

Listening to the mothers of individuals with oral fissures*

ESCUTANDO AS MÃES DE PORTADORES DE FISSURAS ORAIS

ESCUCHANDO A LAS MADRES DE PORTADORES DE FISURAS ORALES

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ABSTRACT

This descriptive study was performed using a qualitative approach. The objective was to listen and report on the etiology of the malformation and learn about the beliefs of relatives regarding the manifestation of oral fissures. Data collection was performed from March to June 2009 using semi-structured interview and analyzed using content analysis. Five categories emerged: mother's reaction, feelings of the mothers and of the family, the behavior of the team, knowledge of the causes, and beliefs. The results permitted to learn about the beliefs regarding the theme and adjust the orientations of the nursing team and other health professionals to mothers of individuals with oral fissures, helping the relatives throughout all the phases of child development during the therapeutic process.

DESCRIPTORS

Cleft lip
Cleft palate
Mother-child relations
Culture
Nursing care

RESUMO

Estudo descritivo com abordagem qualitativa. Objetivou a escuta e o relato sobre a etiologia da malformação e conhecer as crenças atribuídas pelos familiares à manifestação das fissuras orais. Os dados foram coletados de março a junho de 2009 por entrevista semi-estruturada e analisados por análise de conteúdo. Resultou em cinco categorias: reação da mãe, sentimentos das mães e da família, comportamento da equipe, conhecimento da causa e crenças. Os resultados permitiram conhecer as crenças sobre o tema e adequar as orientações da enfermagem e dos demais profissionais às mães de portadores de fissuras orais, auxiliando os familiares em todas as fases de desenvolvimento da criança durante o processo terapêutico.

DESCRIPTORES

Fenda labial
Fissura palatina
Relações mãe-filho
Cultura
Cuidados de enfermagem

RESUMEN

Estudio descriptivo de abordaje cualitativo. Objetivó la escucha y relato sobre la etiología de la malformación y conocer las creencias atribuidas por los familiares a la manifestación de fisuras orales. Datos recogidos de marzo a junio de 2009 por entrevista semiestructurada y analizados por análisis de contenido. Resultó en cinco categorías: reacción de la madre, sentimientos de las madres y de la familia, comportamiento del equipo, conocimiento de la causa y creencias. Los resultados permitieron conocer las creencias sobre el tema y adecuar las orientaciones de enfermería y de los demás profesionales a las madres de portadores de fisuras orales, auxiliando a los familiares en todas las fases de desarrollo del niño durante el proceso terapéutico.

DESCRIPTORES

Láblio leporino
Fissura del paladar
Relaciones madre-hijo
Cultura
Atención de enfermería

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INTRODUCTION

Pregnancy is a time of great expectation for parents, especially for women. In addition to the biological process through which the mother is going, many factors emerge when a woman is becoming a mother, encouraging her and awakening the desire to be a mother. From the time of childhood, women play with dolls and care for them, as if they were their children. Pregnancy reflects psychological experiences prior to conceiving, for example, her experience with parents, her experience in the Edipian triangle and separation from her parents⁽¹⁾. Finally, the woman has to be willing to abandon the role of daughter to play the role of mother⁽²⁾. This decision is triggered by different reasons and impulses.

During pregnancy the woman lives with the psychological presence of three babies: the phantasmal, the imaginary and the real one. The phantasmal baby is the Edipian one, that is, the baby she desired to have with her parents when she went through her Edipian phase. The imaginary baby is the child the parents have desired in their child's play, on whom they deposit their dreams, and who is the symbol of perfection. The real baby is the one who will be born as a human being, susceptible to defects⁽³⁾.

Both father and mother idealize their baby and expect a perfect child. Only after the child's birth, will the gap between the imaginary and real newborn be undone. When a deviation from what is expected occurs, such as when a malformed child is born, the parents experience an outbreak of unexpected feelings. The malformed child hurts maternal narcissism, violates the mother's fantasy of perfection, revealing her limitations and introduces a sense of inability to generate a healthy child. The phantasmal and the imaginary baby, who possesses an important function in the mother's unrealistic relationship and psyche, are devalued and remain in the unreal and dream world⁽⁴⁾.

In craniofacial malformations, as in the case of a cleft lip palate in which the defect is in the face, the parents' acceptance process is more difficult because these are easily seen and acknowledged as abnormal. In this moment, the parents need to let go of that image created during pregnancy and acknowledge their real child⁽⁴⁾.

Oral Facial Clefts (OFC) are congenital malformations—defects present at birth— popularly called a "harelip" because it resembles a hare's lip. The cleft results from the non-fusion of the front nasal and maxillary region process in the embryo first days of formation and can be associated with other congenital or isolated abnormalities. The etiology of cleft lip palate constitutes a multifactor inheritance—caused by the association of environmental and genetic factors. Deviations and flaws in the embryonic process may result in embryo malformation⁽⁵⁾.

The high prevalence of OFC (1/700 births) may vary according to the geographical region, socioeconomic conditions and gender⁽⁶⁾. A total of 16,853 cases were recorded in Brazil from January 1975 to December 1994. The highest index was found in the Midwest and Southeast regions, 0.48 and 0.47 by 1,000 births respectively. The prevalence of cleft lip palate was 74% and cleft palate was 26%⁽⁷⁾.

Cleft lip can be diagnosed through ultrasound from the 13th week of pregnancy and cleft palate from the 18th week of pregnancy. The presence of a cleft may be isolated or suggestive of other associated malformations, which reinforces the importance of a detailed investigation at the time of prenatal care. Abnormalities associated with OFC are: short stature, microcephaly, mental retardation, craniofacial abnormalities, and health defects, among others. An early diagnosis is important both to emotionally prepare the parents and to give the team time to be prepared⁽⁸⁾ and organized to provide initial care.

Children with oral clefts are generally treated in referral centers for craniofacial malformations. Several surgeries for functional and aesthetic corrections are needed, with constant attention from pediatric physicians, plastic surgeons, ear, nose and throat specialists and geneticists, nurses, speech therapists, dentists, psychologists, social workers, and nutritionists, among other specialists. The treatment is often a long process that includes follow-up by a multidisciplinary team^(4,9).

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OBJECTIVES

- Report what mothers of children with OFC know about the malformation etiology.
- Identify the beliefs mothers possess concerning the manifestation of OFC.

METHOD

To obtain satisfactory data collection and to achieve the proposed objective, we opted for a descriptive study with qualitative approach. The study was approved by the Research Ethics Committees at the Federal University of Rio Grande do Sul, Nursing School (protocol nº 08/08) and at the Hospital das Clínicas of Porto Alegre (protocol nº 08-665). The participants received clarification about the study's objectives and signed free and informed consent forms.

Eight individuals aged between 18 and 45, mothers of children with isolated cleft lips or lip/palate clefts with ages between one to five years old participated in the study. Of these: three had cleft lips, four had bilateral cleft lip palates, and one had a unilateral cleft lip palate. All the children were cared for in the Hospital das Clínicas of Porto

Alegre, RS, Brazil. The participants were identified by alphabetic letters according to the order of the interviews.

Data were collected through semi-structured interviews recorded in MP3 format. These will be kept for another five years complying with the law that regulates authorship rights⁽¹⁰⁾. The interviews took an average of 30 minutes and were carried out in a meeting room at the hospital from March to May, 2009.

Content analysis was used in data interpretation, from which categories emerged, that is, the reports that present similarities or common aspects are grouped together.

RESULTS AND DISCUSSION

Five categories emerged from data analysis: Mother's reaction; Mother's feelings; Knowledge of the cause; Team's behavior; and Beliefs concerning malformation.

Mother's reaction: testimonies concerning the responses of the mothers in the face of the diagnosis; how they reacted when the baby's malformation was confirmed and when they saw the child for the first time.

The mothers reported surprise, crying, shock, despair, denial, fright and normality. For most of the interviewed mothers, the reaction was of surprise when they learned their children presented some malformation.

When he was born I got really surprised. The doctor told me he had a malformation (B).

The first time mothers see their children is usually filled with positive feelings and they do not expect their children to have a problem such as a malformation. And at the time of the diagnosis, this type of problem causes them great surprise (frustration).

One of the mothers, who belonged to a large and healthy family, which presumably served as insurance that all her children would be born well, became shocked and surprised when she learned that her child had a malformation.

For me, actually, G. who was my first, he was a surprise. I didn't ever imagine that, because I come from a very large family. It was a shock for my mother's family as well [...] (A).

Often, the fact that several family members are healthy can lead to the false sense of protection; people do not consider in advance that someone may be born with a genetic disease.

Another mother revealed extreme distress and despair, because she did not know her child had a malformation, though she had taken several exams throughout her pregnancy. Apparently, she was calm because the malformation was not visible in the exams (scans).

[...] When he was born, I got desperate, because I didn't know that. I took several scans and nothing came up. I didn't get scared, but wanted to know why it happened [...] (D)

All the technologies of imaging exams are often not a guarantee that all congenital diseases will be identified and diagnosed.

There is a clear contradiction in this report. The mother reports despair but states she was not scared. It is likely she is denying a very strong feeling experienced at the time. Denial was also observed in the testimony of another mother, when she reports that she did not want to show her child to anyone. This behavior might be related to a feeling of embarrassment, guilt, or fear of other people's reaction.

At the time, I didn't want anyone to see her that way (C).

A healthy and beautiful body is a requirement of aesthetic standards and being out of this social position is often difficult. Not meeting these standards—this beauty dictatorship—produces shame, embarrassment and one tries to hide what is *ugly*. Hence, the news about the child's malformation has an impact on the parents, because a child with any kind of illness is not expected. The news concerning the child's deficiency causes shock and depersonalization in the parents, causing in them a desire to leave and deny reality, confusing feelings that vary between love and hate, acceptance and rejection⁽¹¹⁻¹²⁾.

Shock is part of the first phase of the parents' adaptation process. In this stage, the initial response to the child's abnormality, the parents suffer an abrupt rupture of their feelings and irrational behavior is observed such as crying, feelings of helplessness, and a desire for flight⁽¹³⁾.

In an ideal birth in which the infant does not present any illnesses or limitations, the parents identify in the child the presence of the three babies: the phantasmal, the imaginary and the real one. At this point, the parents initiate an internal mourning process for the imaginary child, who is now concrete⁽³⁾. However, when the parents are faced with a child very different from what they had idealized, an internal confrontation between the imaginary and the real begins. It is at this point that parents should initiate a mourning process for the imaginary child, but the discrepancy between the idealized and the concrete hinders both this process and mental reorganization. The way parents develop in this phase will be a determinant for the establishment of bonds and care delivered to the child⁽¹³⁾.

Among the reactions mentioned in this category, despair, denial, fright, and normality, only normality is not among the characteristics of mourning⁽¹⁴⁾. Normality can be seen in situations in which the parents did not pass through a mourning process or are still in denial.

Mother's feeling: feelings experienced by mothers at the moment their children were born with an oral cleft are grouped in this category. Feelings such as guilt, shame and pity were reported. Guilt was mentioned due to the fact they had not taken a medication prescribed by the doctor during prenatal appointments:

[...] and then, when I gave birth, I thought: I should have taken it (calcium) because it could have worked (guilt) (C).

Lack of detailed information about diseases, at least among less informed patients, generally leads them to fantasize about the subject. This report makes clear that the mother does not know the purpose of calcium because she believes it is related to the prevention of oral clefts, which is not mentioned in medical literature.

Shame is also mentioned in the mothers' testimonies. One of the participants said she became ashamed when she saw her child. She currently feels guilty and sad for having had such feelings.

When I gave birth to him, I felt ashamed. Today, I feel sad knowing I felt ashamed at the time (C).

Another feeling is pity, manifested by family members and which might be related to the fact the child was different from the other children or to the fact they knew the child would undergo several hospital procedures. One of the reports reveals this feeling was experienced by the mother herself.

He had an operation, he's ok. But I feel bad for him, because this is not something to be fixed in one day. There will be years and years... So, he's the one suffering [...] (F)

It is expected that parents become concerned for their children and when a child has a health problem, this concern increases. Hence, these families should have the support of a multidisciplinary team during the long treatment so that the child is neither neglected nor overprotected. Both situations can interfere in a child's developmental process.

These feelings that emerged in the interviewed parents are considered normal and fit into the third stage of *natural course of reactions of most parents with a malformed baby*. In this phase, parents are surrounded by strong feelings such as sorrow, anger, anxiety and guilt. They question themselves: *Why did this happen?* They feel guilty and even doubt their ability to develop affection, love and care for the child⁽⁴⁾.

Parents should be encouraged to accept the baby with a malformation and develop coping strategies as soon as possible. One way to help them is positive reinforcement, making them see the child's qualities and potential, because they need to healthily develop attachment and emotional ties for the child to feel welcomed and supported⁽⁴⁾.

Knowledge of the cause: factors that triggered OFC according to the perception of mothers emerged in this category. They identified them as: lack of calcium, genetic factors, genetic factors associated with environmental factors, and drugs used by the husband. Some mothers were unaware of the causes of oral clefts and even today they question the reason their children were born with a malformation.

[...] I thought nothing... I have no idea [...] (A).

I still have this doubt. Why? I wanted to know why. (B).

[...] but I really don't why [...] (F).

These testimonies are surprising since all the mothers are being accompanied by a multidisciplinary team at the facility where the study was conducted, where guidance is constant. Therefore, we infer that they either did not understand the information they received or denied it and tried not to see what may have led their child to have the cleft lip/palate.

OFC are determined by multi-factor causes including both environmental and genetic factors. Hence, parents have difficulty understanding that there is not a single and easily identifiable factor causing the problem. They often become concerned to knowing the exact cause of the problem and become frustrated for not being able to identify a clear determining factor. When there is no acceptable medical explanation for the child's defect, the parents' genetic make-up is questioned. They may try to find a specific non-genetic cause for the problem so as to deny their guilt. Additionally, parents often change their health team or do not conclude the treatment due to their need to alleviate their guilty feelings and not because they are not satisfied with the professionals⁽¹²⁾.

The genetic aspect was mentioned by most of the interviewed mothers. In the testimony below, the mother shows knowledge concerning embryology in the formation of the face, but does not know what occurs in the process to result in a cleft:

According to what I've studied and what I know, any kind of malformation including a cleft lip occurs between the 6th and 10th week of pregnancy for some reason. From my part, I don't know what would cause it [...] (F).

Two mothers talked about multi-factor causes, genetic and environmental. The environmental factor was mentioned by one of them because she believes she lacked vitamins during pregnancy. She also mention the hereditary factor:

[...] it could be lack of vitamins or genetic from the part of my aunt. I believe that it's due to lack of vitamins and (the fact) that my aunt was born like this also contributed to it. I believe it's genetics [...] (G).

In relation to hereditary aspects: there are chances of 0.1% that parents who do not present OFC will have a child with a cleft. If parents already have a child with a cleft, chances increase to 4-6% for the next child. When two children are affected, the chance of recurrence raises to 11-21%. If one of the parents and one child have cleft, the next child has a probability of 17% to born with OFC⁽¹⁵⁾. In addition to the genetic factors, the influence of behavioral exposure has been proven: alcohol, smoking, nutrition (lack of vitamins such as folic acid, riboflavin (B12)) and also environmental factors such as agricultural chemicals (pesticides and herbicides) may play a role^(5-6,16).

Team's behavior: the reports of mothers concerning information provided by the health professionals and their attitudes from the diagnosis up to the moment of birth were

grouped in this category. Both inappropriate and appropriate behaviors of the health team were reported. Appropriate behavior: the mothers reported the behaviors and attitudes of professionals that helped them to accept and cope with the situation.

The following testimony shows that the mother was informed that the cleft would be corrected through surgery, a procedure provided in the hospital and the professional who attended her added information related to eating and speech that calmed her:

When he was born, they told me he had a harelip but the condition could be treated, through surgery. That he would be cared for here. It wasn't a severe condition, had a solution and it would not hinder breastfeeding or speaking [...] (G).

Current technological advancements permit the visualization of several fetal malformations through morphologic ultrasound, including defects in the formation of the face. The prenatal diagnosis is a stressful event; there is the possibility of diagnosing such imperfections. A critical point for the professional who finds the cleft is that it may be associated with other genetic abnormalities. About 30% of those with OFC have syndromic conditions, that is, they have other associated abnormalities, including chromosomal abnormalities, Mendelian diseases and exposure to teratogens (phenytoin, alcohol) in addition to a number of syndromes that are incompatible with life⁽⁷⁾.

When OFC is diagnosed only at birth, the child should be presented to the parents as soon as possible so that they do not develop fantasies and anxiety⁽³⁾. Given the unexpected situation, mothers may have a difficult experience and professionals may experience distress as well, since they also did not expect a child with a malformation.

One of the responsibilities of health professionals who initially care for the child and family is to provide them conditions in which to interact and establish bonds between the parents and the newborn to facilitate the mother's adaptation to the child as early as possible. It is essential to give the parents opportunities to reveal their doubts, feelings, anxieties and issues. The parents are the main focus in the entire treatment. They should receive objective and concrete information and be encouraged to actively participate in the newborn's care and treatment⁽⁹⁾.

On the other side, mothers also mentioned inappropriate behavior observed in the teams. Even though health teams are expected to present only appropriate behavior according to each situation and family, the reports show behaviors that did not please the mothers or the children's relatives. Coupled with this is the fact that there are few referral hospitals that have professionals qualified to care for these patients. Frequently, when children are born in smaller hospitals or in small towns, professionals do not have the appropriate qualifications to manage such cases.

The report of one mother reveals she was not allowed to see the child right after birth and her first contact with the

child occurred only two days after birth. Meanwhile she received only vague information, which left her insecure:

I gave birth on Wednesday and they did not allow me to see him. They only allowed me to see him on Friday. The doctor went to talk to me but wouldn't say for sure what he had(A).

The priority for the health team should be to allow the parents to see the child right after the malformation is identified. Anxiety may make them imagine something worse than reality⁽¹⁴⁾. When the health team appropriately handles the situation, it shows the parents the baby is considered an acceptable replacement for the desired baby – the idealized baby – and not one who should be hidden⁽³⁾.

One of the mothers reported that the news regarding the child's malformation was reported in jest. We can infer that the professionals did not value or appreciate the difficult moment the mother was facing.

When he was born, they told me he had a cleft, playing, laughing (B).

The way information is transmitted certainly mobilizes maternal feelings that should be worked out by the team. The priority of the team at the moment of the diagnosis is the way the issue is addressed with parents, who are usually not prepared to receive all the information at once and need some time to understand what is happening. A team prepared to inform parents of the diagnosis is essential for the family to accept it. An unprepared professional may trigger different feelings in the family, especially the mother who may be weakened by the situation.

It is disturbing and distressing for the parents to experience a discrepancy between their intense emotional comotion and what they believe to be lack of humanity by the part of professionals. The way the diagnosis is reported requires extreme prudence on the part of the professionals and should not tend to extremes: neither serious nor happy, because the parents may interpret it as lack of empathy if one is too objective, or a lack of sensitivity if one is too joyful and smiling⁽³⁾.

Beliefs: this last category includes testimonies on what the parents heard concerning the beliefs of relatives, neighbors, friends, and what they believed concerning their children's malformation. The most frequent reference in the reports was related to carrying keys, followed by medications, smoking and alcohol. Belief related to keys: the first report refers to the belief that carrying keys close to the body during pregnancy such as between the breasts can contribute to the development of an oral cleft. At the moment the mother states that she had never carried keys close to her body conveys the idea that she believes this behavior could have led to the child being born with a cleft. This belief permeated the experience of some participants.

They said: you carried keys near your breasts, something I've never done (A).

People told me that I've carried a key in my bra [...] (D)

Older relatives told me it was because I put a key in my pocket or on my belly [...] (E).

People said: "You kept a key in your bra. I don't believe in it and I don't do it [...]" (F).

Many people say that carrying a key on your neck, but I don't believe it (G).

In the last two reports, the mothers said that even though they had heard about a relationship between keys and OFC, they did not believe there is any relationship. Many mothers reported they heard from older relatives about the relationship between keys and OFC though nothing in the literature reviewed suggested the reason for such analogy.

Medications: were mentioned as potential causes of OFC. Doubts usually arise when mothers need to use medications during pregnancy concerning the possibility it may interfere in the fetus' normal formation. One of the mothers reported the use of medication to treat a urinary infection during pregnancy, though she did not believe it was a determinant for her child being born with OFC.

Medications? I only used medication for a urinary infection but I don't believe that it influenced anything [...] (F).

Often mothers are questioned or even accused of having caused the malformation through potential risk behaviors. One mother was accused of trying to abort with some kind of medication and since it was not successful, the medication had affected the child's formation. The mother denied the attempted abortion.

Ah, there were people who said: she tried to abort and took something, it didn't worked and then it happened, but none of it really happened [...] (A).

Smoking and consuming alcohol: one mother reported that friends told her there was an association between malformation and smoking and consuming alcohol during pregnancy.

I have friends who said it was a result of smoking and drinking, malformation for drinking beer during pregnancy and things like that [...] (B).

Other mothers also heard about this relationship but do not believe that smoking and drinking alcohol may interfere in the fetus' formation and consequently lead to OFC, because they do not smoke or drink and their children were born with the malformation.

I don't drink, don't smoke. I've drunk but it was a bit of wine, I don't believe it (G).

I don't drink or smoke [...] (H).

Some studies in the literature analyzed exposure to smoking and alcohol and conclude that these might be considered risk factors for OFC. It is believed that substances in

cigarettes have the capacity to lower the level of circulating folic acid. Alcohol might interfere in cell migration and organization in the process of face formation⁽¹⁶⁾. There is also proof that the use of anticonvulsant medication, benzodiazepines and corticosteroids increase the risk of OFC.

Congenital malformations have made an impression on mankind since ancient times. The initial findings was found in writings of Cuneiform tablets in the Nineveh library dating from approximately 2,000 B.C.⁽¹⁷⁾. Many ancient civilizations disposed of children with congenital malformations; afterwards many of them would become sculptures, paintings and drawings. The books *The Republic* by Plato and Aristotle's *Politics* for instance, included the planning of Greek cities and measures for the elimination of people born *deformed*. Some African cultures sometimes consider malformations as majestic and sometimes as worthy of sacrifice. Minor anomalies such as protruding eyes were considered forms of power though people with diseases that resulted in a displeasing face, such as mucopoly-saccharidoses, were considered criminal and deserved punishment⁽¹⁷⁾.

Given the lack of scientific studies, it was believed in the 1700s that the mental impressions of mothers would be manifested on their children: if a mother looked at a rabbit or a hare during her pregnancy, it could determine a child with OFC⁽¹⁷⁾. Lack of knowledge concerning congenital defects, fantasy, curiosity and the peculiarity that were attributed to these could be considered a stimulus for the emergence of beliefs and myths in diverse cultures. Myths and beliefs can be considered a vital instinctive knowledge of a people or a person in the face of the unknown, the unexpected, or something about which there is no conclusive knowledge or yet when confronted with mysteries that incite the imagination of people to create symbols in the form of myths and beliefs⁽¹⁸⁻¹⁹⁾.

CONCLUSION

Pregnancy is a time of great expectation for the parents who wait for the arrival of their exquisite child. When a child is born with a malformation, as in the case of OFC, the chaos caused by the unexpected generates psychological turmoil in the parents. Frequently, neither the parents nor the health team expect a child with malformation and the surprise is mutual.

Data analysis revealed how strongly the malformation diagnosis mobilizes unexpected feelings in mothers both during prenatal care and post birth. The importance of addressing the issue and the preparedness of the team at the time of reporting the diagnosis so as to minimize the parents' suffering is highlighted. Specialized care for the family is essential not only at the time of the diagnosis but also in the first days of the child so parents are able to establish healthy bonds with the child.

It is important to listen to mothers of children with OFC concerning their knowledge and beliefs, since little has been

found in the literature about this topic. Hence, this study enabled listening to these mothers who, even while caring for a malformed child, do not always have the knowledge about the causes involved in the process of OFC formation.

One relevant aspect identified in this study was the lack of preparedness of some professionals to take care of families with children with malformations, among which is OFC. OFC is a common type of malformation and health professionals should be apt to recognize this fact and appropriately reveal the diagnosis to parents. A cohesive and integrated multidisciplinary team is required to provide the necessary support for these families throughout the entire treatment.

In relation to the beliefs that permeate the routine of the social group to which the families belong, OFC is most frequently related to the presence of a key close to the woman's body, the use of medications during pregnancy; smoking and alcohol are also mentioned. Therefore, it is also important that professionals have knowledge concerning the beliefs of their patients, which can influence the care provided to children with a malformation.

Further studies addressing the families of children with malformations are recommended. These diseases require careful follow-up of patients' clinical condition, but the patients and their respective families also need psychological and social support to ensure successful treatment adherence. Having knowledge of the patients' and families' context is essential to heeding their doubts, desires and experiences so their children receive appropriate care.

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