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Congenital syphilis in newborns: repercussions for the mother

Sífilis congênita no recém-nascido: repercussões para a mãe

Sífilis congénita en el neonato: repercusiones para la madre

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RESUMO

Objetivo: conhecer as repercussões do diagnóstico da Sífilis Congênita no recém-nascido para a mãe. **Método:** pesquisa qualitativa desenvolvida com 15 mães de recém-nascidos com Sífilis Congênita e internados em um hospital público do sul do Brasil. Os dados foram coletados por entrevistas semiestruturadas, submetidos à análise de conteúdo e aprovados pelo Comitê de Ética em Pesquisa. **Resultados:** as mães manifestaram sentimentos de culpa, desespero, tristeza e horror. Havia esperança de não passar a infecção para o recém-nascido. Verificou-se a reincidência da doença em mais de uma gestação. Referiram medo do estigma social e buscaram informações acerca da doença na *internet*, como também com médicos e enfermeiros. **Conclusão:** há desinformação das mães quanto à infecção da sífilis, principalmente sobre como evitar a transmissão vertical e a reinfecção. Cabe ao enfermeiro, instrumentalizar a mãe para o cuidado ao recém-nascido com Sífilis Congênita, por meio de um processo educativo que qualifique o cuidado da criança e da mãe.

Descritores: Sífilis congênita; transmissão vertical de doença infecciosa; família; enfermagem.

ABSTRACT

Objective: to learn how a diagnosis of congenital syphilis in newborns affects the mothers. **Method:** in this qualitative study of 15 mothers of newborns with congenital syphilis admitted to a public hospital in southern Brazil, data were collected by semi-structured interview, and treated by content analysis. The study was approved by the research ethics committee. **Results:** the mothers expressed feelings of guilt, despair, sadness and horror. They hoped not to transmit the infection to the newborn. The disease was found to have recurred in more than one pregnancy. They reported fear of social stigma, and looked for information about the disease on the Internet, as well as from doctors and nurses. **Conclusion:** mothers are misinformed regarding infection by syphilis, especially on how to prevent vertical transmission and reinfection. It is up to nurses to instruct mothers on how to care for newborns with congenital syphilis, through an educational process to improve care for the child and the mother.

Descriptors: Syphilis, congenital; infectious disease transmission, vertical; family; nursing.

RESUMEN

Objetivo: conocer las repercusiones, para la madre, del diagnóstico de sífilis congénita en el neonato. **Método:** investigación cualitativa desarrollada junto a 15 madres de neonatos con sífilis congénita e ingresados en un hospital público en el sur de Brasil. Se recolectaron los datos a través de entrevistas semiestructuradas y se sometieron al análisis de contenido; después fueron aprobados por el Comité de Ética en Investigación. **Resultados:** las madres expresaron sentimientos de culpa, desesperación, tristeza y horror. Había esperanza de no transmitir la infección al neonato. Se verificó la reincidencia de la enfermedad en más de un embarazo. Declararon el temor al estigma social y buscaron información sobre la enfermedad en *internet,* así como junto a médicos y enfermeros. **Conclusión:** las madres están desinformadas en cuanto a la infección por Sífilis, especialmente sobre cómo prevenir la transmisión vertical y la reinfección. Le toca al enfermero darle a la madre herramientas para que cuide bien al neonato con Sífilis Congénita, a través de un proceso educativo que califique el cuidado del niño y la madre.

Descriptores: Sífilis congénita; transmisión vertical de enfermedad infecciosa; familia; enfermería.

INTRODUCTION

Child infection by *Treponema pallidum* from the mother's placenta leads to the development of Congenital Syphilis (CS). Transmission by contact of the newborn with genital lesions at birth can also happen[1]. Syphilis in pregnancy causes approximately 300,000 fetal and neonatal deaths/year and places 215,000 newborns (NBs) at risk of premature death, low birth weight or CS[1,2].

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When children are diagnosed with CS, many mothers get surprised because they do not expect the newborn to be infected[3]. At this moment, the nurse's role in the support and guidance to the mother becomes important, minimizing doubts about the diagnosis, treatment and care with both the mother and the newborn. The question that guided this study was the following: What is the impact for the mother regarding the diagnosis of CS in the newborn? From this questioning, the objective was to know the impact of the diagnosis of CS in the newborn for the mother. The knowledge produced in this study may assist health professionals/nurses in the support of family in the care for children with CS.

LITERATURE REVIEW

When informed about the diagnosis of CS in their children, some mothers feel sad and guilty for having transmitted the infection, fearing the complications of the disease[3]. Although the diagnosis of syphilis in the mother is confirmed during prenatal care, many women are infected again or do not undergo treatment. A study shows the poor quality of prenatal care as a harm to pregnant women, as this is a time for early detection of various diseases and their immediate treatment[4].

Some mothers only realize the repercussion of CS when their children have to remain hospitalized for treatment. The lack of understanding about the disease, added to the low schooling, contributes to mothers resisting the hospitalization of the newborn after delivery[5].

The diagnosis of CS in the newborn can lead to conflicts in marital relationships[6]. A study pointed to the inadequate treatment of the mothers and their partners during pregnancy[7]. It is necessary that mothers receive guidance on the procedures to be performed in the NB, as well as the performance of periodic examinations and the expected clinical evolution. The professionals should be available and clarify doubts, so that the time spent in the hospital is significant and a source of support[8].

The nurse must understand the repercussions of the hospitalization of the child, as there is a change in the routine, absence of the mother at home, marital conflicts and tension regarding the sick child[9]. CS therapy results in the intravenous antibiotic administration requiring several punctures. In addition, the treatment is painful and includes blood tests, long bone X-rays and lumbar puncture, among others[10].

METHODOLOGY

A descriptive study with a qualitative approach. Fifteen mothers of newborns diagnosed with CS participated. The inclusion criterion was to be a companion mother of the child during hospitalization. Mothers under 18 years old were excluded. The mothers were randomly selected and personally invited to participate in the study by the researcher, who explained the objective, the methodology and the method of data collection.

Data was collected between May and July 2018, in a Pediatric Unit of a hospital in southern Brazil. Data was collected through semi-structured interviews. After accepting, they signed the Free Informed Consent Form. The interview was held in a room attached to the unit. They were asked about the impact of CS diagnosis on them. The interviews were recorded and transcribed.

The technique of content analysis of the reports was held in three stages: Pre-analysis, in which the fluctuating reading of the data and formulation of hypotheses were performed; Exploration of the material, in which data was coded and classified into categories; and Treatment of the results obtained, Inference, Interpretation and Reflection, in which data was discussed[11]. The following categories emerged: Feelings regarding the diagnosis and treatment of CS in the newborn; The recurrence of CS in more than one pregnancy; The fear of stigma surrounding the disease; and the search for information about CS.

The ethical principles of research involving human beings were respected according to Resolution No. 466/12. All participants were identified with the letter F, to ensure anonymity, followed by the Arabic number corresponding to the order of participation in the interviews. The research project was approved by the Ethics Committee with the Opinion No. 33/2018.

RESULTS AND DISCUSSION

15 mothers aged between 18 and 46 years old participated in the research. Two had completed higher education, one had incomplete higher education, four had high school, five had incomplete high school, one had completed elementary school and two had incomplete elementary school. Two were administrative assistants, one was a nurse, three were students and nine were housewives. Ten had stable marital relationships and five were single. Their family incomes ranged from one to five Brazilian regional minimum wages.

The emerging categories of the testimonials are presented below.

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Feelings regarding the diagnosis and treatment of CS in the NB

The mothers received the diagnosis of CS in the newborn by health professionals. Faced with the diagnosis they manifested guilt, despair, sadness and horror. These feelings intensified when following the painful process of treatment in the child.

> *I didn't know, I found out after they had blood tests on him. I didn't know he would have to stay here for 10 days because he had syphilis. It's painful to see them puncturing him all the time. [...]. (F2)*
>
> *I was very devastated […] we thought we were leaving with him and in the end, we had to stay. (F10)*
>
> *The pediatrician told me. I felt I was irresponsible, you know? […] I felt guilty. (F9)*
>
> *[…] I felt desperate. The pediatrician gave me his diagnosis. He said they were suspecting he had CS. (F12)*

The participants reported they hoped that, after the treatment, they would not pass the syphilis infection on to the newborns. They were afraid of the signs and symptoms they could have.

> *I did the treatment, but I was afraid of what would happen to my daughter, [...] how she would grow, what diseases could it cause? [...] many concerns together. (F14)*
>
> *It was awful, because I did the treatment and I thought she wouldn't have to. [...] when she was born, they took the exams that showed she had too. I cried a lot, when they give her medicine, she cries and I cry together! Because it is very painful! (F7)*

Only a mother reported she knew about the possibility of passing the disease on to her child since the beginning of treatment and pointed out that the guidance received by the health professionals was an important aid to accept the diagnosis in the child. Other mothers only found out the diagnosis after birth, but having a treatment for the infection made them more comfortable to cope with it.

> *I already knew he could have it. When she said (doctor), I didn't get so scared [...]. As I only started treatment in the second trimester, she said the risk of passing it on was higher. [...] (F5)*
>
> *I didn't know. I found out after they had a blood test on him. I reacted badly, but I knew there was treatment. […]. (F2)*
>
> *I thought she didn't have it, because with the treatment, the doctor of the Unit said she might not have the disease. I found out […] only after she was born [...]. (F6)*

Given the above, it was found that both the diagnosis and treatment of CS in the NB generate negative feelings in the mother. A study also indicated concern, sadness and guilt for the contamination of the child[3]. Another study showed that parents have feelings of sadness, dread, worry and fear of their child being born with health problems resulting from CS[12]. The need for hospitalization can lead to feelings such as suffering, impotence, stress, worry and anxiety related to multiple venous punctures, the risk of imminent death and waiting for the results of laboratory and imaging exams[12].

A study showed that the infected NBs indicate pregnant women who did not undergo treatment, 19 (35.2%), or with late diagnosis, 50 (92.6%). Among the uninfected NBs, four (19.0%) did not receive any treatment and 14 (77.8%) presented late diagnosis[13]. According to the analysis of CS cases, between 2007 and 2014 in Palmas, it was observed that 161 (78.9%) of the NBs were classified as alive; five (2.5%) died from syphilis; seven (3.4%) died due to other causes; 19 (9.3%) were abortions and 12 (5.9%) were stillbirths[7]. National data revealed that of 24,098 babies born with CS, 2,268 (9.5%) were low birth weight NBs, 2,854 (11.8%) premature, 131 (0.5%) fetal deaths and 172 (0.7%) neonatal deaths[14].

Mothers with Gestational Syphilis are usually advised about the possibility of their children developing sequelae if they are born with the diagnosis of the disease[3]. In this sense, it is noteworthy that quality prenatal care early with pregnant women, health promotion actions, sexual and reproductive orientation and conducting the examination protocol recommended during pregnancy are essential for the prevention of harms to the NB[15].

The recurrence of CS in more than one pregnancy

Mother F3 reported that, as she had already experienced CS in her oldest daughter, this fact made her more prepared to face the same diagnosis in the NB.

> *[...] the shock was with the first. [...] when the other daughter was born I was more vulnerable. With him, I already came to the hospital knowing that […] he was going to spend 10 days. [...] I was prepared already [...]. (F3)*

A study conducted in Rio de Janeiro showed that the occurrence of a previous pregnancy with syphilis did not eliminate the risk of the disease in future pregnancies[16]. Similar data reveal the recurrence of CS in the second child[13,17]. Another research shows that 6,957 (41.1%) of the pregnant women had two serologies registered on their prenatal card[14].

The recurrence of CS for other pregnancies is due to failures regarding educational actions to control and prevent new cases. A study pointed out the women misinformation about vertical transmission, also revealing the lack of guidance from the professionals, compromising the way women understand, face and give due importance to the follow-up of their treatment and of the NBs[3]. Despite the low prevalence of recurrence of CS in the second pregnancy, this is still present in the study, revealing failures in the disease prevention/control methods, contributing to the increase of maternal and child health problems.

The fear of the stigma surrounding the disease

It was verified that the mothers were concerned with people knowing about the child's diagnosis. It was highlighted that they feel stigmatized by the health professionals who assist them. Most mothers chose to hide the diagnosis from some relatives, claiming that the child was hospitalized for another clinical reason.

> *It was worse for me to know that other people knew. Family members don't know, I didn't tell. [...] This way, we say it's for anything else [...] But it's embarrassing, because they are going to say I'm promiscuous [...] Especially the judgment of the people who work with that, it should not be like this. I felt very bad [...]. (F14)*
>
> *I didn't tell because it's syphilis, what would come to their minds: - I'm rotten, you know? (laughs). - So, I didn't tell. (F8)*

The fear of the stigma about the disease may be associated with cultural factors since, for a long time, Sexually Transmitted Infections (STIs) predominated in sex workers, drug users and homosexuals. Even nowadays, there are pre-judgments and association of these infections with promiscuity and risk behaviors. A study pointed out that, in the nurses' view, syphilis has the low socioeconomic status of pregnant women as a risk factor, especially in the case of those living in sexual promiscuity, multiple partners, drug users and low education, reinforcing the stigma of the disease[5]. Syphilis has also been shown to be surrounded by misinformation, prejudice, discrimination and social exclusion[18].

The confirmation of the diagnosis of diseases such as Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) and Syphilis causes important biological and psychosocial changes, due to the stigma associated with the STIs[19]. A research study pointed to the decision of two mothers to omit the true diagnosis of their children, due to the stigma of the disease[17]. The fear of judgment, family rejection and anger of the partner were also presented in a study regarding the diagnosis of STI/AIDS by imprisoned women. They highlighted the advice provided by the nursing professionals as an important means of emotional support in relation to the STI[20]. Professionals ethically committed should defend the dignity, especially of vulnerable women in the face of stigma[21].

The search for information about CS

The mothers sought information about CS on the Internet. They received guidance from doctors and nurses and also received folders about the disease in the Basic Health Units during prenatal care.

> *It was on the internet. My prenatal doctor was the one who gave me the information. She was the one who told me a little about it. [...] then I searched on the internet. (F12)*
>
> *[...] they give a leaflet that tells what can happen to the baby [...]. I also got information on the internet. At the maternity, the doctors and nurses warned me that he would have to stay here for ten days [...]. (F8)*

F11 is graduated in Nursing and revealed that, even having the knowledge, she searched information on the Internet when she received the diagnosis of Syphilis during her pregnancy. She provided guidance to adolescents about Sexual Education in the schools and in the Basic Health Units.

> *We receive information during the undergraduate course. I used to teach Sexual Education in the schools and we had to bring this information. I used to teach health education in the waiting rooms of the Basic Units. But when I received the diagnosis, I searched the internet too. (F11)*

Another aspect highlighted was that mother F15 did not have the courage to search about the disease and only sought to understand the subject after the birth of the child.

> *I had no courage, I just tried to understand it now. (F15)*

Providing parents with guidance on CS represents an important strategy for coping with the disease[5]. A study showed that NBs diagnosed with CS were hospitalized in a much higher proportion and had between two and three times more negative outcomes than those born to non-syphilis-infected mothers[12]. It is emphasized that nurses should be articulators of work processes and of the accountability for the organization of in-service education actions[22]. The nurse plays an important role as an educator[5]. However, data reveal that the technical unpreparedness of the primary care professionals may lead to inefficiency and to poor performance of syphilis control actions[19]. Thus, the continuing education of this professional is necessary, assisting in the dissemination of information by secure sources.

It is important that the practice of advice by the health professionals during prenatal care should extend beyond guidance on STIs and ordering examinations, but also be linked to HIV-positive patients, offering and adhering to treatment, as well as harm reduction and raising the partner's awareness. The autonomy of the subjects, the dialog about their risk practices, the choice of prevention methods and the clarification of doubts about the treatment and coping with stigma are to be observed[23].

CONCLUSION

The repercussions of the mothers were manifested by feelings of guilt, despair, sadness and horror when they received the diagnosis of congenital syphilis in their children. Despite the low prevalence, the disease recurs in the second pregnancy. When facing CS in the NB, the mothers reported fear of the social stigma and sought information about the disease on the Internet, as well as with doctors and nurses.

It was observed that there is misinformation regarding syphilis infection among the mothers, especially on how to prevent vertical transmission and reinfection during treatment. There are gaps in the screening for gestational syphilis that need to be filled by performing early testing for STIs, avoiding late diagnosis and fetal contamination. Public policies are not effective to curb contamination by CS, lacking new strategies to combat infection in health care networks, in order to convey information, promoting the health of the mother and the baby.

The nurses are not taking advantage of prenatal care and the period of hospitalization of the NB with CS to perform the educational practice with the mothers. Health education is revealed as a fundamental tool for spreading knowledge. The nurse should monitor the diagnosis of the mother and the NB, advising on prophylaxis, forms of contagion, signs, symptoms and treatment of the disease. The importance of STI testing during prenatal, of treating the partner, and of condom use during sexual intercourse must be emphasized. With regard to CS, it is important to inform the risks of transmission to the NB, as well as the necessary care that should be given to the NB, also focusing on the need to extend the hospitalization for treatment, the procedures and tests that will be performed for best coping with the disease through an effective educational process. We highlight the importance of ethical performance and continuing education of the health professionals, as measures to help ensure a comprehensive and human care for the mother coping with the diagnosis of CS in the child, generating changes in the presented stigmas.

Further studies are needed to understand the long-term repercussions of CS. The limitations were the denial of 10 mothers selected to participate in the research, as well as it having been performed in a single context, not allowing the generalization of the findings.

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