REVIEW ARTICLE

Feelings of parents of children with congenital malformations in the puerperium

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ABSTRACT

Dealing with reactions experienced by families in the face of the birth of a baby with a congenital anomaly and promoting the acceptance of the structural, functional, anatomical and physical conditions of a child is a dynamic and challenging process. **Objective:** To analyze and synthesize the knowledge produced regarding the feelings that affect the parents of children with congenital anomalies in the puerperal period. **Method:** This is a scoping review conducted through the guiding question: "What feelings affect the parents of children with congenital malformation in the puerperal period?" In the databases BVS (Virtual Health Library), Medline (Medical Literature Analysis and Retrieval System Online), Lilacs (Latin American and Caribbean Literature in Health Sciences), and BDENF (Nursing Database). Overall, 693 studies were excluded, and 19 were included in the sample to meet the inclusion criteria. **Results:** The sample consisted of 19 studies that demonstrate that the feelings of parents of children with congenital anomalies during pregnancy and the puerperium are manifested by anxiety, fear, depression, emotional overload, mourning, crying, suffering, despair, anger, loneliness, exclusion, sadness, surprise, anguish, stress, denial, psychopathological symptomatology, suicidal ideation, rejection, doubt, concern, psychological alterations, and insecurity. **Conclusion:** It is up to the health system to construct public policies and training strategies so that health workers can be prepared to accommodate this demand in a multi-professional manner.

Keywords: Congenital abnormalities, Emotions, Parents, Parenting, Postpartum period.

INTRODUCTION

Congenital anomalies may result from significant changes from the embryonic period, leading to structural, morphological, or functional alterations. They can be apparent or occur internally and are caused by environmental, genetic, or unknown reasons. In Brazil, according to the Ministry of Health[1], congenital anomalies are the second leading cause of death in children under one year old, accounting for about 22% of infant deaths[2,3]. Congenital anomalies have a prevalence of 3% worldwide, and it is estimated that 303,000 newborns die annually in the first month of life due to complications related to congenital anomalies[4,5].

It is also worth noting that congenital anomalies with more alterations are classified according to the severity of anatomical, functional, or aesthetic conditions and have the potential to evolve into total incompatibility with life. Those with fewer alterations usually do not require surgical, medical, or aesthetic interventions, fitting into normal phenotypic standards, but can manifest in multiple ways and even associate with anomalies with more alterations[6].

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Considering these definitions, it is also delimited that significant psychosocial factors are associated with the birth of a child with anomalies. The literature indicates that, in these cases, de-structuring has a significant impact on family dynamics. At the birth of a child with congenital anomalies, the family is significantly affected[7], showing intense reactions of suffering and emotional anguish, which demands every structural effort from the couple and from the family context, as well as challenges the health team in terms of providing health care, specialized care, and structured psychotherapeutic assistance.

The birth of a baby with a congenital anomaly precipitates a complex cascade of emotional reactions among family members, marking the commencement of a nuanced acceptance process. This process navigates through a spectrum of emotions, including initial shock, denial, profound sadness, and anger, eventually leading towards a phase of reorganization and adaptation within the family structure[8]. Such emotional turbulence underscores the critical necessity for healthcare providers to deliver comprehensive, multidisciplinary care. This care should not only aim at preserving the infant's physiological functions. Still, it must also prioritize cultivating a supportive and empathetic care environment that acknowledges the emotional and psychological needs of the family. In this context, it is paramount that the healthcare team is proficient in integrating clinical excellence with a genuine, human-centric approach to care. This dual focus ensures the survival and holistic well-being of the child and their family, facilitating a more effective coping mechanism during this challenging period.

Without proper welcoming care and a stable and empowered support network, the birth of a child with a congenital anomaly can lead to feelings of insecurity, anxiety, hopelessness, and mourning in parents. Complex cases are permeated with doubts, and some scenarios may even assume a chronicity interface.

In this context, this research is justified by the need to identify the feelings that affect parents in relation to their children with congenital anomalies so that strategies and protocols can be developed and later implemented in health services to equip, support, guide, and facilitate their experience and that of the health teams involved in caring for children with these conditions.

Therefore, this research aims to analyze and synthesize the knowledge produced regarding the feelings that affect the parents of children with congenital anomalies in the puerperal period.

MATERIALS AND METHODS

This is a scoping review that follows the proposal of the Joanna Briggs Institute[9]. This review was registered with the number 10.17605/OSF.IO/MTE46: DOI. (https://osf.io/mte46/).

This review was structured through the following steps: 1) formulation of the guiding question and the review's objective; 2) development of the search strategy; 3) database search; 4) selection of articles based on title and abstract reading; 5) selection of scientific articles from the full reading of them; 6) summarization of results; and 7) presentation and discussion of the findings.

For the formulation of the research guiding question and search strategy, the Population, Concept, and Context (PCC) strategy was used. Thus, P – Parents of children with congenital anomalies; C – Feelings/Coping; C - Birth/Puerperium were defined. Following this definition, the following guiding question was formulated: “What feelings affect the parents of children with congenital malformation in the puerperal period?”. Articles containing the three elements of the PCC that answered the research question, written in English and Portuguese from 2010 to 2022, were considered as inclusion criteria, including qualitative research, quantitative research, systematic reviews, case reports, and observational studies in full texts. Articles written in languages other than Portuguese and English, those that did not answer the research guiding question, expert opinion, leaflets, or those whose full texts were not found online were excluded.

The article search was carried out between March 1 and June 8, 2022, with the support of a librarian in the following databases: BVS (Virtual Health Library), Medline (Medical Literature Analysis and Retrieval System Online), Lilacs (Latin American and Caribbean Literature in Health Sciences), and BDENF (Nursing Database).

The review was conducted in the databases using health descriptors (Decs/Mesh), keywords, and their alternative terms listed in the Table below (Table 1). For the search, boolean operators “or”, “and”, and “not” were used.

Table 1 presents the descriptors and keywords used for each item of the mnemonic.

TABLE 1 – Descriptors and/or keywords used in the search. Bauru 2022.

MNEMONICS	Descriptors/Keywords	Decs/Mesh
Population	Anormalidades Congênitas Congenital Abnormalities	Anomalia Congênita Anomalias Congênitas Anomalias Fetais Anormalidade Congênita Anormalidades Fetais Defeitos Congênitos Deformidades Malformações Malformações Congênitas Malformações Fetais
	Doenças e Anormalidades Congênitas, Hereditárias e Neonatais. Congenital, Hereditary, and Neonatal Diseases and Abnormalities	Doenças e Anomalias Congênitas, Hereditárias e Neonatais Doenças e Anormalidades Neonatais Transtornos Congênitos
	Pais Parents	Madrasta Padrasto Padrastos

	Relações Pais-Filho Parent-Child Relations	Interação entre Pais e Filhos Interação Pais-Criança Interação Pais-Filho Interação Pais Filhos Relações entre Pais e Filhos
	Poder Familiar Parenting	Autoridade Parental Deveres e Direitos dos Pais Deveres e Direitos Parentais Direitos e Deveres dos Pais Direitos e Deveres Parentais Maternalidade Maternidade Parentalidade Paternalidade Pátrio Poder Poder Parental Poder Paternal Relação Parental Responsabilidade Parental Responsabilidades Parentais
Concept	Emoções Emotions	Sentimentos
Context	Nascido Vivo Live Birth	Criança Viva Nascido Vivo (NV) Nascidos Vivos Nascimento Vivo Nascimento com Vida Nascimentos Vivos Nativivos
	Período Pós-Parto Postpartum Period	Puerpério

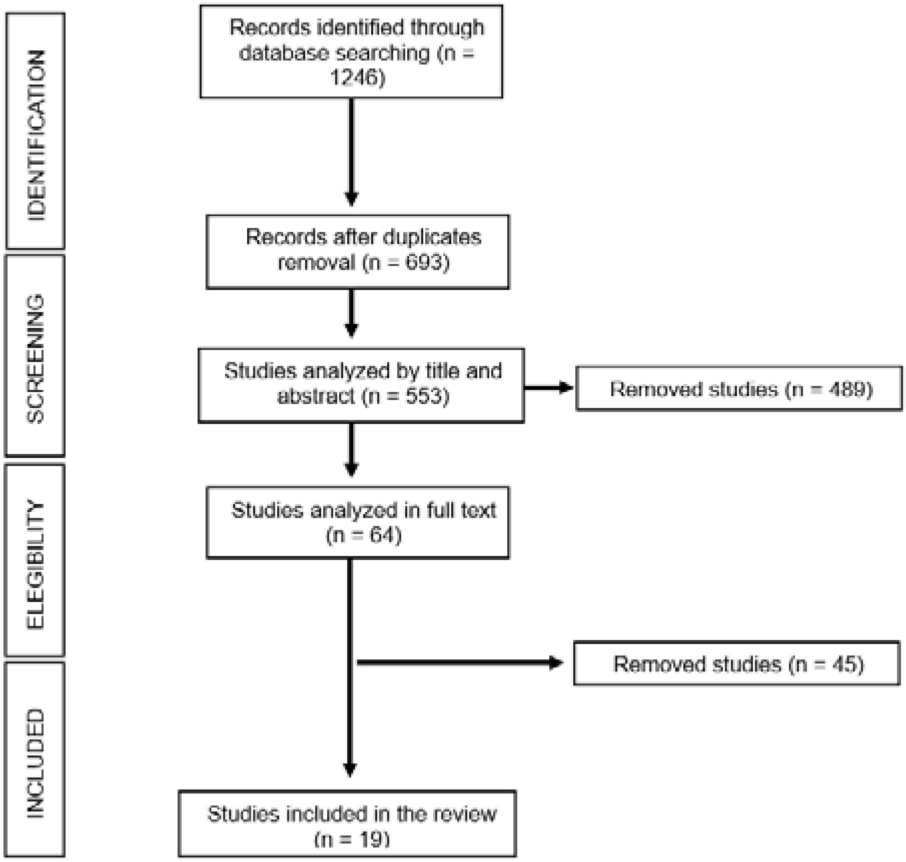
Among the 1,246 articles found, 693 were excluded with the support of Mendeley software for being duplicates, i.e., appearing in more than one database. After careful reading of the titles and abstracts of the remaining 553 articles, 64 of them were selected for full-text reading. Among these, 19 were selected for the sample, resulting in a sample composition of 21 articles.

For analysis purposes, the articles were numbered from 01 to 19 and referred to as "study" (S). The results were presented in the form of tables and a discursive report. To comply with methodological rigor, the Prisma tool adapted for Scoping Review was applied[10].

RESULTS

The final sample of this study consisted of 19 articles. The selection process was carried out by two independent evaluators and is presented in Figure 1.

Figure 1 – Flowchart of the selection process for scoping review



Among the 19 studies that were part of this sample, the majority were published in the last 12 years and are from the American, European, and Asian continents. The country where most of the studies were conducted was Brazil (11; 58%), and the predominant area of publication was Nursing (10; 53%). Table 2 presents the studies according to authorship, year of publication, study title, area, and country of publication.

TABLE 2 – Studies selected according to authorship, year of publication, type of study, area, and country of publication. Bauru, 2022.

Study	Authorship and year of publication	Study Title	Area of publication	Country of publication
S1	KECIR, Kahina Aliouat et al., 2021.	Experiences of fathers having faced with termination of pregnancy for fetal abnormality.	Psychiatry	France
S2	MACKAY, Lyndsay et al.. 2021.	Parental experiences caring for their hospitalized medically fragile infants: a description of grief, stress, and coping.	Nursing	Canada
S3	MARIYANA, Rina; BETRIANA, Feni, 2021	I checked her while she was sleeping just to make sure she was still alive: a qualitative study of parents and caregivers of children with chronic disease in Indonesia.	Nursing	Indonesia
S4	MEDEIROS, Ana Caroline Reis et al., 2021.	Maternal Feelings at Congenital Malformation Diagnosis.	Psychology	Brazil
S5	PÁDUA, Fabiana Almeida; MARINHO, Maria de Fátima Junqueira, 2021.	Mães de recém-nascidos com malformação congênita externa: impacto emocional.[11]	Psychology	Brazil

S6	DE OLIVEIRA, Sheila Jaqueline Gomes et al, 2021.	Ansiedade, sintomas depressivos e qualidade de vida em mães de recém-nascidos com malformações congênitas: um estudo de acompanhamento durante o primeiro ano pós-nascimento.[12]	Medicine	Brazil
S7	DE FREITAS MELO, Cynthia et al, 2020.	A cicatriz invisível: o ser mãe de bebês com fissura labiopalatina.[13]	Medicine	Brazil
S8	ALFWARESS, Firas; ALOMARI, Mahmoud. 2020.	Social and religious attitudes of Jordanian parents toward children born with orofacial clefts.	Medicine	Jordan
S9	LJUBIČIĆ, Marija et al., 2020.	Awakening cortisol indicators, advanced glycation end products, stress perception, depression and anxiety in parents of children with chronic conditions.	Medicine	Croatia
S10	MOONEY-DOYLE, Kim; ULRICH, Connie M., 2020.	Parent moral distress in serious pediatric illness: A dimensional analysis.	Nursing	United States

S11	SUN, Shiwen et al., 2020.	Family support for pregnant women with foetal abnormality requiring pregnancy termination in China.	Nursing	China
S12	BERRY, Shandeigh N.; COLORAFI, Karen, 2019.	The impact of communication surrounding intrauterine congenital anomaly diagnoses: An integrative review.	Nursing	United States
S13	VIANA, Ana Cláudia Gomes et al, 2019.	Mães de bebê mal formado: percepção sobre orientações de enfermeiro.	Nursing	Brazil
S14	FONTOURA, Fabíola Chaves et al, 2018.	Ansiedade de mães de recém-nascidos com malformações congênitas nos períodos pré e pós-natal.[14]	Nursing	Brazil
S15	BORGES, Máira Morena; PETEAN, Eucia Beatriz Lopes, 2018.	Malformação fetal: enfrentamento materno, apego e indicadores de ansiedade e depressão.[15]	Nursing	Brazil
S16	VICENTE, Schwanny Roberta Costa Rambalducci Mofati et al.	Estresse, ansiedade, depressão e Coping materno na anomalia congênita.[16]	Psychology	Brazil
S17	TEIXEIRA SILVA, Liliane de Lourdes et al, 2013.	Pais de bebês malformados: um enfoque vivencial.[17]	Nursing	Brazil

S18	ROECKER, Simone et al, 2012.	A vivência de mães de bebês com malformação.[18]	Nursing	Brazil
S19	ALBUQUERQUE, Sara et al, 2012.	Impacto familiar e ajustamento de pais de crianças com diagnóstico de anomalia congênita: influência dos determinantes da criança.[19]	Medicine	Brazil

The objectives of the studies, the study design, the studied population, the sample size, and the main results and conclusions found are presented in Table 3.

TABLE 3 – Studies selected according to objective, study design, population, sample, results and conclusion. Bauru, 2022.

Study	**Objective**	**Population**	**Sample**	**Main Results and Conclusion**
S1	To describe how parents perceive the termination of their anomalous child's pregnancy, their feelings about the caregivers and their coping strategies.	Father and Mother	08	The parents reported intense emotional tension, fear of losing their partner, feelings of anger, loneliness and exclusion.
S2	To report the experiences of parents caring for their children with fragile health and hospitalized.	Father and Mother	21	The parents used various coping strategies to manage their grief and stressors.
S3	To describe the experiences of parents and caregivers who have cared for children with chronic illnesses.	Father and Mother	11	Parents expressed their feelings through crying, worry, emotional overload, denial, guilt and fear of loss.

S4	To analyze maternal feelings upon receiving a diagnosis of congenital malformation in their child during the prenatal, birth and early childhood periods.	Mothers	97	Categories such as sadness, surprise and despair were repeated in all the periods analyzed in the research, and the earlier the diagnosis of congenital malformation, the more time the couple had to seek information, understand and accept their child's condition.
S5	To investigate the emotional impact on mothers of newborns with external congenital malformations (CM).	Mothers	05	A baby with an external anomaly influences the formation of the mother/ baby bond
S6	To assess the quality of life, anxiety and depressive symptoms of mothers of newborns with congenital malformations admitted to the Intensive Care Unit (ICU) and followed up in their first year of life.	Mothers	07	An increase in trait anxiety and state anxiety scores was observed at six months of the child's life compared to the first assessment. Mothers of children with congenital anomalies showed significant changes in their psychological state.
S7	To understand the process of becoming the mother of a baby with cleft lip and palate and the re-elaboration of maternal feelings from the "dream-baby" to the "born-baby".	Mothers	10	Crying, rejection, questions about the etiology of the malformation, feelings of guilt, anguish, fear and the need to welcome silenced anguish.

S8	Exploring the social and religious attitudes of Jordanian parents towards their children born with cleft lip and palate.	Father and Mother	153	Parents with low levels of education tended to hide their child. Difficulty in making friends was related to the type of cleft lip and palate, as was the belief that the anomaly was caused by an evil spirit. Most families tended to have positive social and religious beliefs.
S9	To investigate whether parents of children with chronic conditions would report a higher level of perceived psychological stress and have a higher accumulation of Advanced Glycation Endproducts (AGEs), as well as a higher risk of depression and anxiety.	Father and Mother	146	There was a positive correlation of both anxiety and depression with age, as well as with all the psychological measures. The association between total morning cortisol production and AGEs may be behind adverse health consequences such as anxiety and depression.
S10	To describe the nature of family moral distress in severe pediatric illness.	Articles	55	Parental moral distress is an important and complex phenomenon that requires more theoretical and empirical research.
S11	To explore family support for pregnant women who have experienced termination of pregnancy due to fetal abnormality, to determine its correlation with female post-traumatic stress symptoms and to investigate the factors that influence family support in this situation.	Pregnant Women	214	Identification of significant correlations between family support and the anxiety symptoms of the women in the study.

S12	To examine the impact of communication when discussing the intrauterine diagnosis of a fetal congenital anomaly on perinatal bereavement.	Articles	15	The knowledge of an intrauterine fetal congenital anomaly is a devastating event for parents. Intense perinatal grief can evolve into adverse psychosocial symptoms throughout life, such as depression, anxiety, Post-Traumatic Stress Disorder, substance abuse and suicidal ideation.
S13	Understand the mother's perception of the nurse's guidelines for continuing to care for the baby's anomaly after hospital discharge	Mothers	10	The responsibility of having to continue the care at home caused the mothers fear and insecurity.
S14	To analyze the level of anxiety of mothers of newborns with congenital anomalies who were diagnosed during prenatal and postnatal care.	Mothers	115	Mothers of newborns with congenital anomalies have moderate anxiety, which was higher when the diagnosis was made in the post-natal period.
S15	To understand the coping strategies used by pregnant women and their relationship with maternal-fetal attachment, anxiety, depression and the diagnosis.	Pregnant Women	33	Pregnant women with a higher level of bonding used focusing on the problem as a priority strategy, and no pregnant woman had anxiety and depression rates classified as severe.
S16	To identify the occurrence of anxiety, depression and maternal coping in congenital anomalies	Mothers	25	This study identified levels of stress, anxiety and depression, as well as coping strategies.
S17	To understand how parents experience the birth of a child with a congenital anomaly.	Father and Mother	08	Suffering permeated the discourse of all the parents, revealing the difficulty in dealing with the unexpected, i.e. their child's anomaly.

S18	To know and understand the experience of mothers facing the diagnosis and birth of babies with congenital anomalies.	Mothers	07	The discovery and confirmation of the anomaly produces crisis and denial in the mother's expectations and in all the family members, triggering changes in her way of life. Still, little by little, the mother shows resilience and learns ways to deal with the problem and the prejudices linked to the anomaly.
S19	To assess the parental burden and individual adjustment of parents of children diagnosed with congenital anomalies and to understand the variability of parental adaptation (burden and individual adjustment) according to the child's determinants.	Future Father and Mother	62	The mothers reported higher levels of psychopathological symptoms and lower perceived quality of life. There were also significant effects of the child's determinants, namely the child's age, on paternal adjustment and the perceived severity of the anomaly on paternal adjustment and maternal burden. The results highlight the complexity of parents' adjustment to diagnosing a child's congenital anomaly, in which various factors interact, particularly those associated with the diagnosis.

To synthesize and respond to the objective of this study by presenting the most frequently mentioned feelings in the studies, Table 4 was constructed below.

TABLE 4 – Feelings mentioned in the analyzed studies. Bauru 2022.

Feelings that were pointed out	Study
Anxiety	S6, S9, S11, S12, S14, S15, S16
Fear	S1, S3, S7, S13
Depression	S9, S12, S15, S16
Emotional Overload	S3, S19
Mourning	S2, S12
Crying	S3, S7
Suffering	S17, S10
Stress	S12 S16
Despair	S4
Anger	S1
Loneliness	S1
Isolation	S1
Sadness	S4
Surprise	S4
Anguish	S7
Denial	S18
Psychopathological Symptomatology	S19
Suicidal Ideation	S12
Rejection	S7
Inquiry	S7
Concern	S3
Psychological Changes	S6
Insecurity	S13

DISCUSSION

Congenital anomalies and congenital genetic diseases represent a health issue for newborns, directly impacting the lives of their families, and actions are deemed necessary to optimize these patients' development in the first years of life since interventions and therapies can demand much in the daily routine of the family nucleus, which will experience periods focused on treatment and hospitalization[20]. Parents of children with congenital anomalies often feel insecure about the future[21-23].

This study demonstrated that care for families of children with congenital anomalies has been a concern in various services, especially in recent years, and that Brazil and Nursing have stood out in the study of this theme (Table 2). This highlights professional action where the role of health professionals in front of the newborn diagnosed with congenital anomaly needs to be individualized with practical propriety[24].

The family can be understood as a reliable and permanent source of support for the child. It is the link to a well-being process. However, parents' attitudes towards their children's congenital anomalies can be influenced by culture, religious beliefs, and prejudice[25,26]. Thus, as shown in Table 3, researchers have sought to understand, at various moments of the newborn's arrival (pregnancy or after birth), the feelings experienced by mothers and fathers since maternal experiences in the postpartum period are influenced by social and cultural factors[27], pregnancy being a period of great physical and psychic vulnerability that can result in ambivalence of feelings[28]. In this sense, it is relevant that from the identification, there is delicacy and sharing of the anomaly information by professionals.

Identifying and communicating with the family about the congenital anomaly can occur both during the prenatal follow-up period and at the time of birth. In both contexts, the multidisciplinary team needs to be prepared to communicate, support, guide, and strengthen the parents, considering the difficult and painful experience of having a child affected by a congenital malformation[29].

Therefore, it is essential to know the details of the anomalous condition, genetic issues, and the ethical aspects involved. Whether they take care of this context positively or negatively, professionals can impact and intensify the reactions that will be issued in the short, medium, and long term[30,31].

Some authors report that circumstances hinder the communication process, including difficult language, lack of sincerity, delicacy, haste, anxiety, unpreparedness, and ignorance of the child's case by the professional. They also highlight that such facts, combined with the use of inappropriate words associated with the non-feeling of "care" for the child with an anomaly and often the fact that the news is transmitted by a professional who is not clinically responsible for the child, bring discouragement to face the treatment and contribute to the loss of hope by the family[31,32].

In Brazil, since 2001, a document has been available with recommendations directed at the neonatologist and/or pediatrician working in the birth center regarding the communication of genetic disease or congenital anomaly. This document recommends professional knowledge, bioethics, as well as mastery of information about biological and clinical processes, permeated by the pillars of multidisciplinary care[30].

Many adversities are listed in the process of accepting a child with a congenital anomaly, among which is the experience of mourning regardless of whether the baby has died (mourning for the idealized child), the fear of establishing an emotional bond by the parents, the fear of loss, the emergence of feelings of incapacity or guilt, and non-conformity by the loss of the healthy baby[8,33,34].

Maternal feelings refer to insecurity regarding the stages to be lived, including fear, confusion, and anxiety[14]. When pregnancy is terminated due to severe anomalies with the potential for incompatibility with life, studies have shown intense emotional tension, emphasizing feelings of anger, loneliness, exclusion, and fear of losing the partner, with the emergence of psychological disorders regardless of gender, with consequences that can manifest several months after the traumatic event[35].

Additionally, caring for children with chronic diseases and significant congenital anomalies is an experience that poses challenging interfaces for parents and caregivers. The fragility and clinical complexities of the child usually establish conditions that require long and repeated hospitalizations[36].

All these factors can trigger stress and adaptation difficulties in parents regarding their parental role and inherent assignments, usually causing them great suffering[37] and leading them to express their feelings through crying, denial, guilt, and fear of loss[38].

Internally and externally, parents experience consolation and anguish due to the impactful power of their children's health conditions, which includes other children, other family members, health professionals, and society in general. Therefore, the team is responsible for welcoming families so that the journey is not so arduous and emotionally draining[39].

As summarized in Table 3, in the puerperium, in the analyzed articles, the most evident feelings were anxiety (S6, S9, S11, S12, S14, S15, S16); fear (S1, S3, S7, S13); depression (S9, S12, S15, S16); emotional overload (S3, S19); mourning (S2, S12); crying (S3, S7); suffering (S17, S10); stress (S12, S16); despair (S4); anger (S1); loneliness (S1); isolation (S1); sadness (S4); surprise (S4); anguish (S7); denial (S18); psychopathological symptomatology (S19); suicidal ideation (S12); rejection (S7); inquiry (S7); concern (S3); psychological changes (S6); and insecurity (S13), demonstrating the variety of support strategies that need to be available among professionals.

The support of other family members, professionals, and religious support can assist and minimize the emotional impact of the diagnosis[23]. Yet, professionals must still consider how parents cope with the situation, which can be diverse. They may resort to various coping strategies to manage their mourning (for the idealized baby that was not born) and manage stressors[37], including suicidal ideation and substance abuse. Some researchers observed that the stress, depression, and anxiety identified in parents of children with chronic conditions raised cortisol levels in themselves, triggering physical implications beyond emotional overload[40].

The needs must be identified, and parents must be welcomed in their anguish[41]. In the country, regarding the context of services and the preparation of professionals, families' experiences are distinct, and there is still no pragmatic action or a qualified standard of care[42]. Therefore, preparing professionals and establishing and disseminating public policies that meet these needs are essential.

CONCLUSION

This study demonstrated that the feelings of parents of children with congenital anomalies during pregnancy and the puerperium are manifested by anxiety, fear, depression, emotional overload, mourning, crying, suffering, despair, anger, loneliness, exclusion, sadness, surprise, anguish, stress, denial, psychopathological symptomatology, suicidal ideation, rejection, doubt, concern, psychological changes, and insecurity, and researchers have directed their actions to identify them. In this sense, it is up to organizations and the system to construct public policies and training strategies for health workers so that they are prepared to accommodate this demand in multi-professional care.

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CONFLICT OF INTEREST

This study does not present any conflict of interest.

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