

# Parenting experiences of mothers with children diagnosed with congenital syphilis: scoping review

Experiências de parentalidade de mães com filhos diagnosticados com sífilis congênita: revisão de escopo

Experiencias parentales de madres con hijos diagnosticados con sífilis congénita: revisión del alcance

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## Abstract

**Objective:** Identify and synthesize the experience of being a mother of a child with congenital syphilis expressed in the literature and discuss research gaps.

**Methods:** Scope review with search in PubMed, Embase, Scopus, Cinahl, Virtual Health Library, Web of Science and Academic Google databases, of publications until 23 and 26 the July 2021. Articles were included according to the criteria: qualitative methodologies, mothers of children with congenital syphilis as participants and studies published in Portuguese, English or Spanish. The process of identification and inclusion of studies for analysis used the PRISMA extension for scope review.

**Results:** 256 articles were identified and ten articles were selected for analysis, all from Brazil. The analysis generated four categories: meanings of parenting, stigmatization of the problem, feelings and scenarios of experiences and knowledge about congenital syphilis.

**Conclusion:** The maternal experience of the child's congenital syphilis comprises the feelings and meanings of the diagnosis while exposing the fear of stigmatization, the lack of knowledge about the disease and limitations of prenatal care. New studies should further develop the understanding of the parenting process in the context of congenital syphilis with an impact care.

## Keywords

Pediatric nursing; Mothers; Parenting; Congenital Syphilis; Review

## Resumo

**Objetivo:** Identificar e sintetizar a experiência de ser mãe de uma criança com sífilis congênita expressa na literatura e discutir lacunas da pesquisa.

**Métodos:** Revisão de escopo com pesquisa em bases PubMed, Embase, Scopus, Cinahl, Biblioteca Virtual em Saúde, Web of Science e Google Acadêmico, de publicações, de 23 a 26 de julho de 2021. Foram incluídos artigos de acordo com os critérios: metodologias qualitativas, mães de crianças com sífilis congênita como participantes e estudos publicados em português, inglês ou espanhol. O processo de identificação e inclusão dos estudos para análise utilizou a extensão PRISMA para revisão de escopo.

**Resultados:** Foram identificados 256 artigos e dez foram selecionados para análise, todos do Brasil. A análise gerou quatro categorias: significados da parentalidade, estigmatização do problema, sentimentos e cenários de experiências e conhecimentos sobre a sífilis congênita.

**Conclusão:** A experiência materna frente à sífilis congênita do filho compreende sentimentos e significados do diagnóstico, enquanto expõe o medo da estigmatização, a falta de conhecimento da doença e limitações da assistência no pré-natal. Novos estudos poderão desenvolver mais amplamente a compreensão do processo da parentalidade no contexto da sífilis congênita com repercussão na assistência.

## Descritores

Enfermagem pediátrica; Mães; Parentalidade; Sífilis congênita; Revisão

## Resumen

**Objetivo:** Identificar y resumir la experiencia de ser madre de un niño con sífilis congénita expresada en la literatura y discutir lagunas en la investigación.

**Métodos:** Revisión de alcance con investigación en las bases de datos PubMed, Embase, Scopus, Cinahl, Virtual Health Library, Web of Science y Google Scholar, de publicaciones entre 23 y 26 de julio de 2021. Se incluyeron artículos según los criterios: metodologías cualitativas, madres de niños con sífilis como participantes y estudios publicados en portugués, inglés o español. El proceso de identificación e inclusión de estudios para el análisis utilizó la extensión PRISMA para la revisión del alcance.

**Resultados:** Se identificaron 256 artículos y se seleccionaron diez artículos para análisis, todos de Brasil. El análisis generó cuatro categorías: significados de la crianza, estigmatización del problema, sentimientos y escenarios de experiencias y saberes sobre la sífilis congénita.

**Conclusión:** La experiencia materna frente a la sífilis congénita del niño comprende sentimientos y significados del diagnóstico al exponer el miedo a la estigmatización, el falta de conocimiento sobre la enfermedad y limitaciones de la atención prenatal. Nuevos estudios deben desarrollar una comprensión más amplia del proceso de crianza en el contexto de la sífilis congénita con repercusiones en el cuidado.

## Descritores

Enfermería pediátrica; Madres; paternidad; sífilis congénita; Revisión

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## Introduction

Syphilis in pregnant women is a preventable health problem, as long as it is diagnosed and treated appropriately. More than half a million children worldwide are diagnosed with congenital syphilis and six million new cases are reported each year, in addition to resulting in more than 200,000 stillbirths and neonatal deaths, according to the World Health Organization (WHO).<sup>(1)</sup> Brazil, even after a simple and gradual decrease in the number of cases reported in 2019, still faces the problem in large urban centers, specifically, in the most vulnerable populations, maintaining notifications above that recommended by the WHO, which is 0.5 cases per every 1,000 live births.<sup>(2,3)</sup>

Many plans, strategies and goals were created to control, reduce and even eliminate congenital syphilis, but not everyone was able to achieve it. The Pan American Health Organization (PAHO), with the consent of the Ministry of Health (MoH), created Technical Cooperation Agreement 112 (TCA 112),<sup>(4)</sup> which established several goals and commitments in line with the Brazilian National Health Plan (2020-23). Among these goals, “strengthening actions to reduce cases of vertical transmission of congenital syphilis” stands out (...)” predicting a 35% reduction in cases by 2030. To achieve this, the MoH, through the Health Surveillance Actions Qualification Program (PQAVS - *Programa de Qualificação das Ações de Vigilância em Saúde*), proposed a drastic reduction in the number of reported cases and incidence of congenital syphilis, including stillbirths in relation to cases of syphilis in pregnant women, determining location and year.<sup>(4,5)</sup>

One of the causes that determines congenital syphilis as a public health concern is underreporting, which may be linked to a lack of knowledge of the clinical signs of the disease, interfering with early diagnosis and treatment.<sup>(6)</sup> In addition to these, we can also mention the lack of knowledge about the disease; insufficient information offered by healthcare professionals; medical inexperience regarding the disease; lack of partner treatment; non-reporting in other countries around the world, and low-quality prenatal care.<sup>(1,6,7)</sup>

The WHO considers quality prenatal care to be one in which pregnant women undergo six or more consultations during the gestational period.<sup>(1)</sup> The

MoH Stork Network guarantees six consultations aiming at continuity of care and monitoring of maternal and perinatal health.

However, studies indicate that the quality of prenatal care is compromised by the lack of regularity in consultations.<sup>(8)</sup> For instance, a survey conducted in the United States highlighted that, although there was an early diagnosis of syphilis in 30.7% of cases, many opportunities were lost due to the lack of adequate maternal treatment and lack of prenatal care, affecting 28.2% of pregnant women.<sup>(9)</sup> Furthermore, another investigation revealed that, although mothers expressed satisfaction with the prenatal care received, they also pointed to the need for more focused attention from professionals to the specific demands of pregnant women.<sup>(10)</sup>

Upon receiving a positive diagnosis for gestational syphilis, mothers receive the recommended treatment and are advised to speak to their partners so that they can seek the unit to be tested.<sup>(11)</sup> If they are diagnosed positive for syphilis, they will receive treatment in accordance with the Clinical Protocol and Therapeutic Guidelines for Comprehensive Care for People with Sexually Transmitted Infections.<sup>(12)</sup>

Considering that the experience of being diagnosed with congenital syphilis is an event that modifies the entire family dynamic, especially the developmental and functional dynamics,<sup>(13,14)</sup> concern for the family has progressively become a focus of attention and also of studies in nursing.

Nursing, not only as theory and practice, but also as science and research, reveals that the family has a significant impact on the health and well-being of each of its members, comprising care, protection, nutrition and socialization functions, thus being able to exert considerable reciprocal influence between family and the health-disease process.<sup>(13-15)</sup>

Faced with a situation of health problems, illness and other problems, the family, as a care unit and a dynamic social group, interacts.<sup>(15,16)</sup> supports and takes action in the face of adversities to promote the well-being for the loved ones,<sup>(17,18)</sup> taking over roles and seeking to meet the needs of sick people, among all activities of daily living.<sup>(19)</sup>

Families are viewed as a group of individuals who are bound by strong feelings of belonging and emotional attachments that promote early childhood

development and parental care.<sup>(14)</sup> That said, parenting is a series of strategies, carefully planned, to ensure not only survival, but also the full development of children in physical, social, mental, cultural, economic, intellectual, behavioral and educational aspects.<sup>(20)</sup>

Parenting has been the purpose of several studies and explored by healthcare professionals using different theoretical and methodological references. Throughout the sensitive period of children's growth and development, the construction of the parental bond will begin through each person's subjectivity, as children have behavioral skills that allow interaction with adults, as soon as they interpret these signs as bonds, remembering that the constitution of subjectivity in this relationship will depend on each person's life story.<sup>(21-23)</sup> Thinking about parenting is not just being involved with biological factors, but also with the psychological process, arising from this new relationship and this new bond that leads to the construction of becoming a father and becoming a mother.<sup>(24-26)</sup>

The evidence presented points to a new look at mothers who had their son diagnosed with congenital syphilis and at the family, which appears as a path little explored in the literature, especially with regard to parenting construction.

Considering the above, this review aims to identify and map the experience of being a mother of a child with congenital syphilis and how parenting is constructed in this context.

## Methods

Considering that the experience of congenital syphilis diagnosis experienced by mothers and the exercise of parenting is a topic little addressed in the literature, the scoping review proved to be an appropriate way to assess the emerging evidence on the topic.

Scoping review is a methodological approach used to map the extent and diversity of a research field, providing a comprehensive view of available knowledge.<sup>(27)</sup> The methodological framework proposed by Arksey and O'Malley<sup>(28)</sup> is a widely recognized structure for conducting scoping studies. This framework consists of five stages: 1) research question identification; 2) survey of relevant studies; 3) study selection for review; 4) data mapping and collection;

5) synthesis and report of results. Each step was carried out systematically and rigorously, ensuring the quality and transparency of the study. This methodological approach is fundamental for producing solid and reliable scoping reviews, as they contribute to the advancement of knowledge in a given field.<sup>(28)</sup>

To formulate the research question, the Population, Concept and Context (PCC) mnemonic strategy was used. The following were defined: Population (P) – Mothers; Concept (C) – Parenting; and (C) – Children diagnosed with congenital syphilis. Based on these definitions, the guiding question stood out: What experiences did mothers have with children diagnosed with congenital syphilis and how was parenting constructed?

Subsequently, the Descriptors in Health Sciences (DeCS) were defined – in Portuguese, and Medical Subjective Headings (MeSH) – in English, without identifying the articles referring to the topic, being: (P) *mãe*/mother or *mães*/mothers, Mother-Child Relations and all variables (parent-child relations, mother child relationship, mother-child bond, mother child relations); Feeling Mothers; (C) *Sífilis congênita*/ Congenital Syphilis and all variables (syphilis, congenital); and (C) *Parentalidade*/Parenting (and all its variables: parents, parentally, parented), using the Boolean operators “and” and “or”.

As a search strategy for the review, we used the following crossing: *mãe* OR *mães* AND *relação mãe-filho* OR *relação pais e filhos* OR *relacionamento mãe-filho* OR *vínculo mãe-filho* AND *sentimento da mãe* AND *sífilis congênita* AND *parentalidade* OR *parentalmente* OR *parental*, for data sources in Portuguese and the crossing: mother OR mothers mother-child relations OR parent-child relations OR mother child relationship OR mother-child bond OR mother child relations AND feeling mothers AND congenital syphilis OR syphilis, congenital AND parenting OR parents OR parentally OR parented for international data sources. Afterwards, the data was crossed, two by two, refining the searches and finding potential articles. The strategy used was adapted for each database, taking into account its search properties. However, consistency in combinations of descriptors was maintained.

The survey of relevant studies followed the peer review method, with the participation of the authors. The search was carried out from July 23 to 26, 2021 in electronic indexing databases such as PubMed, Em-

base, Scopus, CINAHL, Virtual Health Library, Web of Science and Google Scholar. The search strategy was developed by the first author (principal investigator) in collaboration with a librarian at the *Universidade de São Paulo* Nursing School.

The following inclusion criteria were defined in the search: 1) mothers diagnosed with congenital syphilis; 2) empirical or theoretical and qualitative studies; 3) quantitative research; 4) studies published in Portuguese, English and Spanish from 1986 onwards. Editorials, experience reports, theoretical essays, reflection studies, books and other reviews as well as research that was not available in full were excluded.

## Results

From the analysis of 256 studies identified, only ten dealt with the topic and corresponded to the final sample. Study selection was presented in the flow-chart (Figure 1).<sup>(30)</sup>

Selected articles were organized in a chart, in search order, to synthesize them and submit them to thematic content analysis (Chart 1). Analysis was initially carried out by reading selected studies and identifying relevant information, such as authors, year of publication, methodology, results and conclusions.

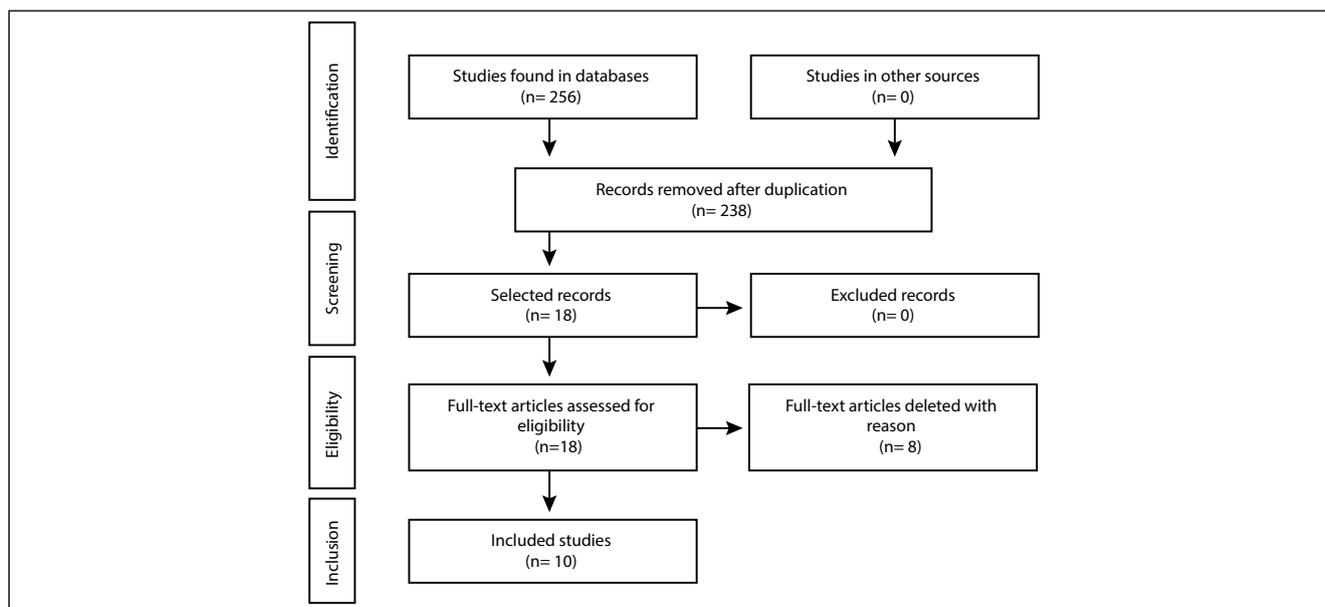
Subsequently, information from the studies was selected and organized into relevant categories, which allowed the synthesis of data in the form of themes. Regarding the country of origin of studies, Brazil stood out with 100% of studies. In the vast search carried out, the absence of studies from other countries was surprising and was confirmed by new rounds of searches with several descriptors in several databases with the support of a librarian.

## Discussion

When reading the ten selected studies, seventeen themes were listed, discussed in a hierarchical manner, which, after analysis, were grouped into four thematic categories: 1. Meanings of parenting; 2. Problem stigmatization; 3. Feelings and experience scenarios; and 4. Knowledge about congenital syphilis. These themes, categories and respective studies can be seen in Chart 2. The categories will be discussed below in the light of the articles reviewed.

### Meanings of parenting

Studies have revealed the meaning of parenting in several aspects. Although mothers have negative



Source: Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and explanation. *Ann Intern Med.* 2018;169:467. <https://doi.org/10.7326/M180850>.<sup>(30)</sup>

**Figure 1.** Study identification and inclusion process - Preferred Reporting Items for Systematic Diagram of Systematic Reviews and Meta-Analyses

**Chart 1.** Synthesis of data from reviewed articles

| Author and year of publication                  | Article title  | Objective   | Research participant   | Specific methodological approach   | Main results   |
|---|--|---|--|--|--|
| Guimarães MS et al. <sup>(31)</sup> 2019        | <i>Parentalidade de pais de recém-nascidos hospitalizados por sífilis congênita à luz da Teoria das Transições</i>                         | Understand the experience of transitions in parenting of parents who had a newborn child hospitalized for congenital syphilis.  | 13 mothers and four fathers of newborns born diagnosed with congenital syphilis in rooming-in and neonatal unit.   | Study with a qualitative approach, using the life narrative method, based on the methodological framework of sociologist Daniel Bertaux through recorded interviews. The analytical process adopted was thematic analysis. | Discovering a mother/father of a newborn child with congenital syphilis and the impact of the diagnosis on the construction of parenting. Rejection of children still in the womb. Experience of transitions in parenting in the face of hospitalization of children with congenital syphilis.   |
| Víctor JF et al. <sup>(32)</sup> 2010           | Congenital syphilis: knowledge of postpartum women and feelings in relation to the treatment of their children                             | Identify the knowledge of postpartum women with positive Venereal Disease Research Laboratory about syphilis and analyze their feelings regarding the treatment of their newborns with congenital syphilis.   | 20 postpartum women with children diagnosed with congenital syphilis participated in the study.  | Qualitative descriptive exploratory research using interviews and qualitative data analysis, using thematic analysis technique   | Knowledge about syphilis and congenital syphilis, how it is transmitted and treated and feelings of postpartum women about the treatment of their newborns. Different feelings were described in relation to the hospitalization period, some postpartum women showed concern and discomfort, mainly regarding the lack of comfort in the hospital, the distance from their family and personal obligations. |
| Brito APA e Kimura AF <sup>(33)</sup> 2018      | <i>Transmissão vertical da sífilis: vivência materna durante a hospitalização para diagnóstico e tratamento de seu filho recém-nascido</i> | Understand the experience of mothers of newborns admitted to a neonatal unit for treatment of congenital syphilis.  | 11 postpartum women in rooming-in at a university hospital in São Paulo. Three sample groups: 1 <sup>st</sup> group with two postpartum women; 2 <sup>nd</sup> group with five postpartum women; 3 <sup>rd</sup> group with four postpartum women. | Qualitative research with theoretical framework in Interactionism Symbolic and Grounded Theory methodology   | Two phenomena were identified from maternal experiences: experiencing the impact of the syphilis diagnosis and experiencing children's hospitalization, which make up the central category "prioritizing children's treatment above my health and well-being".   |
| Siqueira d'A et al. <sup>(34)</sup> 2017        | <i>Sentimentos e conhecimentos de puérperas em face da sífilis congênita neonatal</i>  | Reveal the feelings and knowledge of postpartum women in relation to congenital syphilis.   | Seven women of one maternity ward of a public hospital   | Descriptive exploratory research with a qualitative, hermeneutic approach. Thematic analysis with semi-structured interviews   | Feelings of postpartum women in relation to congenital syphilis in their children; knowledge of postpartum women about transmission syphilis vertical; pregnancy-puerperal cycle: guidance received by postpartum women in relation to syphilis  |
| Silva JG et al. <sup>(35)</sup> 2019            | Congenital syphilis in newborns: repercussions for the mother  | Know the repercussions of congenital syphilis diagnosis in newborns for mothers.  | 15 mothers of newborns hospitalized with a diagnosis of congenital syphilis  | Qualitative research carried out through content analysis carried out through semi-structured interviews   | Feelings aroused by the diagnosis and treatment of congenital syphilis in newborns; the recurrence of congenital syphilis in more than one pregnancy; fear of the stigma surrounding the disease; search for information about congenital syphilis.  |
| Silva LR et al. <sup>(36)</sup> 2004            | What the mothers know and feel on syphilis congenital: an exploitation study and its implications for the nursing practice                 | Identify the maternal knowledge about syphilis and analyze the feelings of mothers of newborns with congenital syphilis in relation to vertical transmission.   | Five mothers who were waiting in the room for the discharge of their children with congenital syphilis.  | Qualitative, exploratory research with thematic analysis carried out through interviews  | Maternal blame for vertical transmission and the meaning of becoming ill for women with a history of syphilis.   |
| Albuquerque CM de A et al. <sup>(37)</sup> 2015 | <i>A compreensão da qualidade de vida atrelada à Sífilis congênita</i>   | Investigate knowledge of mothers about congenital syphilis, knowing the maternal perception about quality of life and identify the maternal view regarding the problems that interfere with the quality of life of children with congenital syphilis. | 12 mothers of newborns admitted to the neonatal unit diagnosed with congenital syphilis.   | Descriptive exploratory study with a qualitative approach with thematic analysis. Non-participant observation technique, consultation of medical records and semi-structured interviews                                    | Understanding congenital syphilis and quality of life from the maternal perspective. Impact of congenital syphilis on quality of life.   |

Continue...

Continuation.

| Author and year of publication           | Article title  | Objective   | Research participant   | Specific methodological approach  | Main results   |
|--|--|---|--|---|--|
| Souza MH, Beck EQ <sup>(38)</sup> 2019   | Understanding the congenital syphilis from the maternal look                                 | Understand maternal perceptions about congenital syphilis and healthcare for these newborns with the disease.   | 15 women mothers of newborns with congenital syphilis in a medium-sized hospital         | Exploratory descriptive qualitative research through individual interviews  | Failure in prenatal care; mothers' knowledge about congenital syphilis; feelings diagnosed in mothers about congenital syphilis.   |
| Silva MRF da et al. <sup>(39)</sup> 2010 | <i>Percepção de mulheres com relação à ocorrência de sífilis congênita em seus conceitos</i> | Analyze the perception of women, residents of Olinda, who performed prenatal care in relation to the occurrence of congenital syphilis in their fetuses, in order to understand, from the point of view of these women, the reasons that led to their children suffering from an easily preventable and treatable disease during prenatal care. | 11 women with children diagnosed with congenital syphilis treated in Family Health Units | Descriptive and exploratory study of a qualitative nature. Narrative content analysis. Individual and semi-structured interview | Maternal perception of syphilis transmission; assistance with pregnancy-puerperal cycle and its influence on knowledge about syphilis; congenital syphilis and maternal suffering.   |
| Araújo SR et al. <sup>(40)</sup> 2020    | <i>A vivência das mães frente a ocorrência de sífilis congênita em seus filhos</i>           | Analyze the experience of mothers facing the occurrence of congenital syphilis in their children, identifying the nursing team role.  | Five women with children diagnosed by SINAN  | Descriptive and exploratory research, qualitative in nature. Content analysis. Semi structured interview                        | Category 1 - Mothers' experience of the occurrence of congenital syphilis in their children; Category 2 - Treatment during prenatal care; Category 3 - Nursing care during hospitalization; Category 4 - Mothers' opinion. |

**Chart 2.** Themes found in articles analyzed

| Themes   | Categories                          | Corresponding articles             |
|--|-------------------------------------|------------------------------------|
| 1. Parenting, transition to parenting, father and child experience and rejection of children in the womb   | Meanings of parenting               | 31, 32, 33, 34                     |
| 2. Distance from family and personal obligations   |                                     |                                    |
| 3. Mothers prioritize the care for their children instead of their own well-being  |                                     |                                    |
| 4. Mothers who also stay in hospital settings generate closeness to children and this is essential for the development of the maternal role, which strengthens the bond between mother and child |                                     |                                    |
| 5. Embarrassment, fear of prejudice and stigma surrounding the disease.  | Problem stigmatization              | 35, 36, 31, 33, 39, 40, 34         |
| 6. They kept their children's illness from their family and close friends  |                                     |                                    |
| 7. Recognition and attribution of blame to oneself for transmitting the injury   |                                     |                                    |
| 8. Feelings of contempt and loneliness during children's hospitalization   |                                     |                                    |
| 9. Feelings regarding diagnosis and treatment in a public hospital   | Feelings and experience scenarios   | 35, 36, 32, 38, 33, 39, 40, 34     |
| 10. Distinct feelings, discomfort, concern and in rooming-in   |                                     |                                    |
| 11. The meaning of illness for mothers in a reference maternity hospital   |                                     |                                    |
| 12. Feelings diagnosed in mothers about congenital syphilis such as anguish and concern in a medium-sized hospital   |                                     |                                    |
| 13. Mothers' knowledge about congenital syphilis and syphilis reinfection  | Knowledge about congenital syphilis | 35, 36, 32, 37, 38, 33, 39, 40, 34 |
| 14. Prenatal care failure  |                                     |                                    |
| 15. Deficiency in knowledge about the disease transmission process   |                                     |                                    |
| 16. Knowledge about syphilis and congenital syphilis and knowledge about treatment   |                                     |                                    |
| 17. Understanding congenital syphilis and quality of life from the maternal perspective  |                                     |                                    |

feelings about the diagnosis of congenital syphilis, they also feel worried about the distance from the family (other children), personal obligations and changes in routine.<sup>(31-34)</sup> A study<sup>(31)</sup> identified mothers' initial rejection of children during pregnancy, but upon learning of the diagnosis, they began to build parental bonds, accept children and worry about

children's well-being. Mothers expressed the need to reformulate their identities, in the sense of personal growth, responsibility for themselves and their children, adopting a preventive stance in relation to sexually transmitted infections,<sup>(31)</sup> awareness of the importance of treatment and experiencing parenting in positive way. It was possible to reveal that mothers'

stay during children's hospitalization is important, as this union begins a series of sensory, physiological, immunological and behavioral events that contribute to parenting construction.<sup>(32)</sup> A study<sup>(33)</sup> highlighted that the meaning and construction of parenting are expressed in mothers when they prioritize care for their children rather than their own well-being and show concern about having to divide themselves between hospitalized children and others at home, in addition to other responsibilities, even if they feel overwhelmed. Other mothers stated that the hospitalization of a child generates changes in the family routine, as they remain in the hospital. However, it reveals that this closeness is important for them and their children, as it strengthens the bond between them.<sup>(34)</sup>

### Problem stigmatization

Problem stigmatization involving the disease both within the family and by professionals is part of mothers' experience, identified in all articles.<sup>(31-40)</sup> This fear and stigma are so overwhelming that, in agreement with their partners, mothers hide their children's illness from family members and people close to them. Studies have reported mothers' perception of the prejudice of people close to them and, when asked about the reason for hospitalization, they respond that it is just an infection.<sup>(31-39)</sup>

In the studies analyzed, mothers are blamed for vertical transmission,<sup>(35-40)</sup> in cases where they had already had syphilis in another pregnancy, underwent treatment, but lost their children as a result of the disease. These mothers believed that because they had received treatment once, they would not be reinfected.<sup>(35,36)</sup> Hence, mothers revealed the heightened feeling of hope, beliefs in something greater (faith), verbalizing that, if children are treated, they will not be sick.<sup>(35,34)</sup>

The studies indicated that mothers went through emotional changes, were blamed, held responsible for the situation, but were concerned about children and their well-being, despite the guilt and anxiety they reported feeling.<sup>(33-40)</sup> Some of these mothers<sup>(35-39)</sup> did not accept the disease, but sought in faith in God the necessary support to overcome the problem.

### Feelings and experience scenarios

Feelings and experience scenarios are elements that emerge from the studies analyzed. In all studies, mothers were in a hospital setting, in a maternity ward, rooming-in or neonatal inpatient unit.<sup>(31-40)</sup> Some of the mothers' manifestations when faced with the diagnosis of congenital syphilis revealed feelings of guilt, despair, sadness, discomfort, impotence, panic, shock and horror, which intensified with children's hospitalization.<sup>(33-35,39)</sup> It was possible to observe in the studies that mothers, when trying to express the meaning and feelings of the disease, were angry at not accepting the diagnosis and their feelings oscillated between concern about children's prognosis and well-being.<sup>(31,36,39)</sup> Not unlike other reports, in other studies, mothers demonstrated sadness and suffering for their children, at the time of medication, and others blamed themselves for their children's suffering.<sup>(32-35,38,40)</sup>

### Knowledge about congenital syphilis

Other feelings reported by mothers about congenital syphilis were anguish and concern about the children and the infection as well as factors such as feelings of remorse and lack of knowledge.<sup>(31-39)</sup> Although prenatal care is the best way to prevent the disease, four studies found knowledge about congenital syphilis to be flawed in light of mothers' diagnosis and, consequently, children's disease.<sup>(33-39)</sup> These studies revealed that, even though women were diagnosed prenatally, it was not efficient in informing and guiding them about the treatment and their insecurities and weaknesses in relation to knowledge of the disease.

It is a fact that there is a lack of knowledge about the diagnosis of congenital syphilis among mothers, a situation expressed in seven studies.<sup>(32-39)</sup> Many mothers, when informed about their child's diagnosis, received little guidance, leading them to search for information on the Internet to better understand the disease.<sup>(35)</sup> Women do not know, even in a simple way, how to conceptualize syphilis. Lack of knowledge about the disease is an important concern, as it allows contamination, lack of identification of the disease and, consequently, lack of treatment.<sup>(32-39)</sup> Studies highlight that, when mothers are asked about their knowledge about the disease, many verbalize unprotected sexual inter-

course, but the form of transmission is still confusing for them.<sup>(32,37,38)</sup> Other factors revealed were feelings of remorse and lack of information, as women stated that this could influence their understanding of treatment, compromising care for their children.<sup>(38)</sup>

The results were supported by Brazilian studies, the only source that emerged in the search. The absence of studies from other countries can be attributed to a series of factors. Firstly, it is important to consider that congenital syphilis is a condition that mainly affects developing countries, where healthcare resources are limited and infection rates are higher.<sup>(1)</sup> Therefore, it is possible that the lack of research and publications on the subject in other countries focuses on the incidence and prevalence rates of the condition as perceived during the searches, avoiding looking at the phenomenon of parenting, which is the core of this review. Furthermore, congenital syphilis is a stigmatized disease and is often associated with risky behaviors,<sup>(5,7)</sup> which can lead to a silencing of discussion and research on the topic. Finally, it is important to consider that parenting construction in the context of congenital syphilis is a complex and multifaceted issue, involving social, cultural and public health issues. Therefore, it is possible that the lack of articles published in other countries on the topic is also related to the low prioritization of research on the topic.

## Conclusion

The research suggests that there is a gap in the literature at a national and international level regarding the experience of mothers who have had children diagnosed with congenital syphilis and how parenting is constituted in this situation. Parenting appeared in an incipient form in the studies analyzed, with elements of mother's suffering being observed from the experience of having a child with congenital syphilis. Mothers' knowledge about the disease focused on biomedical aspects, recognizing it as a communicable disease, as well as the need for preventive measures and diagnosis through prenatal care. Even after two years of carrying out this review, the production picture in the literature has not changed, which highlights the relevance of this text, as congenital syphilis continues to be a public health problem in many countries, and

the construction of parenting in this context is still a topic little explored. In this sense, this research, in addition to making a contribution to the topic, is an incentive for healthcare professionals and researchers to expand understanding and support for women mothers who face this challenging situation in the face of parenting. Therefore, it is important that other studies are developed to better understand the experiences of mothers, their feelings and challenges in relation to the roles they develop, how parenting is constructed in this context, in addition to analyzing how these issues influence family dynamics, and how nursing can act in patient- and family-centered care.

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