

Maternal Perception of Pregnancy Loss: Protocol for a Thematic Synthesis

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Introduction: The number of women who present this perineal loss is high. Identifying the existing knowledge about the women's experiences and perceptions of pregnancy loss is essential to understand the impact of the phenomenon on women. This identification is also crucial to adapt and improve the healthcare provided.

Subjects and Methods: A systematic literature review, meta-synthesis, of qualitative studies will be developed with the goal of obtaining a comprehensive understanding of mothers' perception of pregnancy loss and identifying their specific support needs.

Inclusion Criteria: This review will consider qualitative investigations that study the perceptions or experiences of adult women who have suffered prenatal loss. All studies published in English, Spanish or Portuguese between January 1, 2012, and December 31, 2022 will be considered. This systematic review will follow the Joanna Briggs Institute statement for systematic reviews of qualitative design. The Psychology and Behavioral Sciences Collection, Scopus, CINAHL[®], MEDLINE[®] and Cochrane Database of Systematic Reviews (CDRS) databases will be utilized for research. Data extraction will be performed in-peers by the researchers, using the Joanna Briggs Institute model. Finally, the available data will be analysed using a meta-aggregation approach.

Conclusion: A better understanding of this phenomenon will be useful, identifying, on the one hand, the support needs of women who have suffered fetal loss and, on the other hand, also identifying the support and interventions that can be implemented by health professionals.

Systematic Review Registration Number: PROSPERO[®] (CRD42023407314).

Keywords: mother, gestational loss, perinatal loss, systematic review, thematic synthesis

Introduction

The loss of a baby is an overwhelming experience for the family.¹ The death of a child through miscarriage, neonatal loss, stillbirth or voluntary termination due to foetal abnormalities is an experience with devastating impacts, affecting more than 5 million women worldwide.² It is estimated that approximately one in five parents suffer intense and prolonged grief after the death of a baby at the time of birth. It is essential that parents and families are provided with adequate support from carers and their direct social network.³ Worldwide, between 20% and 30% of pregnancies result in miscarriage, and the foetal death rate of all births worldwide in 2015 was 18.4%.⁴ Worldwide, there are a staggering number of stillbirths every day. In 2021, more than 5000 babies a day were stillborn at 28 weeks or more gestation, accounting for around 1.9 million stillbirths that year.⁵

With the death of the foetus, the loss of dreams of a future life with the baby causes deep wounds in the parents' lives and causes great suffering.⁶ Although both parents experience painful grief after a perinatal loss, reactions to grief can vary according to gender.⁷ Pregnancy and childbirth are critical and happy transitions for mothers, and are part of the

preparation for the baby's arrival. Perinatal loss interrupts this transition and can change the way the mother perceives herself, as well as being a potential source of stress with significant psychological and physical impacts.⁸

Several primary studies have been published on gestational and perinatal loss, with a notable increase in the last decade. Most of these studies have focused on quantifying gestational loss or its causes. Others have addressed the experiences of mothers following the loss.⁹ Qualitative review studies have mainly analysed the phenomenon from the perspective of the couple or the father.^{10,11}

To provide gender-appropriate, culturally sensitive, individualised and holistic care, the needs and values of parents experiencing perinatal loss must be identified.¹⁰ Understanding the perceptions, experiences and impacts of pregnancy loss on mothers is fundamental to improving the care provided to these women. Thus, we intend to study the experience of pregnancy loss from the unique perspective of the "mother", systematising the results found.

Following a preliminary search of the Joanna Briggs Institute (JBI) *Database of Systematic Reviews and Implementations Reports*, MEDLINE[®], CINAHL[®], Psychology and Behavioural Sciences Collection, Scopus[®], the *Cochrane Database of Systematic Reviews*, and PROSPERO[®] (*International Prospective Register of Systematic Reviews*), no literature reviews (published or in progress) were found on this topic in relation to the mother.

Subjects and Methods

A systematic review of the literature will be performed.

Review Question

"What are mothers' perceptions of pregnancy loss?"

Inclusion Criteria

The inclusion and exclusion criteria are presented in [Table 1](#). Inclusion criteria were primary studies with qualitative research designs, having women aged 18 years or older which experienced a pregnancy loss as participants, in which death occurred before or during childbirth and studies that address the experience/perception of pregnancy loss. Given the nature of the phenomenon under study (experiences), only qualitative or mixed studies were selected. Exclusion criteria were articles written in languages other than English, Spanish or Portuguese, articles in which the pregnancy loss occurred due to voluntary or medical termination of pregnancy, twin pregnancies and articles in which baby's death occurred after birth.

In order to achieve the objectives, a systematic review of qualitative evidence¹² will be designed in accordance with the guidelines defined by the Joanna Briggs Institute¹³ for this type of review. The recommendations described in the JBI Systematic Review of Qualitative Evidence Protocol Template¹³ will be followed to draft this protocol.

The Protocol has been registered with PROSPERO[®] under the number CRD42023407314.

Research Strategy

To carry out the search, the respective descriptors in English will be identified, using the appropriate search syntaxes for each of the databases: Medline[®] (Medical Literature Analysis and Retrieval System Online), CINAHL[®] (Cumulative

Table 1 Definition of Inclusion Criteria

	Inclusion Criteria
POPULATION (P)	Studies in women, aged 18 years or older. (<i>Mother, Pregnant, Parents</i>)
CONTEXT (C)	Studies in which participants have experienced a pregnancy loss, in which death occurred before or during childbirth. (<i>Perinatal loss, Gestational death, Perinatal death, Gestational loss, Fetal death, Fetal loss</i>)
CONCEPT (C)	Studies that address the experience/perception of pregnancy loss. (<i>Experience; Attitude; Perception; Perspective, View</i>)
Types of studies	Qualitative methods in data collection (eg, individual interviews) and qualitative methods in data analysis (eg, phenomenology and grounded theory). Mixed method studies with a qualitative component.
Language	Studies published in English, Spanish or Portuguese.
Publication Date	Studies published between January 2012 and December 2022.

Note: Italics indicate the search keywords extracted from population, context and concept.

Index to Nursing and Allied Health Literature), Psychology and Behavioural Sciences Collection, Scopus and CDRS (Cochrane Database of Systematic Reviews). Combinations of descriptors/medical subject headings (MeSH), subject headings and subject terms will be used for each of the databases, using the Boolean operators: “OR” and “AND” and the “*” tool, which will enhance the search by creating new variations of the same word (Box 1).

The research will be conducted by the principal investigator of this project, the language of the research will be English. In order to select the most recent scientific evidence, all studies published from 1 January 2012 to 31 December 2022 will be considered.

Study Selection

The results of each search will be imported into bibliographic reference management software (Endnote X8[®]; <https://endnote.com>, Philadelphia, United States). Duplicate references will be removed and the initial selection by title and abstract will be conducted independently by two researchers, according to the defined inclusion/exclusion criteria. The full texts of the remaining references will be obtained, with the aim of including/excluding the article, based on their full reading. Discrepancies in the final decision to include or not include an article will be discussed with a third researcher in the search for a consensus. The PRISMA model - *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*¹⁴ - will be used to organise the information resulting from the article selection process. The articles that will make up the bibliographic sample will be given a code (Sn), numbered in ascending order, from the oldest to the most recent.

Methodological Quality Assessment

The *Critical Appraisal Skills Program* (CASP) 10-item tool for qualitative research will be used to assess rigour, credibility and relevance, thus indicating the quality of the studies. Two reviewers will apply the tool independently. Disagreements will be resolved through Discussion with a third researcher. Each tool criterion will be scored as (0) if the

Box 1 Boolean Research Syntaxes

MEDLINE [®]
((("Parental*") OR (MH "Mothers") OR (MH "Fathers") OR (MH "Pregnant Women") OR (MH "Parents"))) AND ((("Perinatal loss") OR ("Gestacional death") OR (MH "Perinatal Death") OR (Gestacional loss) OR (MH "Fetal Death") OR (MH "Fetal Mortality") OR (MH "Perinatal Death") OR ("Fetal loss"))) AND (("Experience*") OR (MM "Attitude") OR ("Perception*") OR (MM "Behavio*") OR ("View*") OR ("Perspective*")))
CINAHL [®]
((("Parental*") OR (MH "Mothers+") OR (MH "Fathers+") OR ("Pregnant*") OR (MH "Expectant Parents+")) AND ((("Perinatal loss") OR ("Gestacional death") OR (MM "Perinatal Death") OR ("Gestacional loss") OR ("Fetal death") OR ("Fetal loss"))) AND ((("Experience*") OR (MM "Attitude") OR ("Perception*") OR (MM "Behavior") OR ("Perspective*") OR ("View*")))
Psychology and Behavioral Sciences Collection [®]
((("Parental*") OR ("Mother*") OR ("Father*") OR ("Pregnant*") OR (DE "PREGNANT women") OR (DE "PARENTS"))) AND ((("Perinatal loss") OR ("Gestacional death") OR (DE "PERINATAL death") OR ("Gestacional loss") OR (DE "FETAL death") OR ("Fetal loss"))) AND ((DE "EXPERIENCE") OR ("Attitude*") OR ("Perception*") OR (DE "BEHAVIOR") OR (DE "VIEWS") OR ("Perspective*")))
Scopus [®]
(TITLE-ABS (("Parenta*") OR ("Mother*") OR ("Father*") OR ("Pregnant*") OR ("Parent*"))) AND (TITLE-ABS ((("Perinatal loss") OR ("Gestacional death") OR ("Perinatal death") OR ("Gestacional loss") OR ("Fetal death") OR ("Fetal loss")))) AND (TITLE-ABS ((("Experience*") OR ("Attitude*") OR ("Perception*") OR (MM "Behavio*") OR ("View*") OR ("Perspective*"))))
Cochrane Database of Systematic Reviews [®]
((("Parental*") OR ("Mother*") OR ("Father*") OR ("Parente*") OR ("Pregnant*"))) AND ((("Perinatal loss") OR ("Gestacional death") OR ("Perinatal death") OR (ZE "perinatal mortality") OR ("Gestacional loss") OR (ZE "fetal death") OR ("Fetal loss"))) AND ((("Experience*") OR ("Attitud*") OR ("Perception*") OR ("Behavio*") OR ("View*") OR ("Perspective*")))

criterion has not been met and (1) if the criterion has been met, being 10 the maximum score for an article. All studies will be subjected to data extraction and synthesis, regardless of their methodological quality. The evaluation will be carried out to ensure transparency in the potential risk of bias. It will be carried out in narrative form and the score obtained in each study will be presented in tabular form.

Data Extraction and Synthesis

The data will be extracted by a reviewer using the customised extraction form created for this purpose with the JBI *Qualitative data extraction tool*.¹³ Data will be registered with precise details about the study design and its methodology, participants, phenomenon of interest, and context named in the review question and taking into account the specific objectives proposed. The following information will be recorded for each study: a) authorship, year of publication and country; b) study objective; c) participant characteristics; d) data collection method and methodological design; e) results and f) score obtained through the assessment of methodological quality (CASP). A second reviewer will also carry out the extraction of data from the articles that will be compared to ensure that extraction errors are minimised. In the process of extracting and synthesising the data, successive full readings of the selected articles will be carried out first, from which the data will be extracted independently. The researchers will then re-evaluate all the extracted data together, reaching consensus on any discrepancies in the initial assessment. The level of credibility will be analysed and assigned to the extracted results and its graphics. Any disagreement between the reviewers will be resolved by consensus using a third reviewer.

Firstly, data analysis will involve carefully double reading the studies in order to assess, familiarise, extract, organise, compare, relate and map the available data. Thematic synthesis will be used to summarise the data.¹² Based on this approach, an analysis will be carried out in three stages,¹⁵ as recommended. The primary step will be a codification of the whole text, line-by-line, introducing the text in the findings and interpretation sections of the articles on the ATLAS.ti[®] software. The initial coding of the included articles will be carried out independently by two researchers. To finish this first step, authors' categorisations (second-order constructs) will also be considered for the raw coding of the emerging themes, in addition to participants' expressions (first-order constructs).

In a second stage, the raw codes of the first stage will be categorized to create "descriptive themes" to be discussed and Stablished by the researchers. From this consensus on the "descriptive themes", the "analytical themes" will be produced utilizing an inductive approach.¹⁵ To ensure each code captures similar themes, codes will be constantly matched and related in each of the articles. Graphics and conceptual models will be used to expose and debate the "analytical themes" between the researchers.

In the third step, the "analytical themes" on consensus among the team of researchers will be defined as "main themes", made up of various "sub-themes" and comprising several "descriptive themes". To illustrate these relationships between the themes and sub-themes, a graphical illustration will be created.

When necessary, the corresponding authors of the selected articles could be emailed to get further data or clarification.

Discussion

The death of a child during pregnancy or childbirth is a traumatic^{1,16,17} and complex experience.¹⁸ Knowing the perception of pregnant women who have experienced foetal death and understanding their experiences is fundamental to identifying the necessary and appropriate forms of support to implement in this context. By carrying out a systematic review of the literature on mothers' perceptions, we aimed to assess the state of the art in relation to the research question identified, in order to identify all the qualitative studies published worldwide on the subject. Identifying all the primary research collected in the selected databases will allow us to increase the understanding of the phenomenon under study, identifying, on the one hand, the support needs of women who have experienced foetal loss and, on the other hand, also identifying the support and interventions that can be implemented by health professionals, particularly nurses, to respond to these needs, as well as the results obtained.

A systematic literature review is a scientific research project that seeks to understand and give reasoning to a wide body of documents with its own objectives, research problems, methodology, results and conclusion. It must follow specific protocols that focuses on its reproducibility by other researchers, explicitly presenting the bibliographic

databases that were consulted, the search strategies, the process of article selection and selection criteria, and data analysis. It also explains the Limitations of each article analysed, as well as the limitations of the review itself. Thus, the systematic literature review has a high level of evidence and is an important document for decision-making.¹⁹

The results of this analysis could provide valuable information that can be used for various purposes. Firstly, they can serve as a basis for restructuring current hospital care and support systems for mothers who suffer a pregnancy loss. In addition, these results can serve as a guide for identifying areas of research aimed at improving healthcare provision. Finally, nursing leaders, health policy makers and government bodies could consider using these findings as a basis for improvements to services.

Limitations

This review aims to synthesise and interpret the experiences of women who have experienced a pregnancy loss, regardless of when the death occurs, as long as it is during pregnancy. It is important to recognise that the research strategy used may inadvertently lead to the exclusion of important information. The decision to exclude studies that do not clarify whether the moment of death occurred before or after the birth could also result in the omission of valuable information about how mothers perceive pregnancy loss. What's more, the results we are looking for will be limited to selected qualitative studies, which may limit the breadth of knowledge. Finally, it should be noted that this review will exclusively include articles written in English, Portuguese and Spanish, which could potentially limit the diversity of perspectives considered.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work.

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