

Prenatal discovery of baby's cleft lip and palate: pregnant women's main doubts

A descoberta pré-natal da fissura labiopalatina do bebê: principais dúvidas das gestantes

El descubrimiento prenatal de la fisura labial y palatina del bebé: principales dudas de las embarazadas

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ABSTRACT

Objective: to identify pregnant women's main doubts at prenatal diagnosis of baby's cleft lip and/or palate. **Method:** this retrospective, quantitative, descriptive study considered a sample of 15 pregnant women attending nursing appointments in 2016 at a public institution in São Paulo. After the project was approved by the research ethics committee, data were collected using an institutional instrument. Doubts were categorized into feeding, hygiene, surgical protocol, diagnostic hypothesis, postoperative care and suffering/bullying. The results were subjected to descriptive statistical analysis. **Results:** the mothers' mean age was 30 (± 5.9) years, the fathers' mean was 31 (± 10.4) years. The following features predominated: low mean socioeconomic position – 8 (53%); higher education – 15 (52%); male babies – 11 (73%); left unilateral transforaminal cleft – 7 (47%). Doubts were raised on: food – 15 (100%) and hygiene – 9 (60%). **Conclusion:** the pregnant women's main doubts were about food and hygiene. Identifying them made it possible to adjust guidelines to this clientele's real needs.

Descriptors: Cleft lip; cleft palate; nursing; pregnancy.

RESUMO

Objetivo: identificar as principais dúvidas de gestantes com diagnóstico pré-natal do bebê de fissura de lábio e/ou palato. **Método:** estudo descritivo, retrospectivo, quantitativo. A amostra foi composta por 15 de gestantes atendidas na consulta de enfermagem, em 2016, numa instituição pública paulista. Para a coleta de dados, utilizou-se instrumento institucional após aprovação do projeto por Comitê de Ética em Pesquisa. As dúvidas foram categorizadas como alimentação, higiene, protocolo cirúrgico, hipótese diagnóstica, pós-operatório e sofrimento/bullying. Os resultados foram submetidos à análise estatística descritiva. **Resultados:** idade média materna de 30 anos ($\pm 5,9$), paterna de 31 anos ($\pm 10,4$). Predomínio das seguintes características: classificação socioeconômica média inferior – 8 (53%); escolaridade dos progenitores, ensino superior completo – 15 (52%); bebês do sexo masculino – 11 (73%); diagnósticos de Fissura Transforame Unilateral Esquerda – 7 (47%). Salientaram-se dúvidas sobre: alimentação – 15 (100%) e higiene – 9 (60%). **Conclusão:** as principais dúvidas das gestantes foram sobre alimentação e higiene. Identificá-las permitiu direcionar as orientações para as necessidades reais dessa clientela.

Descritores: Fenda labial; fissura palatina; enfermagem; gravidez.

RESUMEN

Objetivo: identificar las principales dudas de mujeres embarazadas con diagnóstico prenatal del bebé de fisura de labio y/o palatina. **Método:** estudio descriptivo, retrospectivo, cuantitativo. La muestra se compuso de 15 mujeres embarazadas atendidas en la consulta de enfermería, en 2016, en una institución pública de São Paulo. Para la recolección de datos se utilizó un instrumento institucional después de la aprobación del proyecto por el Comité de Ética en Investigación. Las dudas se categorizaron como alimentación, higiene, protocolo quirúrgico, hipótesis diagnóstica, postoperatorio y sufrimiento/bullying. Los resultados se sometieron al análisis estadístico descriptivo. **Resultados:** promedio de edad materna de 30 años ($\pm 5,9$), paterna de 31 años ($\pm 10,4$). Predominio de los siguientes aspectos: clasificación socioeconómica media inferior – 8 (53%); escolaridad de los progenitores, enseñanza universitaria completa – 15 (52%); bebés de sexo masculino – 11 (73%); diagnósticos de Fissura Transforamen Unilateral Izquierda – 7 (47%). Se destacaron dudas sobre: alimentación – 15 (100%) e higiene – 9 (60%). **Conclusión:** las principales dudas de las embarazadas se basaron en alimentación e higiene. Identificarlas permitió consucir las orientaciones hacia las necesidades reales de esa clientela.

Descriptores: Lábio leporino; fissura del paladar; enfermería; embarazo.

INTRODUCTION

Lip and palate fissures (LPFs) are characterized by the non-migration of cells during the formation of lip and/or palate structures. They can be partial or total and occur in the first trimester of pregnancy, that is, a cleft lip and alveolar ridge are formed until the 8th week, while a palate fissure develops until the 12th week of intrauterine life^{1,2}.

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Different LPF classification forms are described in the literature; however, the classification using the incisive foramen as a reference is utilized in the whole country by various institutions that treat such specific patients. Nevertheless, it is not applied internationally, which shows the need for a universal classification reference³.

In this study, the model used at the Hospital for Rehabilitation of Craniofacial Anomalies of the University of São Paulo (HRAC/USP), as proposed by Spina and later modified by Silva Filho⁴, is applied with the incisive foramen as a reference, according to the following classification: pre-incisor foramen fissures, trans-incisor foramen fissures, post-incisor foramen fissures and rare facial fissures^{1,4}.

Pre-incisor foramen clefts are those that previously affect the incisive foramen and may include the lip and the alveolar ridge. They are classified as total when they go through the nasal floor and as partial when they affect only the lip. They can be unilateral (left or right) or bilateral^{1,4}.

The group classified as trans-incisor foramen clefts include those that reach the whole maxillary extension, from the lip to the uvula, and can be unilateral, bilateral or median^{1,4}.

Post-incisor foramen clefts, in turn, affect exclusively the palate and may be total (affecting the hard and soft palates) or partial (affecting only the hard or the soft palate)^{1,4}.

In Brazil LPF occurrence is one case out of every 650 live births, representing 25% of all congenital anomalies. Unilateral LPFs correspond to 30%, and bilateral cases to 14%^{1,5}.

There is a wide etiology involving genetic factors (usually associated with syndromes) as well as environmental factors, such as: smoking, exposure to antiepileptic drugs, folic acid antagonists, excessive intake of alcoholic beverages, ionizing radiation, infections, vitamin deficiencies and excess vitamin A in the first pregnancy trimester^{6,7}.

In view of the above, the need to conduct this study was justified, and, for that purpose, the following guiding question was designed in face of LPF diagnosis in pregnancy: What are the main questions presented by pregnant women who will give birth to children with a cleft lip and palate during the nursing consultation?

Therefore, the objective of this study was to identify the main questions presented by pregnant women who have had prenatal diagnoses of babies with a cleft lip and/or palate.

LITERATURE REVIEW

This type of malformation can affect any individuals regardless of their social class, race, gender or ethnicity. However, studies show that individuals from lower social classes are more vulnerable to such changes due to the fact that they have greater difficulty in accessing health services for prenatal care or conditions to keep a healthy diet, which influences the baby's development⁷.

For the early diagnosis of malformation, ultrasonography is the method most often used nowadays as the baby can be visualized from the 28th to the 33th week of pregnancy. In addition, this method can determine gestational age, location and size of the placenta, number of babies and the presence or not of congenital malformation. This diagnosis favors the follow-up and effective preparation for the mother and family members².

The ideal moment to identify and inform pregnant women and their relatives about the existence of any congenital malformations is during prenatal care, according to guidelines established by the Ministry of Health⁸.

Studies report on the benefits of prenatal diagnosis, such as: the possibility of parents' better preparation and qualification for the baby's care as well as the family's better adherence during the treatment and establishment of a therapeutic plan or surgical treatment by health care professionals^{2,5}.

Another study on mothers of children diagnosed with Down Syndrome showed that if such diagnosis were identified during pregnancy, there would be a longer period of time for these mothers to overcome it and adapt to that information. Thus, they would be better prepared to receive their baby, in addition to seeking knowledge about the care needed after birth⁹.

Pregnancy is the period when women undergo various physiological and emotional changes as well as experience moments of doubt, fear and insecurity^{10,11}. Pregnant women usually idealize an aesthetically and functionally perfect baby. An LPF diagnosis causes these mothers to experience a feeling of loss, since the real baby is different from the idealized one⁵.

As regards congenital anomalies, LPFs are more difficult to be accepted by parents because they affect their child's face and, therefore, are easily visible and pointed as an abnormality¹¹.

A study has reported that, when presented with a diagnosis of congenital malformation, parents constantly experience despair, and feelings of anger, shock, confusion, anxiety, guilt and sadness are common¹².

The presence of an LPF causes functional problems, such as difficulties in chewing, due to dental positioning, swallowing, hearing, phonation and breathing, as well as frequent otologic dysfunctions. As one becomes older and social relations begin, psychosocial problems appear (a different physical appearance, an often altered voice), and that can lead to differentiation or even to social exclusion^{5,13}.

It is at this moment that the importance of professional help and orientation is pointed out, for both the mother and the family, aiming to provide better ways to cope with the situation¹³.

It is imperative that the therapeutic follow-up be performed by a multidisciplinary team, including a plastic surgeon, an otorhinolaryngologist, a speech therapist, an orthodontist, a psychologist, a geneticist, a pediatrician and a nurse, among others, who are properly trained and qualified⁷.

Among these professionals, nurses play an important role in providing information to family members, which is often done during the nursing consultation with the pregnant woman. It is in this consultation that the professional provides, especially to the pregnant woman, information about LPF types, their causes, care procedures, breastfeeding and oronasal hygiene.

For such orientation to be really effective, it is necessary to know about the needs and questions that are most often presented by pregnant women in view of the diagnosis of an orofacial anomaly in order to plan and implement nursing interventions.

METHODOLOGY

This is a descriptive, retrospective and quantitative study. The sample consisted of 15 pregnant women who attended the public health sector of HRAC/USP in 2016 for nursing consultation.

The data collection instrument was a form standardized by the institution for the nursing consultation of pregnant woman with a prenatal diagnosis of craniofacial anomaly, comprising questions on sociodemographic variables, diagnostic hypothesis according to ultrasonography, gestational age, probable date of delivery, a brief summary of the main orientation provided to the pregnant women during consultation and a space for nursing notes, including the main questions presented.

Because they were secondary data (medical records/charts), the use of an Informed Consent Form (ICF) was not necessary, according to Resolution no. 466/12 by the National Health Council. Therefore, a Commitment and Information-Handling Instrument was formalized.

Data collection began in May, 2017 following approval of the project by the Committee for Ethics in Research on Human Beings (CEP) of HRAC/USP and the National Commission of Ethics in Research (CONEP), under the CAAE approval number: 66923717.9 .0000.5441.

After collection, the questions were categorized as regards food, hygiene, surgical protocol, diagnostic hypothesis, postoperative period and suffering/bullying and, subsequently, tabulated by using Excel 2010 worksheets.

The data were analyzed by descriptive statistical analysis and presented in the form of tables and figures that could be clearly understood.

RESULTS AND DISCUSSION

Fifteen nursing consultation forms used with the pregnant women were analyzed, which comprised a final sample of 29 parents with a maternal mean age of 30 years (± 5.9) and a paternal mean age of 31 years (± 10.4), according to Table 1. In view of the parents' age range, they were considered to be young adults. Studies report that the younger the parents, the greater their readiness to learn about the specific care to be provided to a baby with a congenital anomaly^{14,15}.

In order to evaluate the patients' socioeconomic status in the hospital, an institutionalized instrument is used. It is based on a classification involving a scoring system that evaluates the users' life conditions and profiles, including socioanalytical income considerations, occupation, family demographic formation, education and housing infrastructure conditions. In this study, the lower middle class socioeconomic family classification was predominant ($n=8.53\%$), according to Table 1. Such result shows that the families had better housing infra-structure, good education and good wages¹⁶.

TABLE 1: Distribution of parents according to variables: parents' socioeconomic classification and education. Bauru, São Paulo, Brazil. 2016

Variables	n	%
Parents' social classification		
Lower middle class	8	53
Upper middle class	6	40
Middle class	1	7
Parents' education		
College graduates	15	52
High school graduates	12	41
Incomplete high school	1	3.5
Incomplete elementary school	1	3.5

The family's socioeconomic classification is fundamentally important, since it can influence their knowledge of the public resources and services for diagnosis and treatment, which enables them to quickly find answers to their questions and positively cope with the rehabilitation process¹⁷.

However, studies show that the higher a family's socioeconomic status, the lower their level of acceptance of a baby's malformation when compared to families from lower social classes. This is due to the fact that families from higher social levels are aware of the difficulties and obstacles in relation to the social acceptance to be experienced by their future child, in addition to the demands and standards imposed by their milieu¹³.

As regards education, college graduates prevailed - 15 (52%), according to Table 1. Education levels influence people's search for knowledge, their capacity to learn and their development of specific skills for actions related to a baby's daily life¹⁷.

Considering the experience of the authors of this study in the institution, it is possible to point out the incidence of a good socioeconomic classification and a high education level in the group under study, which facilitates their access and attendance to the services provided to pregnant women.

In the study, left unilateral trans-foramen clefts prevailed - 7 (47%), according to Table 2.

TABLE 2: Characterization of lip and palate fissures according to diagnoses by ultrasonography. Bauru, São Paulo, Brazil. 2016. (N=15)

Diagnostic Hypothesis	n	%
Left unilateral trans-foramen fissure	7	47
Bilateral trans-foramen fissure	4	27
Left unilateral pre-foramen fissure	3	20
Right unilateral trans-foramen fissure	1	6

There was a predominance of male babies - 11 (73%). This figure corroborates the literature as it shows a higher incidence of trans-foramen fissures in males, among which unilateral fissures are twice as frequent on the left side and nine times more recurrent than bilateral clefts^{6,7}.

In the study, questions regarding the newborn's feeding - 15 (100%) and hygiene - 9 (60%) were noteworthy, according to Table 3. It is important to point out that, in some cases, the pregnant women had more than one question.

Feeding was one of the main doubts presented by the pregnant women in this study, since the fissure affects the oral cavity and can lead to low food intake, thus compromising the baby's development as well as its weight and height.

Studies report that the process of feeding a baby with a fissure is a major challenge, as each cleft type leads to different degrees of difficulty. Among the recurrent complications, the following are noteworthy: inefficient sucking (due to changes in intraoral pressure), prolonged bottle or breastfeeding time and nasal reflux of milk, which may lead to increased risk for aspiration⁷.

According to the literature, breastfeeding is considered ideal when exclusive (breast milk only) during the first six months of the baby's life (it should be free-standing) and partial until the end of the first year^{18,19}. However, in the case

of babies with an LPF, especially when the palate is involved, the breastfeeding process is very difficult due to the deficiency or even absence of intraoral pressure, which makes it impossible for the baby to suck^{19,20}.

TABLE 3: Distribution of pregnant women according to the variable main questions presented during the nursing consultation. Bauru, São Paulo, Brazil. 2016. (N = 15)

Main questions	n	%
Feeding	15	100
Hygiene	9	60
Surgeries	8	53.3
Diagnostic hypothesis	6	40
Post-operative period	2	13.3
Suffering/bullying	1	6.6

Studies have reported that when mothers of babies with LPF were questioned about breastfeeding, they showed great difficulties. Only 39% offered breastfeeding to their children, and 65% breastfed the baby in the horizontal position²⁰.

A study on mothers attending a specialized center in the city of Blumenau (SC) identified that the babies showed difficulty in properly latching to the mother's breast and sucking²¹. However, LPFs should not be an impediment to breastfeeding since it is important for the development and strengthening of the entire stomatognathic system, in addition to providing nutrients necessary for the baby's development²².

However, difficulties are commonly found when feeding babies with LPF. The main difficulties shown by this group during feeding were: choking, coughing and reflux. Thus, the child presents impaired sucking and swallowing, which is associated with low intake and weight gain deficit²⁰.

In view of such obstacles, it is necessary to seek alternatives to breastfeeding, such as the use of bottles with appropriate nipples and holes, cups and spoons that have been effective in the process, thus enabling the baby's development and growth^{20,23}.

Along with the proper utensils, it is necessary to follow some recommendations, such as: correctly positioning the baby during milk supply, which consists of placing it in the semi-fowler's position with the head slightly tilted back, thus preventing aspiration; observing if it performs the suction-swallowing-breathing process and pauses to breathe, which is also necessary to facilitate eructation; stimulating the areas near the cleft site by approaching the breast or bottle; and at the end of feeding, positioning the baby in lateral decubitus so as to reduce the risk for choking and even milk aspiration^{23,24}.

One of the problems during breastfeeding is inefficient sucking. This is one of the characteristics of the baby's feeding difficulty that leads to higher energy expenditure for concomitant sucking and low milk intake, with its resulting weight loss. Another problem observed is nasal reflux of food¹⁹, as it can lead to the development of recurrent otitis and even aspiration pneumonia, which require hospitalization for treatment²³.

Thus, the development of a baby with LPF may be impaired, which consequently delays the performance of primary surgeries and interferes with the development of speech and language²³.

Another important question presented by the pregnant women in this study was related to hygiene. It was observed that the presence of LPF causes a greater accumulation of nasal fluids, retaining food in the oral and nasal cavity.

It is known that oronasal hygiene is of paramount importance for health. However, when such anomalies exist, that type of care becomes more important. As previously mentioned, nasal milk reflux is common in this group due to the oronasal communication when there is a cleft palate, which requires frequent cleaning in order to prevent the accumulation of milk particles in the site⁷.

A study conducted at the same institution, which included pregnant women and fathers, showed that, after receiving a nurse's advice during the nursing consultation, the participants reported feeling more relaxed and better prepared for the newborn's birth and care²⁴.

This study has shown the importance of the nurse's presence when providing care for pregnant women, as well as that of the prenatal nursing consultation in the case of a baby with a diagnosis of craniofacial anomaly, pointing out the relevance of the orientation given for the construction of knowledge with the family.

The health care team plays an important role in a newborn's development and in family support. Nurses perform fundamental functions in the specific treatment of LPF cases, since family members, when faced with a diagnosis of congenital malformation, rely on those professionals and expect their help for the baby's initial care. However, it is should be noted that, before giving any information or orientation to pregnant women and their relatives, the existence of a diagnosis of LPF or other malformations must be verified²⁵.

However, a study on mothers of babies with LPF showed that, after the child's birth, 68% reported having received care instructions from health professionals, and 32% reported having received no orientation at all. It was shown that health professionals do not always know or master the information that should be given to this specific population group. Therefore, it is important to identify these pregnant women's main questions and thus contribute to a better quality of life, for both the baby and parents²⁰.

CONCLUSION

The main questions presented by pregnant women whose children had a prenatal LPF diagnosis concerned food and hygiene. Identifying such questions allows for directing orientation to these clients' real needs. This research pointed out nurses' importance in promoting the baby's health and in preparing the pregnant woman and her relatives to cope with difficulties and the necessary care.

It is expected that this study can contribute to the improvement of nursing knowledge as well as facilitate and implement the systematized planning of nursing actions in order to answer pregnant women's questions.

Among the limitations of the study are the retrospective method, since it restricted data collection to the pregnant women's consultation forms that lacked specific fields to record important information, and the small sample, which prevented the generalization of findings. It is recommended that such forms should be revised with the purpose to incorporate new fields with variables of interest so as to better explore the topic and, consequently, better orientate pregnant women.

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