolic tokens, such as memory pebbles or commemorative trees, were deeply appreciated and perceived as validating (GET 5). These items offered tangible acknowledgement of the baby's existence and the mother's grief. However, participants also described inconsistencies in how milk donation was communicated and supported by staff. In some cases, opportunities to discuss lactation were missed, or information was delivered insensitively, contributing to feelings of distress and marginalisation. These findings highlight the importance of timely, compassionate, and informed staff communication in post-loss care pathways. This resonates with literature on the need for improved professional awareness and sensitive engagement with lactation in the context of bereavement.

Taken together, the findings demonstrate that breast milk donation following baby loss can serve as a meaningful psychological and relational process. It is shaped by a complex interplay of grief, identity, physicality, social relationships, and systemic factors, all of which warrant careful consideration in both clinical and policy settings.

Theoretical Integration

The findings of this study contribute to understanding how bereaved mothers navigate loss through embodied, relational, and symbolic practices. They offer support for the continuing bonds framework (Klass, Silverman & Nickman, 1996), which suggests grief often involves maintaining an enduring connection with the deceased rather than severing ties. Participants described milk donation as a tangible way of sustaining their relationship with their baby, reaffirming maternal identity and offering care in the absence of their child. These bonds were not solely emotional but materially expressed through lactation and socially legitimised by donation. Rather than resolving grief, mothers actively constructed meaning and identity around their loss, with milk serving as a conduit.

The findings also resonate with Stroebe and Schut's (1999) Dual Process Model of bereavement, which describes a dynamic movement between loss-oriented and restoration-oriented coping. Participants engaged with their loss (through donation and remembrance) while also oscillating away from it (via emotional suppression or stopping lactation). Expressing milk became both a means of processing and, for some, a source of vulnerability to manage. These findings underline the complexity of psychological adaptation following baby loss and reinforce that both confronting and avoiding grief can be functional aspects of bereavement coping.

Further, the findings align with meaning-making theories, including Neimeyer's (2001) model of meaning reconstruction and Oreg's (2019, 2020) work on perinatal loss. Participants described donation as a reparative act, transforming trauma into narratives of care, legacy, and contribution. This supports Oreg's view that meaning-making often occurs through embodied practices and that reconstructing maternal identity aids psychological recovery. Donation offered mothers a sense of agency during profound helplessness, allowing them to find coherence and value amid disorientation. Several expressed that "something good" emerged from their grief, reflecting both cognitive reappraisal and existential integration.

The MMG service's recent establishment offers a unique opportunity to explore these experiences further, informing bereavement care and potentially increasing post-loss milk donations for vulnerable infants.

Clinical Implications

This study highlights the need for milk donation after baby loss to be recognised as a psychologically meaningful act, not just a biological or altruistic one. For many mothers, donation was a powerful form of meaning-making, identity preservation, and connection to their baby. Clinicians, midwives, and support services must acknowledge this symbolic and emotional depth. The findings have specific implications for the Memory Milk Gift service and similar programmes. Participants described donation as empowering, reparative, and central to their sense of motherhood. Incorporating these insights into donor materials and communications could affirm emotional experiences, reduce isolation, and help mothers navigate donation with confidence. Sensitive, well-timed discussions that respect emotional readiness are key. Staff should offer clear, compassionate information and avoid assumptions. Routinely including donation as part of post-loss care may increase uptake and psychological benefit.

Psychology services have a vital role in shaping care pathways, supporting reflective staff conversations, and offering space for mothers processing grief, lactation, and identity. Recognising donation as a reparative act may inform psychological formulation and early bereavement support. Raising awareness of its significance could also promote public health goals, encouraging milk donation and reducing stigma when framed as both generous and personally meaningful. The value of symbolic recognition also emerged strongly. Tangible acknowledgements, like plaques or commemorative pebbles, helped mothers feel their baby was seen and remembered. These gestures should be routinely offered and their emotional impact recognised in bereavement care.

Finally, the findings highlight the need for enhanced staff training and clear policies within hospital trusts and milk banks. Embedding trauma-informed, grief-literate approaches into care and training can ensure compassionate, consistent support for bereaved families at every stage of the donation process.

Strengths and Limitations

This study offers a novel contribution to the underexplored field of perinatal bereavement by examining the psychological and relational experiences of mothers who donated breast milk following the death of their baby. While existing literature has addressed lactation or grief separately, this is, to the author’s knowledge, the first study to focus specifically on milk donation after loss within a Scottish context. Using Interpretative Phenomenological Analysis (IPA) enabled an in-depth exploration of meaning-making, maternal identity, and psychological adaptation.

IPA’s idiographic approach preserved the emotional and contextual complexity of individual accounts while allowing for interpretative synthesis across participants. Semi-structured interviews encouraged openness and participant-led narratives, grounding themes in lived experience. Despite varied experiences, types of loss, and donation durations, mothers consistently described donation as a positive and meaningful part of their grief process at different stages. Reflexivity was embedded throughout, with the researcher acknowledging their dual role as a Trainee Clinical Psychologist and a parent. Reflective journaling, supervision, and transparent analytic decisions supported credibility and mitigated potential bias.

Several limitations must be acknowledged. The self-selecting sample included only mothers who had chosen to donate milk, excluding perspectives of those who declined, discontinued, or were unaware of donation options. The sample also lacked demographic diversity, with all participants identifying as cisgender women from broadly similar cultural and socio-economic backgrounds, limiting transferability. Remote interviews, though flexible, may have affected rapport or emotional containment. Finally, this research captures experiences at a single point in time and does not address how the meaning of milk donation may change longitudinally.

Future Research

Future research should explore the experiences of bereaved mothers who did not donate, whether by choice, inability, or lack of opportunity, to capture the full emotional landscape of lactation after loss, including regret, relief, or ambivalence. Longitudinal studies could offer insight into how the meaning and psychological impact of donation evolve over time, beyond the acute grief captured here. Given the increased number of donors now using the Memory Milk Gift service, future research could explore psychological aspects of donation by comparing groups, for example, donors following pregnancy loss versus stillbirth or infant loss, to examine differences and commonalities that may further inform clinical practice.

Further research should also examine the perspectives of partners, family members, and non-birthing parents, given the varied roles described by participants, from supportive to disapproving. This could inform how families are engaged in bereavement care. The views and practices of healthcare professionals likewise warrant attention, particularly around how donation is discussed and the emotional or ethical complexities they navigate, with findings potentially informing training, communication, and policy. Finally, the role of symbolic memory items deserves further exploration, including their psychological and cultural significance within grief rituals across diverse contexts.

Conclusion

This study provides an in-depth exploration of the psychological, relational, and systemic experiences of bereaved mothers who donated breast milk following the death of their baby. Through rich, idiographic accounts, it highlights how milk donation can serve as a reparative and meaning-making act, one that affirms maternal identity, facilitates continuing bonds, and offers emotional purpose in the aftermath of profound loss. While deeply individual, these experiences were shaped by broader relational, cultural, and institutional contexts. Participants navigated complex emotional terrain, often in the absence of consistent systemic support or informed guidance**.** These findings align with and extend existing bereavement and meaning-making theory, particularly in illustrating how symbolic caregiving can support identity reconstruction and continuing bonds. The findings underscore the need for greater clinical, psychological, and policy recognition of the significance of lactation and milk donation within bereavement care. By giving voice to these underrepresented experiences, this study contributes to a more nuanced understanding of grief, caregiving, and maternal agency. It offers valuable insight for clinical psychologists, healthcare professionals, and policymakers seeking to support families after loss, not only in addressing their pain, but in recognising the quiet acts of love, strength, and remembrance that continue beyond death.

References

Alvarez-Calle, M., & Chaves, C. (2023). Posttraumatic growth after perinatal loss: A systematic review. *Midwifery, 121*, 103736. https://doi.org/10.1016/j.midw.2023.103651

Alyahya, W., Barnett, D., Cooper, A., Garcia, A. L., Edwards, C. A., Young, D., & Simpson, J. H. (2019). Donated human milk use and subsequent feeding pattern in neonatal units. *International Breastfeeding Journal*, *14*(1), 39. https://doi.org/10.1186/s13006-019-0233-x

Armstrong, D. S. (2002). Emotional distress and prenatal attachment in pregnancy after perinatal loss. *Journal of Nursing Scholarship*, *34*(4), 339-345. DOI: 10.1111/j.1547-5069.2002.00339.x

Badenhorst, W., & Hughes, P. (2007). Psychological aspects of perinatal loss. *Best Practice & Research Clinical Obstetrics & Gynaecology*, *21*(2), 249-259. https://doi.org/10.1016/j.bpobgyn.2006.11.004

Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative research in sport, exercise and health*, *13*(2), 201-216. https://doi.org/10.1080/2159676X.2019.1704846

Carroll, K. E., Lenne, B. S., McEgan, K., Opie, G., Amir, L. H., Bredemeyer, S., Hartman, B., Jones, R., Koorts, P., McConachy, H., Mumford, P., & Polverino, J. (2014). Breast milk donation after neonatal death in Australia: a report. *International Breastfeeding Journal*, *9*(1), 23. http://www.internationalbreastfeedingjournal.com/content/9/1/23

Carroll, K., Noble-Carr, D., Sweeney, L., & Waldby, C. (2020). The “Lactation After Infant Death (AID) Framework”: a guide for online health information provision about lactation after stillbirth and infant death. *Journal of Human Lactation*, *36*(3), 480-491. https://doi.org/10.1177/0890334420926946

Eatough, V., & Smith, J. A. (2017). Interpretative phenomenological analysis. *The Sage handbook of qualitative research in psychology*, 193-209. https://doi.org/10.4135/9781526405555.n12

Gibbs, B. G., Forste, R., & Lybbert, E. (2018). Breastfeeding, parenting, and infant attachment behaviors. *Maternal and Child Health Journal*, *22*(4), 579-588. https://doi.org/10.1007/s10995-018-2427-z

Herbert, D., Young, K., Pietrusińska, M., & MacBeth, A. (2022). The mental health impact of perinatal loss: A systematic review and meta-analysis. *Journal of Affective Disorders*, *297*, 118-129. https://doi.org/10.1016/j.jad.2021.10.026

Klass, D., Silverman, P. R., & Nickman, S. L. (Eds.). (1996). *Continuing bonds: New understandings of grief*. Taylor & Francis. https://doi.org/10.4324/9781315800790

Krol, K. M., & Grossmann, T. (2018). Psychological effects of breastfeeding on children and mothers. *Bundesgesundheitsblatt-Gesundheitsforschung-Gesundheitsschutz*, *61*(8), 977-985. https://doi.org/10.1007/s00103-018-2769-0

Markin, R. D., & Zilcha-Mano, S. (2018). Cultural processes in psychotherapy for perinatal loss: Breaking the cultural taboo against perinatal grief. *Psychotherapy*, *55*(1), 20. http://dx.doi.org/10.1037/pst0000122

Neimeyer, R. A. (2001). *Meaning reconstruction & the experience of loss*. American Psychological Association. https://doi.org/10.1037/10397-000

Neimeyer, R. A., & Thompson, B. E. (2014). Meaning making and the art of grief therapy. In *Grief and the Expressive Arts* (pp. 3-13). Routledge. https://doi.org/10.4324/9780203798447

Oreg, A. (2019). Milk donation after losing one's baby: Adopting a donor identity as a means of coping with loss. *Social Science & Medicine*, *238*, 112519. https://doi.org/10.1016/j.socscimed.2019.112519

Oreg, A. (2020). The grief ritual of extracting and donating human milk after perinatal loss. *Social Science & Medicine*, *265*, 113312. https://doi.org/10.1016/j.socscimed.2020.113312

Robson, C. (2002). *Real world research* (Vol. 2). Oxford: Blackwell.

Smith, J. A., & Nizza, I. E. (2022). *Essentials of interpretative phenomenological analysis*. American Psychological Association. https://doi.org/10.1037/0000259-000

Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies*, *23*(3), 197-224. https://doi.org/10.1080/074811899201046

Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on. *OMEGA-journal of Death and Dying*, *61*(4), 273-289. https://doi.org/10.2190/OM.61.4.b

Tuffour, I. (2017). A critical overview of interpretative phenomenological analysis: A contemporary qualitative research approach. *Journal of healthcare communications*, *2*(4), 52. http://dx.doi.org/10.4172/2472-1654.100093

Uren, T. H., & Wastell, C. A. (2002). Attachment and meaning-making in perinatal bereavement. *Death Studies*, *26*(4), 279-308. https://doi.org/10.1080/074811802753594682

Waldby, C., Noble-Carr, D., & Carroll, K. (2023). Mothers, milk and mourning: The meanings of breast milk after loss of an infant. *Sociology of Health & Illness*, *45*(1), 109-127. **https://doi.org/10.1111/1467-9566.13551**

Ward, G., Adair, P., Doherty, N., & McCormack, D. (2023). Bereaved mothers' experience of expressing and donating breast milk: An interpretative phenomenological study. *Maternal & Child Nutrition*, *19*(3), e13473. **https://doi.org/10.1111/mcn.13473**

Welborn, J. M. (2012). The experience of expressing and donating breast milk following a perinatal loss. *Journal of Human Lactation*, *28*(4), 506-510. https://doi.org/10.1177/0890334412455459

Xu, F., Li, Z., Binns, C., Bonello, M., Austin, M. P., & Sullivan, E. (2014). Does infant feeding method impact on maternal mental health?. *Breastfeeding Medicine*, *9*(4), 215-221. https://doi.org/10.1089/bfm.2013.0142

Appendices

Appendix 1.1: ENTREQ Checklist

Item No.	Guide and Description	Report on page #
1. Aim	State the research question the synthesis addresses	17
2. Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis)	22-23
3. Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved)	18-19
4. Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type)	19
5. Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources	18
6. Electronic Search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)	18 & 80
7. Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies)	19-20
8. Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions)	25-29
9. Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development)	21

10. Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings)	29
11. Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting)	29
12. Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required	20
13. Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale	29-30
14. Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software)	22
15. Software	State the computer software used, if any	None used
16. Number of reviewers	Identify who was involved in coding and analysis	22
17. Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts)	30
18. Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary)	31-32
19. Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive	30
20. Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation	33-38
21. Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct)	39-42

Appendix 1.2 : CASP Checklist

https://casp-uk.net/casp-checklists/CASP-checklist-qualitative-2024.pdf

Appendix 1.3: Example Search Strategy – EMBASE

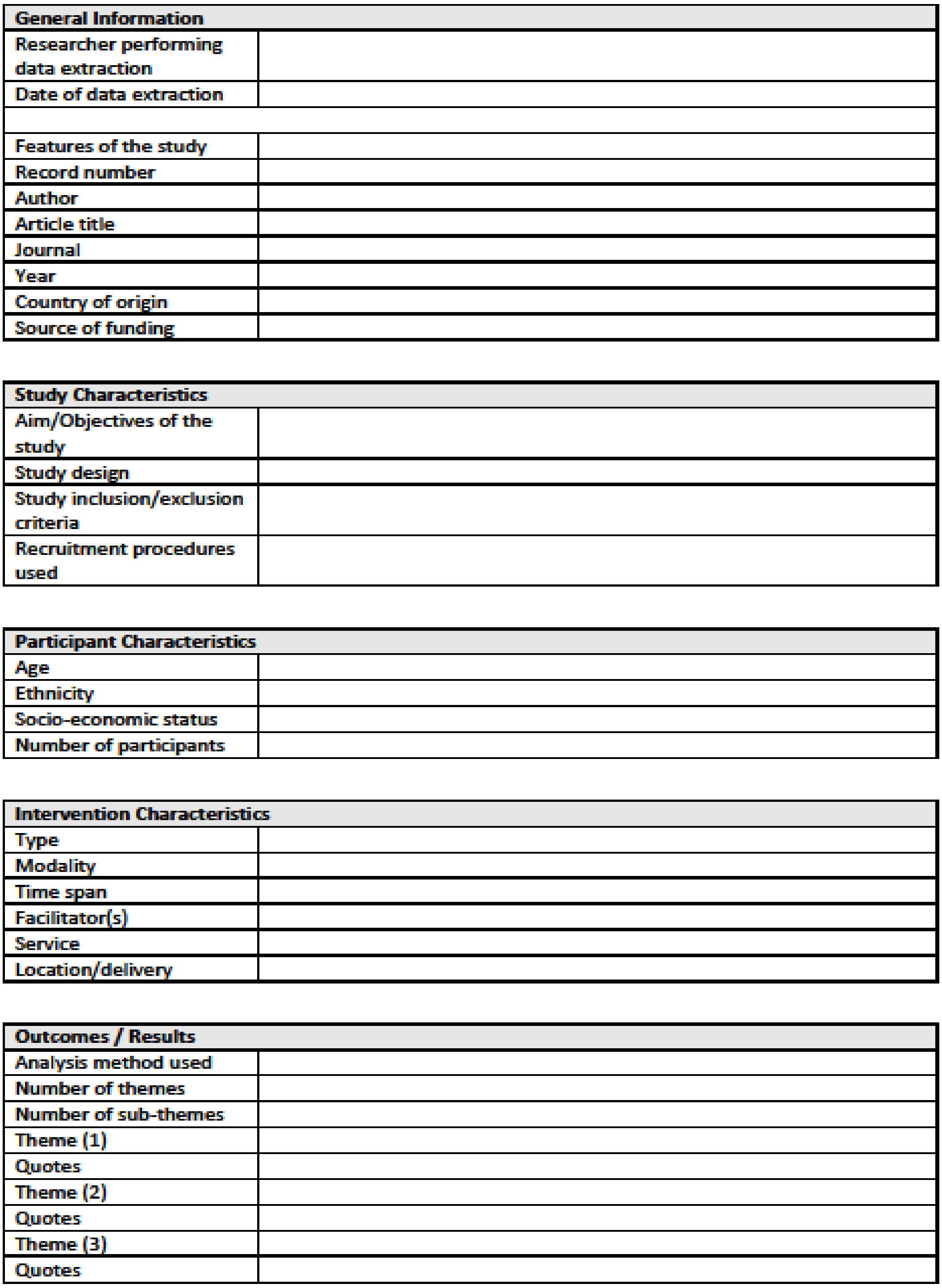
EMBASE search strategy

1	Title	"antenatal loss" OR "antenatal death" OR "perinatal loss" OR " "perinatal death" OR "baby loss" OR "baby death" OR "fetal loss" OR "foetal loss" OR "fetal death" OR "foetal death" OR prenatal loss" OR "prenatal death" OR "still birth" OR "stillbirth" OR "perinatal loss" OR "perinatal death" OR "pregnancy loss" OR "death of a baby"	36292
2	Abstract	"antenatal loss" OR "antenatal death" OR "perinatal loss" OR " "perinatal death" OR "baby loss" OR "baby death" OR "fetal loss" OR "foetal loss" OR "fetal death" OR "foetal death" OR prenatal loss" OR "prenatal death" OR "still birth" OR "stillbirth" OR "perinatal loss" OR "perinatal death" OR "pregnancy loss" OR "death of a baby"	9635
3	Keyword Heading word	"antenatal loss" OR "antenatal death" OR "perinatal loss" OR " "perinatal death" OR "baby loss" OR "baby death" OR "fetal loss" OR "foetal loss" OR "fetal death" OR "foetal death" OR prenatal loss" OR "prenatal death" OR "still birth" OR "stillbirth" OR "perinatal loss" OR "perinatal death" OR "pregnancy loss" OR "death of a baby"	7130
4		1 OR 2 OR 3	40151
5	Title	"grounded theory" OR "grounded analysis" OR "case stud*" OR "ethnograph*" OR "narrative analysis" OR "focus group*" OR "interpretative phenomenological analysis" OR "content analysis" OR "interviews" OR "thematic analysis" OR "discourse analysis" OR "qualitative" OR "hermeneutic analysis" OR "lived experience" OR "qualitative interviews" OR "qualitative" OR "interview*" OR "attitude*" OR "view*" OR "perception*" OR "perspective*" OR "feeling*" OR "thought*" OR "experience*"	4454981
6	Abstract	"grounded theory" OR "grounded analysis" OR "case stud*" OR "ethnograph*" OR "narrative analysis" OR "focus group*" OR "interpretative phenomenological analysis" OR "content analysis" OR "interviews" OR "thematic analysis" OR "discourse analysis"	213694

EMBASE search strategy

7	Keyword Heading word	"grounded theory" OR "grounded analysis" OR "case stud*" OR "ethnograph*" OR "narrative analysis" OR "focus group*" OR "interpretative phenomenological analysis" OR "content analysis" OR "interviews" OR "thematic analysis" OR "discourse analysis" OR "qualitative" OR "hermeneutic analysis" OR "lived experience" OR "qualitative interviews" OR "qualitative" OR "interview*" OR "attitude" OR "view*" OR "perception*" OR "perspective*" OR "feeling*" OR "thought*" OR "experience*"	1249537
8		5 OR 6 OR 7	5107065
9		4 AND 8	7027
10	Title	"psychology* intervention*” OR “psychosocial intervention*” OR “psychosocial support” OR “group intervention*” OR “group” OR “support” OR “intervention”	7416474
11	Abstract	"psychology* intervention*” OR “psychosocial intervention*” OR “psychosocial support” OR “group intervention*” OR “group” OR “support” OR “intervention”	203417
12	Keyword heading word	"psychology* intervention*” OR “psychosocial intervention*” OR “psychosocial support” OR “group intervention*” OR “group” OR “support” OR “intervention”	7416474
13		10 OR 11 OR 12	7461436
14		4 AND 8 AND 13	2795

Appendix 1.4: Data Extraction Template



General Information	
Researcher performing data extraction	
Date of data extraction	
Features of the study	
Record number	
Author	
Article title	
Journal	
Year	
Country of origin	
Source of funding	

Study Characteristics	
Aim/Objectives of the study	
Study design	
Study inclusion/exclusion criteria	
Recruitment procedures used	

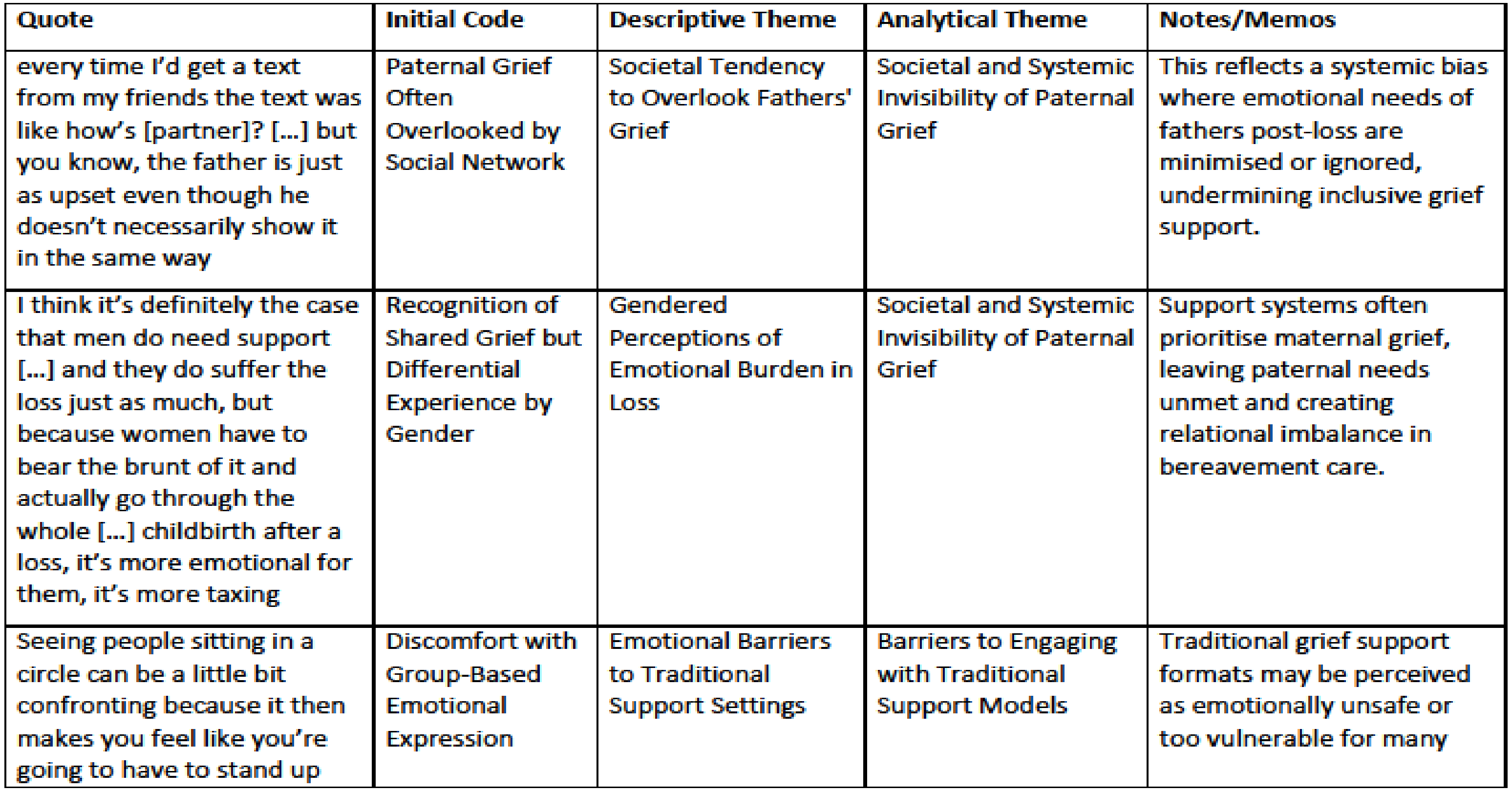
Participant Characteristics	
Age	
Ethnicity	
Socio-economic status	
Number of participants	

Intervention Characteristics	
Type	
Modality	
Time span	
Facilitator(s)	
Service	
Location/delivery	

Outcomes / Results	
Analysis method used	
Number of themes	
Number of sub-themes	
Theme (1)	
Quotes	
Theme (2)	
Quotes	
Theme (3)	
Quotes	

Study Conclusions	
Conclusions of the study	
Limitations of the study by author	
Limitations of the study by researcher	
Quality assessment - researcher	

Appendix 1.5: Thematic Analysis Coding Excerpt – Paper 8



Quote	Initial Code	Descriptive Theme	Analytical Theme	Notes/Memos
every time I'd get a text from my friends the text was like how's [partner]? […] but you know, the father is just as upset even though he doesn't necessarily show it in the same way	Paternal Grief Often Overlooked by Social Network	Societal Tendency to Overlook Fathers' Grief	Societal and Systemic Invisibility of Paternal Grief	This reflects a systemic bias where emotional needs of fathers post-loss are minimised or ignored, undermining inclusive grief support.
I think it's definitely the case that men do need support […] and they do suffer the loss just as much, but because women have to bear the brunt of it and actually go through the whole […] childbirth after a loss, it's more emotional for them, it's more taxing	Recognition of Shared Grief but Differential Experience by Gender	Gendered Perceptions of Emotional Burden in Loss	Societal and Systemic Invisibility of Paternal Grief	Support systems often prioritise maternal grief, leaving paternal needs unmet and creating relational imbalance in bereavement care.
Seeing people sitting in a circle can be a little bit confronting because it then makes you feel like you're going to have to stand up	Discomfort with Group-Based Emotional Expression	Emotional Barriers to Traditional Support Settings	Barriers to Engaging with Traditional Support Models	Traditional grief support formats may be perceived as emotionally unsafe or too vulnerable for many

Sometimes it’s easier to talk to a stranger [...] it couldn’t have been a woman though, for me at least, I’d want to speak to another bloke because [...] even though here’s no difference or whatever, there is in my head.	Preference for Male Support Providers	Comfort with Gender-Matched Emotional Expression	Masculine Identity and Help-Seeking Conflict	Gender-sensitive matching in support delivery could enhance trust and emotional openness among bereaved fathers.
I think personally the way to reach out to men and make them connect with [support] is to frame the proposition completely differently. And not make it about support.	Disengagement from Traditional Support Framing	Resistance to Traditional 'Support' Framing	Standard terminology and framing of 'support' may deter men who associate vulnerability with weakness or stigma.	Barriers to Engaging with Traditional Support Models

Appendix 1.6: Excerpt from Reflective Diary – Systematic Review

Available for download: https://osf.io/vg3ba

Appendix 2.1: COREQ Checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	56
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	57
Occupation	3	What was their occupation at the time of the study?	57
Gender	4	Was the researcher male or female?	57
Experience and training	5	What experience or training did the researcher have?	57
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	57
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	57
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	57
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	53 & 57
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	53 & 54
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	53
Sample size	12	How many participants were in the study?	54
Non-participation	13	How many people refused to participate or dropped out? Reasons?	None
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	56
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	54 & 55
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	103
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	56
Field notes	20	Were field notes made during and/or after the inter view or focus group?	No
Duration	21	What was the duration of the inter views or focus group?	56
Data saturation	22	Was data saturation discussed?	56
Transcripts returned	23	Were transcripts returned to participants for comment and/or	56

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	57
Description of the coding tree	25	Did authors provide a description of the coding tree?	104 & 106
Derivation of themes	26	Were themes identified in advance or derived from the data?	58
Software	27	What software, if applicable, was used to manage the data?	None
Participant checking	28	Did participants provide feedback on the findings?	57
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes, 58-68
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes
Clarity of major themes	31	Were major themes clearly presented in the findings?	Yes 58
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Yes 58-68

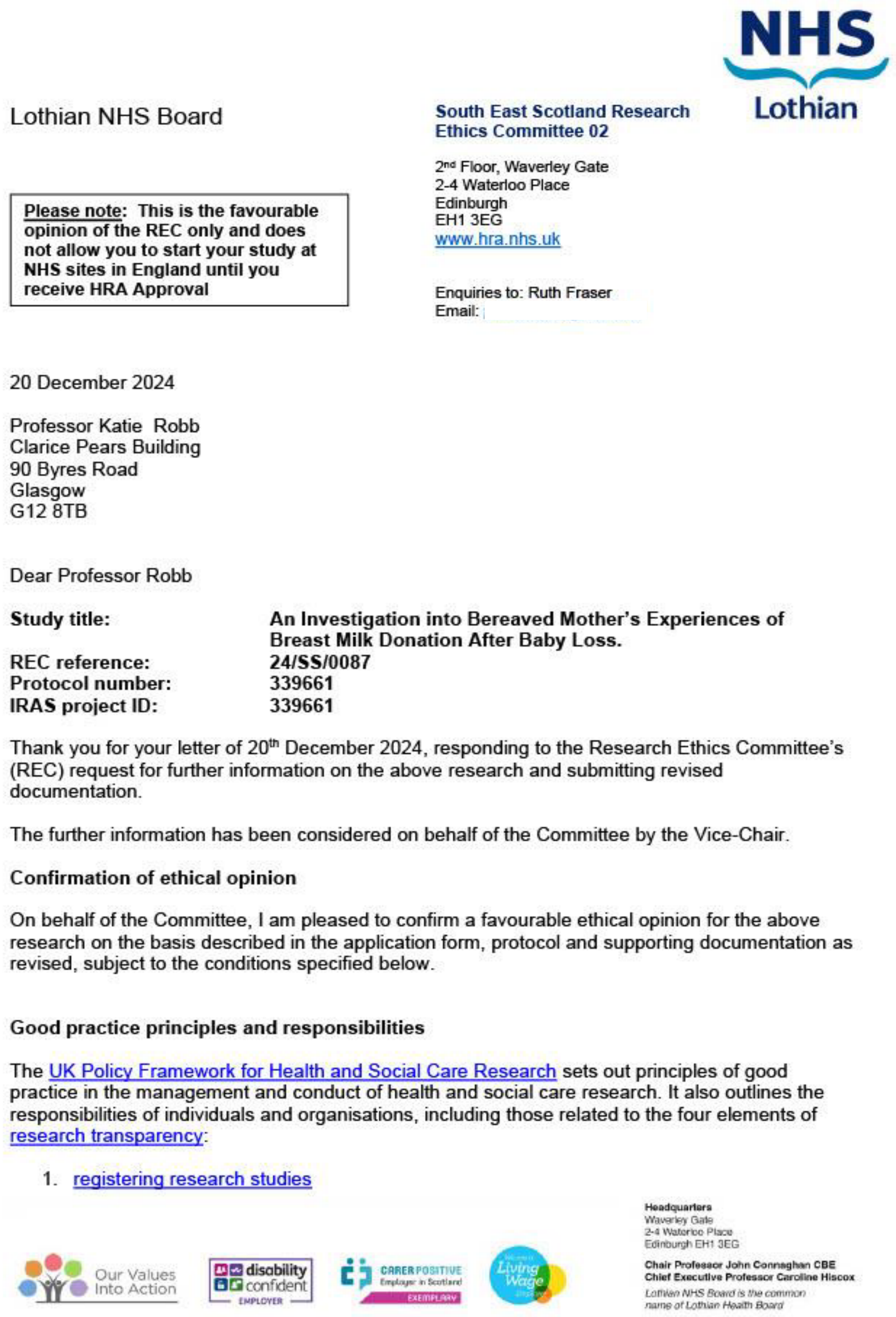
Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 2.2: Final Approved MRP Proposal

Available for Download: https://osf.io/dfzsw

Appendix 2.3: REC Favourable Opinion Correspondence



Lothian NHS Board

South East Scotland Research Ethics Committee 02

2nd Floor, Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
www.hra.nhs.uk

Enquiries to: Ruth Fraser
Email: [redacted]

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

20 December 2024

Professor Katie Robb
Clarice Pears Building
90 Byres Road
Glasgow
G12 8TB

Dear Professor Robb

Study title:	**An Investigation into Bereaved Mother's Experiences of Breast Milk Donation After Baby Loss.**
REC reference:	**24/SS/0087**
Protocol number:	**339661**
IRAS project ID:	**339661**

Thank you for your letter of 20th December 2024, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies

2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

Where a deferral is agreed we expect the sponsor to publish a minimal record on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform deferrals@hra.nhs.uk and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, a minimum research summary will still be published in the research summaries database. At the end of the deferral period, we will publish the full research summary.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: Research summaries - Health Research Authority (hra.nhs.uk)

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at Managing your approval - Health Research Authority (hra.nhs.uk)

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper [Cover Letter to REC (Ammendments)]	1	20 December 2024
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Letter]		28 June 2024
GP/consultant information sheets or letters [Participant GP Letter]	1	05 December 2024
Interview schedules or topic guides for participants [Interview Schedule]	2	05 December 2024
IRAS Application Form [IRAS_Form_25102024]		25 October 2024
Letter from sponsor [Proceed to Ethics letter]		22 November 2023
Letters of invitation to participant [Participant Research Invitation]	2.1	04 October 2024
Other [Data Protection Impact Assessment]	1	25 October 2024
Other [Privacy Notice]	2	05 December 2024
Other [Participant Debrief Sheet]	2.1	05 December 2024
Participant consent form [Participant Consent Form]	2.2	19 December 2024
Participant information sheet (PIS) [Participant Information Sheet]	3	05 December 2024
Research protocol or project proposal [Study Protocol]	2.2	04 October 2024
Summary CV for Chief Investigator (CI) [CI CV]		09 January 2024
Summary CV for student [PI CV]		25 October 2024
Summary CV for supervisor (student research) [Supervisor CV]		09 January 2024

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: Quality assurance - Health Research Authority (hra.nhs.uk)

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: Learning - Health Research Authority (hra.nhs.uk)

IRAS project ID: 339661 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

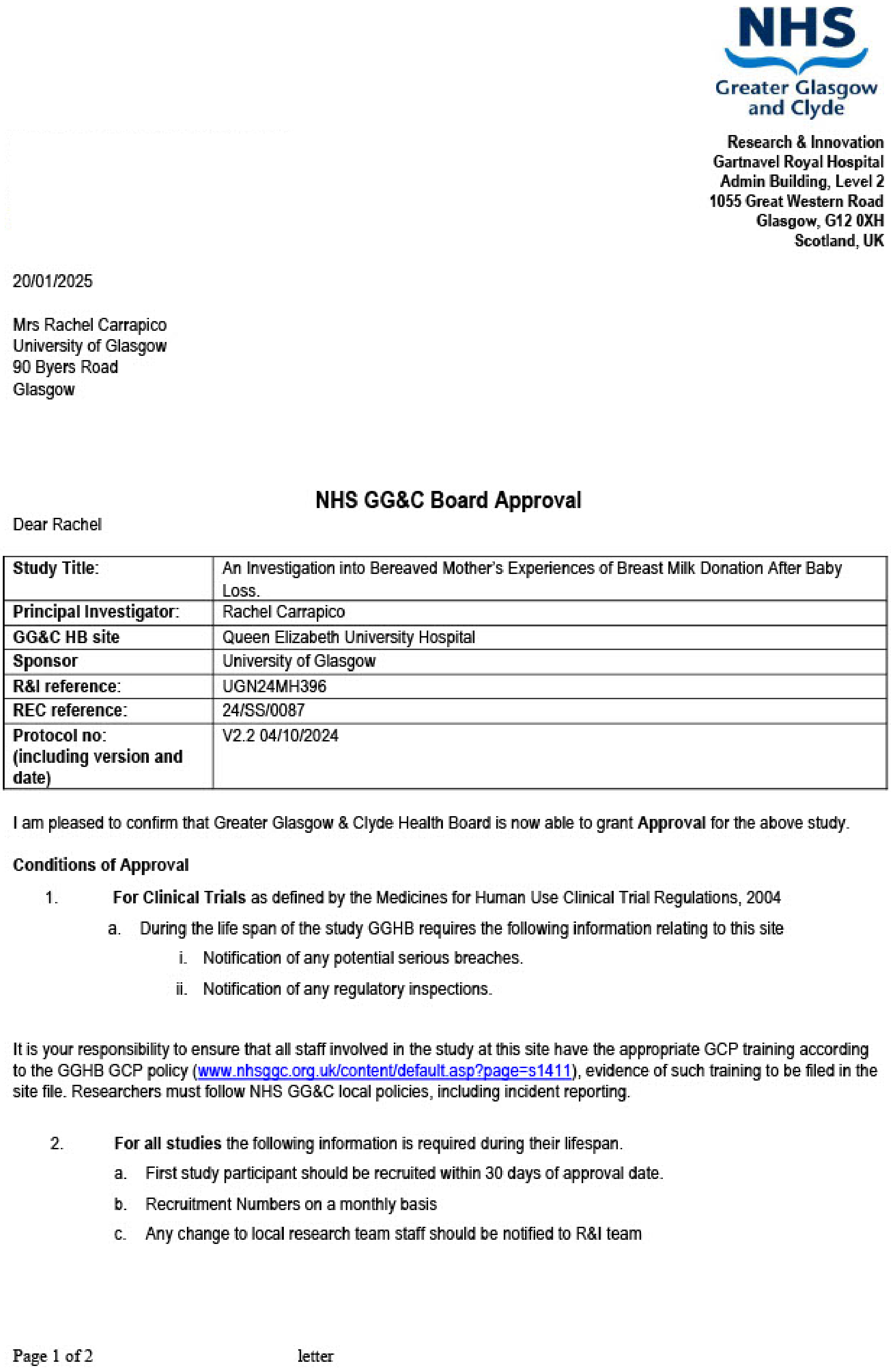
Dr Sarah Gregory
Vice Chair

Email:

Enclosures:	"After ethical review – guidance for researchers" *[SL-AR2]*
Copy to:	Ms Sinead Traynor

Lead Nation
Scotland: gram.nrspcc@nhs.scot

Appendix 2.4 : NHS GGC R&I Approval Letter



NHS
Greater Glasgow
and Clyde

Research & Innovation
Gartnavel Royal Hospital
Admin Building, Level 2
1055 Great Western Road
Glasgow, G12 0XH
Scotland, UK

20/01/2025

Mrs Rachel Carrapico
University of Glasgow
90 Byers Road
Glasgow

NHS GG&C Board Approval

Dear Rachel

Study Title:	An Investigation into Bereaved Mother's Experiences of Breast Milk Donation After Baby Loss.
Principal Investigator:	Rachel Carrapico
GG&C HB site	Queen Elizabeth University Hospital
Sponsor	University of Glasgow
R&I reference:	UGN24MH396
REC reference:	24/SS/0087
Protocol no: (including version and date)	V2.2 04/10/2024

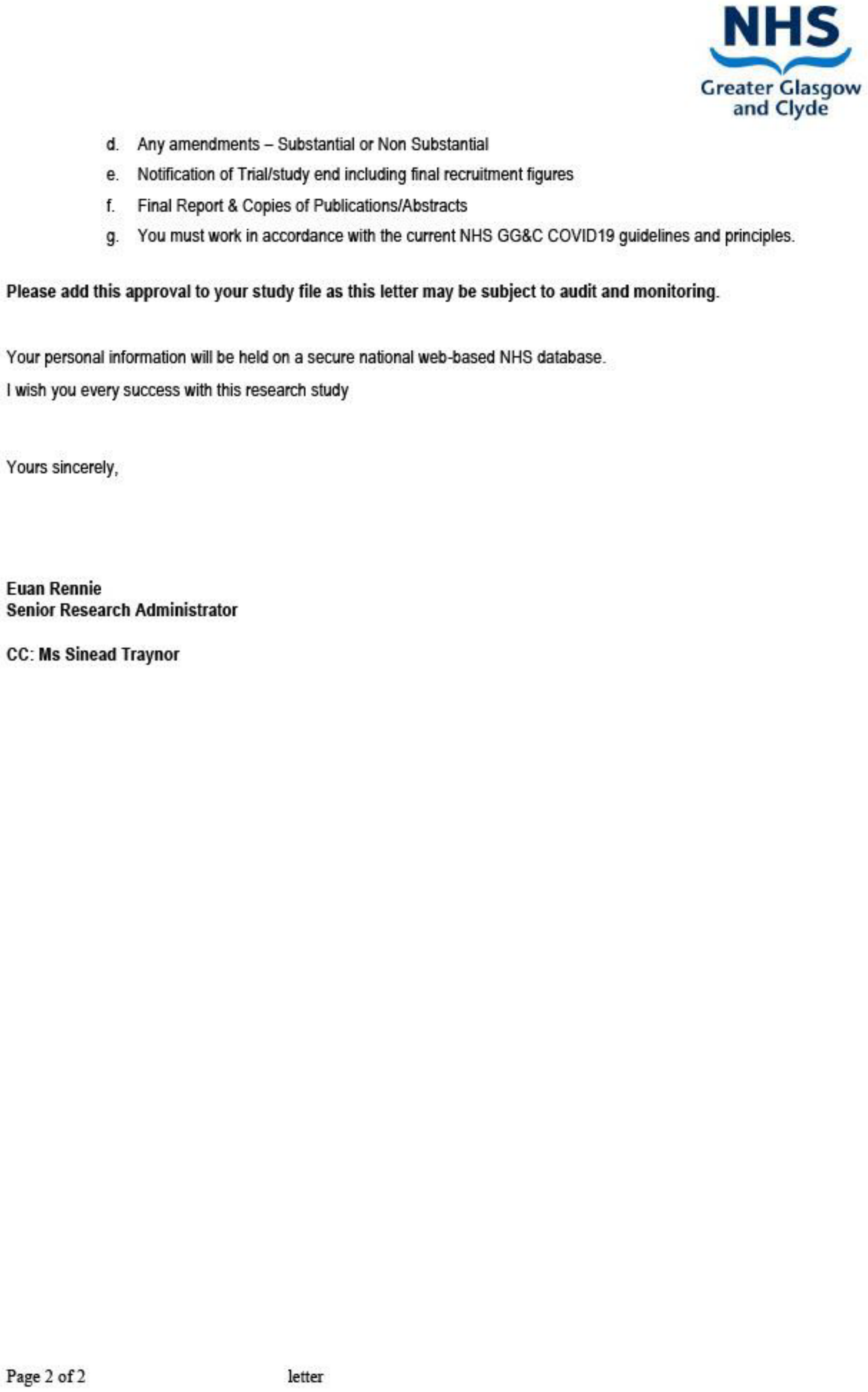
I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
    a. During the life span of the study GGHB requires the following information relating to this site
        i. Notification of any potential serious breaches.
        ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file. Researchers must follow NHS GG&C local policies, including incident reporting.

2. **For all studies** the following information is required during their lifespan.
    a. First study participant should be recruited within 30 days of approval date.
    b. Recruitment Numbers on a monthly basis
    c. Any change to local research team staff should be notified to R&I team



d. Any amendments – Substantial or Non Substantial
e. Notification of Trial/study end including final recruitment figures
f. Final Report & Copies of Publications/Abstracts
g. You must work in accordance with the current NHS GG&C COVID19 guidelines and principles.

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

Euan Rennie
Senior Research Administrator

CC: Ms Sinead Traynor

Appendix 2.5 : Proceed to Ethics Letter

University of Glasgow
School of Health & Wellbeing

BC/PR

22 November 2023

Dear Rachel,

Major Research Project Proposal

An Investigation into Bereaved Mother's Experiences of Breast Milk Donation After Baby Loss

The above project has been reviewed by your University Research Supervisor and by a member of staff not involved in your project and has now been deemed fit to proceed to ethics.

Congratulations and good luck with the study.

Yours sincerely

Dr Breda Cullen
Senior Lecturer in Clinical Psychology
DClinPsy Research Director

School of Health & Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow
Mental Health and Wellbeing, Clarice Pears Building
90 Byres Road, Glasgow G12 8TB
Email: dclinpsy@glasgow.ac.uk

Appendix 2.6: Participant Information Sheet

Available for Download: https://osf.io/pfxa2

Appendix 2.7: Participant Research Invitation

Available for download: https://osf.io/28vfx

Appendix 2.8: Participant Consent Form

Available for download: https://osf.io/3cebg

Appendix 2.9: Participant Debrief Sheet

Available for download: https://osf.io/r2vya

Appendix 2.10: Participant GP Letter

Available for Download: https://osf.io/2drtg

Appendix 2.11: Semi-Structured Interview Schedule

Available for download: https://osf.io/qxtn4

Appendix 2.12: Data Availability Statement

The data from this study is not available for sharing due to strict ethical and confidentiality considerations. It contains sensitive, personal information related to perinatal bereavement, and participants did not consent to its disclosure beyond the research team. For any queries about the data, please contact the corresponding author.

Appendix 2.13: Data Analysis Plan

Available for download: https://osf.io/wgae6

Appendix 2.14: Excerpts from Reflective Diary

Available for download: https://osf.io/z4uha

Appendix 2.15: Group Experiential Theme 1.1 Excerpt

Available for download: https://osf.io/vye5s

Appendix 2.16: Transcript Analysis & Personal Experiential Theme Development – Transcript 5

Available for download: https://osf.io/78awd