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REVIEW

Parental grieving experiences after stillbirth: a thematic synthesis in the context of Latin America

Experiências de luto parental após um natimorto: uma síntese temática no contexto da América Latina

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ABSTRACT

Objective: To synthesize qualitative studies on Latin American parents' grieving experiences after a stillbirth. **Method:** A systematic qualitative review was conducted in four electronic databases using the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guideline. The methodological quality of included studies was assessed using the Critical Appraisal Skills Programme, and a thematic synthesis was performed. **Results:** One hundred ten studies were found, and four were chosen based on the eligibility criteria. Four themes were identified concerning the experience of parental grieving: impact, suffering, and transformation after fetal death; preoccupation with the deceased baby's body; dissatisfaction with the quality of health care; and family and religion as the primary sources of support. **Conclusion:** Stillbirth in Latin America must be explored in future research, and a lack of assistance still marks the grieving process.
Descriptors: Stillbirth; Latin America; Bereavement.

RESUMO

Objetivo: Sintetizar estudos qualitativos sobre as experiências de luto após um natimorto em pais que vivem na América Latina. **Método:** Revisão sistemática qualitativa realizada em quatro bases de dados eletrônica e que utilizou o *Guideline Enhancing Transparency in Reporting the Synthesis of Qualitative Research* (ENTREQ). A qualidade metodológica dos estudos incluídos foi avaliada usando o *Critical Appraisal Skills Programme* e uma síntese temática foi realizada. **Resultados:** Um total de 110 estudos foram encontrados e quatro estudos eleitos com base nos critérios de elegibilidade. Quatro temas apresentam a experiência de luto parental: impacto, sofrimento e transformação após a morte fetal; preocupação com o corpo do bebê falecido; insatisfação com a qualidade da assistência em saúde; e família e religião como principais fontes de apoio. **Conclusão:** A natimortalidade na América Latina precisa ser explorada em pesquisas futuras e ainda é marcada pela desassistência no processo de luto.
Descritores: Natimorto; América Latina; Luto.

INTRODUCTION

The birth of a child is frequently recognized as synonymous with happiness for many families. However, several pregnancies end in loss. Stillbirth is the fetal death inside the mother's uterus or during delivery[1]. The 10th edition of the International Classification of Diseases (ICD-10)[2] defines stillbirth as the birth of a baby with no sign of life after 22 weeks or a birth weight of more than 500 grams.

Perinatal death has great relevance in public health[3,4]. Around 2.6 million babies were stillborn during the entire gestational period in 2015, representing a worldwide rate of 18.4 stillbirths per 1000 births[5]. Most of these deaths occurred in developing countries, where rates remained stable or decreased modestly over the years due to high education, better quality of life, and more remarkable ability to avoid stillbirths, in contrast to developed countries[6,7]. The highest stillbirth rates are found in Sub-Saharan Africa, followed by South Asia and Latin America[8]. Stillbirth rates in Latin America range from 15 to 25 per 1000 births[9].

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Stillbirth is one of the parents' most challenging grieving experiences, causing psychological, social, spiritual, and financial impacts[10,11]. Such impacts affect the subsequent pregnancy, the marital relationship, and other family members[12]. The loss of a child alters the parents' life cycle expectations, blocks dreams, and diminishes hope[13]. Bereaved parents may experience deep sadness, fear, anger, depression, isolation, and disbelief, in addition to the risk of later presenting psychological disorders[14] and complicated grieving[15].

Through proximity and adequate handling of feelings, trained health professionals can help positively and effectively in the grieving process experienced by parents[14]. However, not all health professionals know how to approach a perinatal loss, resulting in unpreparedness in caring for parents who have experienced a loss[14]. It is essential to understand how parents face perinatal mourning, specifically in Latin American countries with peculiar sociodemographic and cultural profiles and high rates of stillbirths. Thus, mapping and synthesizing the grieving experiences of parents in these countries can direct strategies and public policies aimed at perinatal grieving that consider this region's religious, cultural, and psychic particularities. This review aims to synthesize qualitative studies on Latin American parents' grieving experiences after a stillbirth. To meet the objective above, we seek to answer the following research question: "What are the Latin American parents' grieving experiences after a stillbirth?"

METHOD

A systematic qualitative review with meta-synthesis was conducted[16]. The Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines[17] were used to report the qualitative synthesis.

Preliminary studies with a qualitative data collection method (for example, focus group interview, individual interview, and observation) and data analysis (thematic analysis, content analysis, and grounded theory, among others)[18] were included. The phenomenon of interest is the experience of parental grieving after a stillbirth, defined as fetal death from 20 weeks of gestation and onwards[19]. Study participants were parents (fathers and mothers) who experienced a stillbirth in Latin American countries: Argentina, Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Ecuador, El Salvador, Guatemala, Haiti, Honduras, Mexico, Nicaragua, Panama, Paraguay, Peru, Dominican Republic, Uruguay, and Venezuela. Studies with mixed samples of parents who experienced other perinatal losses (e.g., miscarriage and neonatal death) were included when: a) the results of the participants' grieving experience could be differentiated from the results of those who experienced a loss other than stillbirth, or b) most of the sample had experienced stillbirth.

Mixed studies, editorial articles, experience reports, literature reviews, dissertations, theses, and conference proceedings were excluded, as well as studies with adolescent parents (<18 years), health professionals, or other family members.

In May 2021, a comprehensive literature search was performed in multiple electronic databases (PubMed, CINAHL, LILACS, and CUIDEM), including studies published in English, Spanish, and Portuguese in Latin America.

The search strategy included descriptors from the Health Science Descriptors (DeCS), Medical Subject Headings (MeSH), and Cumulative Index to Nursing and Allied Health Literature (CINAHL) and keywords related to parents, countries of Latin America, stillbirth, mourning, and qualitative research (Figure 1). The specific components of the SPIDER framework (sample, phenomenon of interest, design, evaluation, and research type) were used to develop the research question and define the scope of the review, leading to the search strategy described in Figure 1[20].

The researchers independently identified the articles in the databases, imported them into the Rayyan software, and selected the studies based on the inclusion and exclusion criteria through title and abstract screening. The full screening of the articles was conducted to ascertain inclusion in the final sample. The PRISMA flowchart was used to report the study selection process[21] (Figure 2).

The selected articles were evaluated for methodological quality using the CASP (Critical Appraisal Skills Program) tool[22]. Two reviewers extracted data using a form developed by the authors to collect the general characteristics of the studies: year of publication, authors, country of origin, objective, and methodological aspects (study design, participants, and data collection procedures).

The thematic synthesis was used to identify and develop themes. The following steps proposed by Thomas and Harden[16] were used to outline

SPIDER COMPONENT		SEARCH TERMS
Sample	#1	"Family"[Mesh] OR (Families) OR "Parents"[Mesh] OR (Parent) OR "Mothers"[Mesh] OR (Mother) OR "Fathers"[Mesh] OR (Father) OR "Spouses"[Mesh] OR (Spouse) OR (Husbands) OR (Husband) OR (Wives) OR (Wife) OR (Couple).
	#2	"Latin America"[Mesh] OR (Latin America) OR "South America"[Mesh] OR (South America) OR (Argentina) OR (Bolivia) OR (Brazil) OR (Chile) OR (Colombia) OR (Ecuador) OR (French Guiana) OR (Guyana) OR (Paraguay) OR (Peru) OR (Suriname) OR (Uruguay) OR (Venezuela) OR "Central America"[Mesh] OR (Central America) OR (Belize) OR (Costa Rica) OR (El Salvador) OR (Guatemala) OR (Honduras) OR (Nicaragua) OR (Panama) OR (Latin Caribbean) OR (Caribbean Region) OR (Bahamas) OR (Cuba) OR (Dominican Republic) OR (Haiti) OR (Jamaica) OR (Puerto Rico) OR (Mexico)
Phenomenon of Interest	#3	"Stillbirth"[Mesh] OR (Stillbirth) OR "Fetal Death"[Mesh] OR (Death, Fetal) OR (Deaths, Fetal) OR (Fetal Deaths) OR (Intrauterine death) OR (Intra-uterine death) OR (fetal loss) OR "Perinatal Death"[Mesh] OR (Death, Perinatal) OR (Deaths, Perinatal) OR (Perinatal Deaths) OR (perinatal mortality) OR (Perinatal Loss) OR (Perinatal bereavement) OR (perinatal grief) OR (Pregnancy loss) OR (Late Pregnancy Loss) OR (Late Pregnancy Losses) OR (Pregnancy Loss, Late) OR (Pregnancy Losses, Late) OR (Late fetal death)
Design	#4	"Focus Groups"[Mesh] OR (Focus Group) OR (Group, Focus) OR "Anthropology, Medical"[Mesh] OR (Medical Anthropology) OR "Grounded Theory"[Mesh] OR (Theory, Grounded) OR (Culture) OR (Thematic synthesis) OR "Hermeneutics"[Mesh] OR (Hermeneutic) OR (Ethnographic) OR (ethnographic research) OR (Phenomenology) OR (phenomenological research) OR (Narrative) OR "Interviews as Topic"[Mesh] OR (Interviewers) OR (Interviewer) OR (Interviewees) OR (Group Interviews) OR (Group Interview) OR (Interview, Group) OR (Interviews, Group) OR (in-depth interview) OR (qualitative interview) OR (content analysis) OR (semantic analysis)
Evaluation	#5	Experience) OR (Experiences) OR (Feeling) OR (Feelings) OR (Meaning) OR (Meanings) OR "Behavior"[Mesh] OR (Behaviors) OR (Acceptance Processes) OR (acceptance Process) OR (Process, Acceptance) OR (Processes, Acceptance) OR (grief) OR (mourning) OR (Bereavements) OR "Bereavement"[Mesh]
Research type	#6	"Qualitative Research"[Mesh] OR (Research, Qualitative) OR (Qualitative studies) OR (Qualitative) OR "Empirical Research"[Mesh] OR (Research, Empirical)
(#1 *AND* #2) *AND* #3 *AND* #4 *AND* #5 *AND* #6		

Source: Prepared by the authors, 2022.

Figure 1 - Example of the search strategy with descriptors and keywords used in PubMed, based on the SPIDER framework. Teresina, PI, Brazil, 2022

the thematic synthesis: (a) 'line by line' text coding by two reviewers, based on the results of the studies, for the elaboration of free codes validated by a third reviewer for meaning and content; (b) development of 'descriptive themes' through meetings involving four reviewers, who organized the free codes by hierarchy and similarity; and (c) generation of 'analytical themes' during meetings of the research team, who jointly developed and interpreted the descriptive themes carefully to adjust the codes and build the thematic synthesis. The codes were double-checked and discussed until the team reached a consensus to ensure validity and reliability, which has experience in qualitative research and perinatal grieving of Brazilian and Canadian cultural origin.

RESULTS

Figure 3 shows the main characteristics of the articles included, studies carried out in Brazil and published between 1990 and 2015. The studies included 40 women who lost their children and experienced the process of pregnancy, stillbirth, and miscarriage. Furthermore, they seek to understand how the parents experienced and faced the situation of pregnancy loss based on the

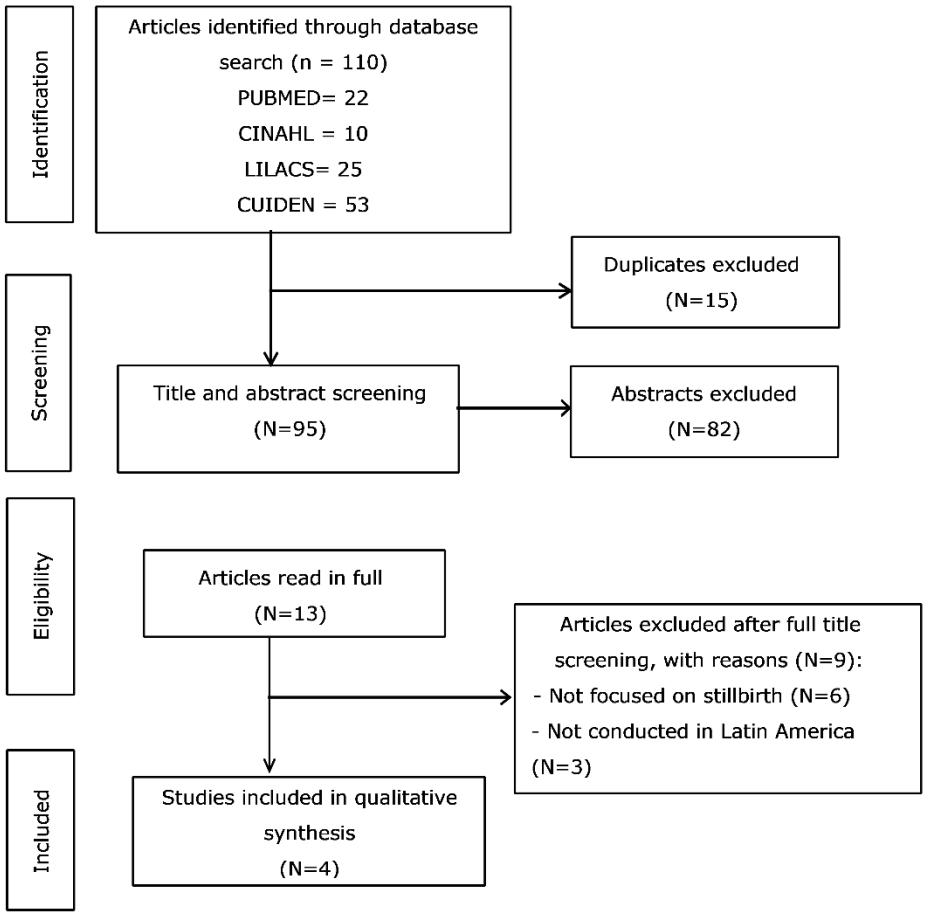
investigation of cognitive and emotional aspects. The quality of the studies selected in the meta-synthesis was satisfactory, and all met the evaluation criteria (Figure 4).

Knowledge synthesis

The analysis of the studies led to the elaboration of four themes on the grieving experiences after a stillbirth in Latin America: "Impact, suffering, and transformation after fetal death", "Concern with the deceased baby's body", "(Dis)satisfaction with the quality of health care", and "Family and religion as main sources of support" (Figure 5).

Impact, suffering, and transformation after fetal death

The results showed a trajectory of suffering, pain, and life changes after the diagnosis of fetal death. The feeling of shock, denial of mourning, and the need for time to assimilate the news of fetal death were part of the moment of diagnosis[26,25]. "For God's sake, tell me that's a lie. Tell me he's sleeping, or that he was mistaken for another baby. Please tell me that you guys are kidding... because I won't handle it"[25]. Sadness, feeling like losing a part of themselves, emptiness, surprise, longing for the pregnancy, impotence, frustrated plans, dreams, hallucinations, and the desire to die is identified in mothers facing gestational loss[24,26]. At the same time, although the physicians did not give hope, the feelings of hope for the baby's survival were maintained, increasing frustration[26].



Source: Prepared by the authors, 2022.

Figure 2 - PRISMA flowchart of the study selection process. Teresina, PI, Brazil, 2022

Author, year, and country	Objective	Study design and location	Participants' characteristics
POPIM; BARBIERI, 1990[23]. Brazil	To uncover facets of the meaning of perinatal death in the eyes of mothers.	Qualitative approach. Phenomenological analysis. Data collection using interviews. Ribeirão Preto, SP.	Ten hospitalized women who had lost their babies (stillbirth or neonatal death) between the 28th week of gestation and the 28th day after birth.
SANTOS; ROSENBURG; BURALLI, 2004[24]. Brazil	To recognize the meaning of fetal loss for women who went through the experience, from the understanding of the pregnancy process, based on their reports.	Qualitative approach. Content analysis. Data collection using oral history technique. Aruja, SP.	Seven women with stillbirth, aged between 17 and 38 years old, five were married, and two were single. All pregnancies had no prior planning.
CARVALHO; MEYER, 2007[25]. Brazil.	To identify the main aspects to be faced by women in the immediate moment of pregnancy loss.	Collective case study. Content analysis. Data collection using semi-structured interviews. Porto Alegre, RS.	Twelve women with late pregnancy loss (mean gestation time 28 weeks). The age ranged between 20 and 39 years, and most women had low socioeconomic status. No participant had experienced a previous pregnancy loss.
LEMOS; CUNHA, 2015[26]. Brazil	To study how women experience and face the situation of pregnancy loss, based on the investigation of related cognitive (perceptions and meanings) and emotional (feelings) aspects.	Qualitative approach. Data collection using open interviews. Content analysis. Rio de Janeiro - RJ.	Eleven hospitalized women with pregnancy loss (spontaneous abortion and stillbirth). The age ranged from 16 to 43 years. Most women had not completed high school, six were married, five were single, three were Catholic, two were Spiritists, two were Protestants, and four had no religion.

Source: Prepared by the authors, 2022.

Figura 3 – Characterization of the included studies regarding the author, year, country, objective, method, and participants' characteristics. Teresina, PI, Brazil, 2022

Mothers need to find meaning in the loss, as the experience brings with it the need for an explanation for attributing a cause[23]. Some mothers attributed stillbirth to feelings and self-blame due to their lifestyle or intercurrences during pregnancy, such as abuse from their husbands, stress during pregnancy, and feeling like fright and anger[23,26]. Others found meaning based on the medical team's explanations or considered the loss an inexplicable mystery or a fatality[23-24,26]. Thinking about having children in the future is common among mothers who lost their children, even if a new pregnancy does not replace the child who died[25]. For some mothers, there is a fear of experiencing the pain of loss again[26]. Body care and physical and psychological preparation for future pregnancies are evidenced and suggested by women who intend to get pregnant again, thus avoiding future suffering[24].

Faced with the loss, many mothers change, and, due to such changes, they can find new missions in life, including valuing their other children, developing new work plans, doing projects for a future pregnancy, having new perspectives on the future, resuming studies, and realizing that it is essential to value and enjoy life, accompanied by the intention to help other people in similar situations[24].

Concern for the deceased baby's body

Mothers have concerns and doubts about the child's burial and the destination to be given the body[23]. Sometimes, families were not advised about the possibility of having a funeral and did not realize this need. Consequently, they did not plan the destination to be given to the baby's body after birth[25]. It accentuated the concern of postpartum mothers, who were relieved by the family taking on the performance of the baby's funeral rituals[23].

CAPS questions	POPIM; BARBIERI, 1990[23]	LEMOS; CUNHA, 2015[26]	CARVALHO; MEYER, 2007[25]	SANTOS; ROSENBURG; BURALLI, 2004[24]
1. Was there a clear statement of the aims of the research?	•	•	•	•
2. Is a qualitative methodology appropriate?	•	•	•	•
3. Was the research design appropriate to address the aims of the research?	•	•	•	•
4. Was the recruitment strategy appropriate to address the aims of the research?	•	•	•	•
5. Was the data collected in a way that addressed the research issue?	•	•	•	•
6. Has the relationship between researcher and participants been adequately considered?	?	?	?	?
7. Have ethical issues been taken into consideration?	•	•	•	•
8. Was the data analysis sufficiently rigorous?	•	•	•	•
9. Is there a clear statement of findings?	•	•	•	•
10. How valuable is the research?	•	•	•	•
Total score	9	9	9	9

Source: Prepared by the authors, 2022.

Figure 4 - Evaluation of the quality of studies, according to the Critical Appraisal Skills Programme (CASP). Teresina, PI, Brazil, 2022

Note: Yes (•); No (x); Not reported (?)

ANALYTICAL THEMES	DESCRIPTIVE THEMES
Impact, suffering, and transformation after fetal death	- Suffering and pain from the diagnosis - Need to find meaning in loss
Concern for the deceased baby's body	- Need to assign an identity to the baby - See and touch the baby
(Dis)satisfaction with the quality of healthcare	- (Dis)satisfaction with the quality of prenatal, delivery, and postpartum care - Hospital context as a source of suffering
Family and religion as primary sources of support	- Religiosity as a source of support - Support from family, partner, and others

Source: Prepared by the authors, 2022

Figure 5 - Analytical and descriptive themes related to parental grieving experiences after a stillbirth in Latin America. Teresina, PI, Brazil, 2022

The decision to see the baby and say goodbye brings doubts and insecurities. The imagination and fantasies created about the appearance of the baby lead them to think that they can preserve themselves with the decision not to see the child so as not to carry the memory of an unbeautiful baby: "He was very small and ugly. I think it was much better not to have seen it"[28]. While other mothers thought it was better to see the baby instead of trying to imagine what it would be like and said they felt much better after the decision: "She was normal. I thought she looked a lot like her sister. She was very hairy"[25]. The image and memory of the child were part of the mourning experience[24].

(Dis)satisfaction with the quality of healthcare

Dissatisfaction with the quality of health care occurred due to the lack of empathy of the multidisciplinary team[24]. Feelings of frustration,

guilt, sadness, disappointment, and revolt are revealed after reflecting on the disqualified assistance they received during and after the loss of the baby[24]. Criticism of the medical team due to the "normality" they attributed to the moment angered women who suffered from fetal loss[24]. Humanized assistance in the context of the loss of a baby refers to a health professional who is attentive and listens to reports of insecurity, embraces the pain, worries about the physical pain manifested by the woman after medical interventions, and is attentive to the psychological pain, in addition to the preparation of the mother for the grieving process[26].

The hospital experience, the crying of other babies, and the stigma felt by being a mother without a baby in a maternity context generate suffering for the mothers: "For me, it is very difficult. It's bad to stay in this room full of crying babies"[25]. Comparing oneself with other pregnant women who had a successful pregnancy intensified the suffering[26]. The distress and discomfort of sharing the same ward with other puerperal women happy to have their babies make stillbirth explicit, as it is easy to differentiate stillbirth mothers from those with healthy babies[26].

Family and religion as primary sources of support

The need to find meaning makes the bereaved mothers understand the loss and suffering as a divine plan, in addition to feeling comforted in their relationship with God[23,26,24]: "For me, only God can explain, but at the same time, it was He who comforted me the most, and made me see that we are nothing in the face of the universe, and only then, made me understand that the loss of my baby, instead of meaning nothing, meant everything"[24]. Feelings of ambiguity were present in the mothers' spiritual experience of mourning: a mixture of sadness, loneliness, and disconsolation with comfort and trust in God for believing that everything happens through divine permission[26].

The support of a religious leader in the process of maternal mourning is highlighted, as well as the support of the family to help deal with the suffering and move on with life[24]. The presence, acceptance, and words of comfort from the family were significant in the acceptance process, giving hope for a new pregnancy[24,26].

Health professionals highlighted the importance of the family being prepared to support the grieving process: "I had no support... none. I think so... the family should be prepared, guided for such... a situation"[25]. The partner's support was also highlighted as essential for overcoming the pain and feelings generated after the loss of the child. However, this was not always the reality: "My mother is helping me a lot. If it weren't for her, I don't know if I would have endured. My husband left us. He couldn't stand it and left. I can't accept that"[25].

Mothers also needed to isolate themselves from others not to be questioned about their child's death, as they did not feel emotionally prepared to explain the loss. Avoiding talking about the loss with many people was also a way of alleviating the pain, as not all comments received are positive, and not all people recognize the pain of grieving, which enhances the suffering experienced by mothers[26].

DISCUSSION

This review synthesized the experience of parental grief after a stillbirth in the Latin American region. The suffering and transformation that occurred after fetal death, the concerns about the body of the deceased baby, and the fragility of health care and support received were highlighted. The results of this meta-synthesis corroborate other reviews on perinatal grieving[3,24,27,28].

Although fetal death is a health problem with a high rate, it does not receive the same attention as other types of infant death[8]. The stillbirth experience results in a different, unusual mourning[8] since a baby is born with no signs of life. This situation leads to intense frustration since it involves the frustration of plans, dreams, and idealizations.

This review revealed that multidisciplinary professional support was insufficient both in the process of diagnosing the loss and after the loss. According to Aguiar and Zorning[29], it is common for health professionals, friends, and family members to contribute negatively to the parents' perinatal mourning period. Parents, after stillbirth, feel alone and do not recognize that they are parents[13].

The hospital experience and context can generate suffering, characterizing a difficult time. According to the results found in this meta-synthesis, some mothers considered being in the wards with other puerperal women disturbing. Some looked forward to hospital discharge, which generated anxiety. In contrast, others avoided going home not to worsen the suffering when they got home empty-handed.

When you lose a child, you also lose hopes, dreams, desires, and unwanted feelings, giving way to what was previously occupied by hope and joy[29]. Therefore, professional embracement and the exercise of empathy through the information and bureaucracies instilled in the mourning process of a stillborn child are of paramount importance. In addition to understanding the stages of grief, the team should advise, listen, and clarify doubts[30]. Promoting the privacy and freedom of bereaved parents to know and treat their babies how they would like and providing the necessary contact time for parents with the stillborn baby are ways for health professionals to deal with the situation[29].

Religious acceptance is significant in the grieving process. This meta-synthesis found that faith in a higher plane can relieve bereaved parents, minimizing pain. In addition, spirituality is an important source of meaning for the loss, as mothers attribute this suffering to plans arising from the spiritual world.

This meta-synthesis also showed the partner's support as a fundamental element for coping with grief. However, another study highlighted how the death of a child opens a gap in the marital relationship and that the partner may also have their grief not recognized by society[31]. Although the studies of this meta-synthesis did not involve men, the father must be recognized as a bereaved parent[38].

This meta-synthesis has limitations, such as the small number of studies that do not consider the diversity of Latin American countries. In addition, three included studies are descriptive and used content analysis as methodological guidance. There is a need for more research on the subject in other Latin American countries, with theoretical references to explore the research questions and more homogeneous samples, including the father as a participant. Despite the limitations, the review has important implications, as the results can guide health professionals' practice and nursing students' teaching to support grief. The main contribution of the review is understands how parents deal with the news of a perinatal loss, which weaknesses are involved in grieving care by health professionals, and the importance of humanization, funeral rituals, family, and spiritual support.

CONCLUSION

The review allowed us to understand the experience of mourning after stillbirth in Latin American countries. The main results are the suffering and transformation that occurs after fetal death, the concerns about the body of the deceased baby, the health care received during prenatal care, delivery, and postpartum, and the support of health professionals, the family, and the religious community.

Improving care is challenging, given the need for monitored and humanized care during and after the loss. The results have the potential to contribute to the improvement of health care, as well as to the training of health care students for situations of fetal death. Finally, the results of this meta-synthesis included the experience of 40 bereaved mothers, involved different databases, and highlighted the need for further studies with Latin American male parents, couples, and single stillbirth samples.

CONFLICT OF INTERESTS

The authors have declared that there is no conflict of interests.

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