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Understanding the congenital syphilis from the maternal look

Compreendendo a sífilis congênita a partir do olhar materno Comprendiendo la sífilis congénita a partir de la mirada materna

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Resumo: Objetivo: compreender as percepções maternas sobre sífilis congênita e os cuidados de saúde desses recémnascidos. Método: pesquisa descritiva exploratória de caráter qualitativo, realizada em hospital de médio porte, localizado na cidade satélite Paranoá, Distrito Federal, Brasília, no período de março a agosto de 2017. Fizeram parte do estudo 15 mulheres, mães de recém-nascidos portadores de sífilis congênita. Resultados: os dados resultaram em três eixos temáticos: Falhas na realização do pré-natal; Conhecimento das mães em relação à sífilis congênita e sentimentos das mães acerca do diagnóstico de sífilis congênita. Apesar da realização do pré-natal, evidenciaram-se inseguranças, fragilidades e insuficiência de conhecimentos em relação à doença no que se refere ao diagnóstico, tratamento e prevenção. Conclusão: acredita-se que a educação em saúde, com linguagem acessível e melhores estratégias pelos profissionais de saúde a estas gestantes e parceiros com sífilis, pode-se prevenir a sífilis congênita.

Descritores: Sífilis; Sífilis Congênita; Pré-natal; Enfermagem obstétrica; Saúde da mulher

Abstract: Aim: understand the maternal perceptions about congenital syphilis and the health care of these newborns. Method: this is a descriptive exploratory research with a qualitative character, developed in a mediumsized hospital, located in the satellite city Paranoa in the Federal District - Brasilia, between March and August of 2017. Fifteen women, mothers of newborns with congenital syphilis, were part of the study. Results: the data resulted in three thematic axes: Failure to perform prenatal care; Knowledge of mothers regarding congenital syphilis and the feelings of mothers about the diagnosis of congenital syphilis. Despite the completion of prenatal care, there were insecurities, weaknesses and insufficient knowledge regarding the disease regarding the diagnosis, treatment and prevention. Conclusion: it is believed that health education, with accessible language and better strategies by health professionals for these pregnant women and partners with syphilis, can prevent congenital syphilis.

Descriptors: Syphilis; Congenital Syphilis; Prenatal; Obstetric nursing; Women's health

Resumen: Objetivo: comprenderlas percepciones maternas sobre sífilis congénita y los cuidados de salud de esos recién nacidos. Método: estúdio cualitativos com caracterdescriptivo, desarrollado en Hospital de porte mediano, localizado em la ciudad satélite Paranoá em el Distrito Federal Brasília, entre los meses de marzo y agosto de 2017.

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Hicieron parte del estúdio 15 mujeres, madres de recién nacidos portadores de sífilis congénita. **Resultados:** los datos resultaron em tres ejes temáticos: Fallas em La realización del prenatal; Conocimiento de las madres en relación a la sífilis congénita y Sentimientos de las madres sobre el diagnóstico de sífilis congénita. A pesar de la finalización de la atención prenatal, hubo inseguridades, debilidades y conocimiento insuficiente sobre la enfermedad en términos de diagnóstico, tratamiento y prevención. **Conclusión:** se cree que la educación em salud, com lenguaje accesible y mejores estratégias por los profesionales de salud a estas gestantes con sífilis, puede prevenir la sífilis congénita.

Descriptores: Sífilis; Sífilis Congénita; Prenatal; Enfermería Obstétrica; Salud de la Mujer

Introduction

Syphilis is a chronic systemic infectious disease caused by the gram-negative bacterium *Treponema pallidum*, of the highly pathogenic spirochete group. The natural history of the disease is characterized by phases of clinical activity and predominantly sexual transmission latencies.¹

It has been observed an increase in the prevalence of syphilis in developing and industrialized countries, highlighting the rise in cases of primary and secondary syphilis in women of childbearing age.

According to the Boletim de Vigilância Epidemiológica (Epidemiological Surveillance Bulletin) from 2005 to June 2018, 259,087 cases of syphilis in pregnant women were reported in the Notification Recordings Information System (SINAN).² Syphilis in pregnancy leads to over 300,000 fetal and neonatal deaths worldwide each year, and places an additional of 215,000 children at increased risk of premature death.³

Regarding congenital syphilis from 1998 to June 2018, 188,445 cases of congenital syphilis in children under one year of age were notified in SINAN, of which 83,800 (44.5%) were resident in the Southeast Region, 57,422 (30.5 %) in the Northeast, 20,922 (11.1%) in the South, 15,898 (8.4%) in the North and 10,403 (5.5%) in the Midwest.² These numbers display an increase in the registrations of Congenital Syphilis (CS), which suggests difficulties in the diagnosis and / or notification of this aggravation and deficiencies in the quality of prenatal and childbirth

assistance.⁴ These factors result in a high financial cost to the health system, as well as a social impact related to the effects of the disease.⁵

Accordingly, it is necessary to know the Health Care Network (RAS), that is, the territory where people live, the available health services, the flow of attendance, the work process of professionals involved in care, the local epidemiological and socioeconomic characteristics. This is an essential instrument for qualifying the adoption of public health policies.⁵

It is extremely relevant to analyze the understanding and perception of women who have had the experience of having children with CS, so that the content and symbolic representations that permeate the attitudes and practices of these women can improve the understanding of care with the disease. Furthermore, it is considered important to intensify researches on this aspect of the CS context, since the current studies focus on epidemiological data, which is understandable given the severity of this disease.

From this perspective, the question that guided this investigation is emphasized: How do mothers of newborns with CS understand the care of this disease? In view of the above, this article aimed to understand the maternal perceptions about CS and the health care of these newborns with the disease.

Method

The present study is a qualitative research with a descriptive character. Qualitative researches address issues that cannot be quantified, seeking to understand values and signifiers of human phenomena. The investigation was carried out at a medium-sized hospital located in the satellite city Paranoá, in the Federal District, Brasilia. The place for conducting the study was chosen for being the researcher work environment in which an increase in cases of CS has been observed in recent years. Fifteen women, mothers of newborns with CS answered the questions. Were inclusion criteria in the sample: Being over 18 years old and being hospitalized

following the treatment of their child. As exclusion criteria, it was considered: Residing outside the study coverage area.

Individual interviews were carried out with the participants from March to August 2017. The guiding questions were transcribed based on the following questions: Tell us what do you know about syphilis and congenital syphilis. When did you receive the positive result for syphilis? Where was your test performed and how did you proceed from that point? How many appointments did you have during prenatal care? How did you perform the treatment? Has your partner been treated at the health service?

The interviews were performed respecting the privacy and interaction between researcher and participants. The place also facilitated the contextualization of experiences, backgrounds and meanings that contributed to clarify the research problem. The data were collected after approval of the project by the Comitê de Ética em Pesquisa (The Research Ethics Committee) of the Franciscan University (UFN), under opinion No. 1.881.757. The identification of participants was made from the initials HW (Hospitalized Women) according to the text entry (WH1, WH2,...,WH15).

The results were analyzed by predicting the following steps: the ordering of the collected data, the classification of the data and the final analysis (taking into account the research aims and the themes that emerged from the interviews). After the achievement of this process, it is presented a discussion of the findings, the approximation with the existing literature and pertinent to the theme.

Results and Discussion

Participated in the investigation mothers of newborns with CS aged 18 to 37 years and almost all of them had not concluded Elementary School. Most of the interviewees presented a family income of a minimum wage and had no paid occupation. Some of them claimed to have

only the "Bolsa Família" social benefit, which consists of transferring government funds directly to families in poverty, subject to compliance with health education conditionalities. All interviewees were multiparous and maintained active contact with their sexual partner.

Regarding the social conditions of the interviewees, it is clear that they had low education levels. These data were similar to the research carried out in Sobral, a medium-sized municipality in northeastern Brazil, whose predominance was in brown mothers with incomplete primary education.⁸

Often, this is the profile of individuals with a less favored socioeconomic condition and less access to quality health. However, syphilis cannot be said to be a risk condition exclusively for poorer populations; on the contrary, regardless of social or economic status, all can acquire the infection, although, the risk is higher in more vulnerable populations.⁹

Failures in prenatal care

Most of the interviewees reported that prenatal care occurred in the appropriate period, that is, in the first trimester of pregnancy. Only one of the women mentioned having started late in the third trimester of pregnancy. When narrating the moment of diagnosis, they revealed that it was done at the first consultation, through the rapid syphilis test.

Despite having a greater offer of diagnostic tests for pregnant women and their partners, with the introduction of rapid tests in Health Centers, epidemiological data presented no decline in cases. This fact displays that only access to diagnosis is not sufficient to improve the quality of care for pregnant women with syphilis.¹⁰

It is noteworthy that five of the interviewees had abortion and two, stillborn. Of these, seven were diagnosed with syphilis in previous pregnancies. In this study, six premature births and nine term births were evidenced, which may or may not be associated with CS. Contamination of the fetus is known to result in miscarriage, stillbirth, prematurity or a wide

spectrum of clinical manifestations; Only very severe cases are clinically apparent at birth. According to the Health Ministry, among women with untreated early syphilis, 40% of pregnancies result in spontaneous abortion. ¹¹

In relation to treatment, nine women received three doses of medication recommended by the Health Ministry. However, only three partners performed the treatment together. It is a constant data that the main risk factor for CS is inadequate prenatal care, related to about 70 to 90% of cases. Among the problems related to prenatal care, it is highlighted syphilis serology not performed in the recommended periods (1st and 3rd trimesters); inadequate interpretation of syphilis serology; non-treatment of the sexual partner, inadequate information provided by the care team. ¹²

Although the results point to an adequate prenatal search, a favorable outcome of syphilis treatment was not ensured, generating the diagnosis of CS in the baby. Better organization of health services, constant monitoring of syphilis cases in pregnant women and CS along with sensitization of practitioners can alleviate failures in syphilis prevention and care.¹⁰

It was observed that the main factor of treatment failure of pregnant women was the lack and / or inadequate treatment of the sexual partner. This is one of the deficiencies that remain in primary care in the country, especially at the time of prenatal care. Although the results indicate a considerable increase in adherence to prenatal consultations and, consequently, an earlier diagnosis of infection, the treatment of pregnant women is still mostly inadequate and most of their partners are not treated, thus contributing to undesirable outcomes. ¹³

During the interviews, it was possible to perceive the lack of guidance on the disease and its prevention:

My son's illness could have been prevented. There was a lack of information about the need for condom use in intercourse with my partner, that not using condom would cause

problems for my baby. I thought it would be all right for the baby because I took all three doses of the medication. (HW5)

It is evident the need for qualification of prenatal care. Such action can happen through qualification of health professionals to help in the early identification of infected pregnant women, reducing the number of cases of the disease and its aggravations. ¹⁴ Thus, there may be increased adherence to treatment and reduced vulnerability. of women and their partners to sexually transmitted infections (STIs).

Mothers' knowledge of congenital syphilis

When asked about syphilis transmission, participating mothers pointed to the risk of unprotected sex. However, regarding the transmission of CS, they were sometimes confusing:

I know syphilis is transmitted through sex, but I'm not sure about how it goes to the baby. Even though I'm taking injections, do I need to keep taking care? (HW14)

These questions can be clarified during prenatal care, once the moment these consultations occur is a rich space for discussing doubts and avoiding CS. Prenatal consultation, when not understood as a welcoming moment, may decrease the pregnant woman's satisfaction and confidence in the professional who leads her care. Mothers said they knew that their children could develop sequelae if they were diagnosed with CS, however, they showed uncertainties in reporting what these complications would be. Information about the aftereffects of CS was sometimes acquired by television and the internet:

I saw on television that a child may be born deaf. (WH11)
I saw on the internet that causes stain on the body, wounds in the private parts. (WH2)

A recurrent problem, pointed out by the research participants, was regarding the guidance received during prenatal care by health professionals. The statements reveal insufficient communication:

The prenatal doctor informed me that the baby could be born with heart, brain, and malformation problems. But I didn't quite understand what that would be like. (HW8)

At the Health Center they said it was bad for the baby, and that I had to treat, I was afraid. But I didn't get it right. (HW9)

According to the World Health Organization (WHO), health service users should be informed about syphilis and be convinced that prevention and treatment can result in important benefits for maternal and unborn child health. Importantly, community-based approaches may be relevant in informing the vulnerable public and stimulating the search for means for syphilis detection. ¹⁶ Regarding treatment, new doubts were observed:

I don't know many things yet, they tell me, but I don't understand much. It seems they last 10 days. (HW9)

I don't really know about the treatment. They didn't explain to me, [...] I'm taking some injections. (HW10)

The complexity of the treatment for CS, added to the lack of knowledge about the disease, may explain the limitations of the mothers regarding the understanding of appropriate therapy. However, it was noticed through the testimonies, the need for better guidance, because the correct treatment consists of a chance of cure for the newborn (NB) and prevention of serious complications.

After discharge, the child should remain in monthly outpatient care up to six months of life and bimonthly from the sixth to the 12th month. Nontreponemal examinations should be regular up to 18 months or two consecutive negative examinations. Specialized care in ophthalmology, neurology and audiology should be semiannual until the age of two. ¹⁷ Mothers'

insecurity regarding CS can lead to different discomforts, which may intervene in the treatment of infected children.

Mothers Feelings About Congenital Syphilis diagnostic

During the testimonies, the mothers expressed with emotion when they remembered the moment of the diagnosis of the disease. In this sense, they narrated some feelings of anguish and concern regarding their children's infection:

I was very upset when I received the diagnosis because the child is not to blame for anything. I feel very sad, I cried a lot. I don't like it because he cries, I wanted to feel his pain, what he's feeling I wanted to feel. I don't like it at all. (HW3)

I should have convinced my husband to have the treatment so that our son would not have been born with this disease. I get sad. Knowing she took it from me, no mother wants to see her son suffer. (HW5)

It is horrible. When I saw the baby being stung and knowing it was our fault. After I saw my hospitalized child I realized that treatment is important. It is a very difficult situation for me, because seeing my son crying every time he takes these injections makes me suffer because he took it from me. (HW2)

The narratives revealed guilt and suffering. Factors such as feelings of remorse and lack of information seem to influence their understanding of treatment and may compromise the care of NB. Supporting these women is very important, as is not allowing the transfer of guilt for the transmission of the disease to them. Instead of reinforcing their guilt about responsibility in the circumstances in which they live, the practitioner should instead adopt a clear dialogue with succinct language.

Various feelings of concern and insecurity can be reduced through clear, effective and specific communication by the staff, making the bond more solid and effective. The health team in this context plays a crucial role in mediating needs of this population contingent, offering assistance support, guidance and clarification.

Thus, individually or in groups, with the adoption of educational strategies and respecting the beliefs and culture of each woman, these workers can contribute significantly to the adherence to the exam. In addition, they can make them aware of the importance of having the preventive exam and encourage the search for health facilities.¹⁹⁻²⁰

The elements that permeate the diagnosis, treatment and prevention of syphilis and CS in women, may signal factors that are influencing care and, thus, favor the implementation of health education strategies that aim the health of this population. This method may include the work of health education through informational materials and being aware of what the service user understood from the message.

Final considerations

The study evidenced the importance of reviewing the procedures adopted and greater perception of health professionals and managers before the CS, especially in the aspects related to communication with users of the service, taking into account the failures noticed in the care of these women during their prenatal care. Emphasizing throughout the research, insecurities regarding the diagnosis, treatment and prevention.

The knowledge of women is essential for accession to treatment of the disease and proper prevention. It is suggested the promotion of educational actions through informative materials, accessible language, which may be distributed to mothers at the time of discharge for the monitoring of care with their newborn. In the case of acquired syphilis and CS, prevention is already known and widespread in the health environment, but better strategies are needed to put prevention into practice.

However, a limitation of this study was the non-participation of partners in the research, since initially there was a prediction of participation of women, mothers of newborns with CS.

It is noteworthy that including the partners in this process can elucidate some points regarding not performing effective treatment in them.

CS is a preventable condition as long as it is properly diagnosed and treated. The persistence of high rates of vertical transmission, even after seeking prenatal care, indicates difficulties in its control and intervention. The fragility in the diagnosis and treatment of women and partners increases the vulnerability to the occurrence of CS. Therefore, it is believed that the guidance of a health professional to pregnant women with syphilis, especially about the risks that children take when infected with Treponema pallidum can minimize the risks of CS.

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