Having a Child with Cleft Lip and Palate: Transformations in the Family

Tendo uma Criança com Fissura Labiopalatal: Transformações na Família

Tener un Hijo con Fisura Labio Palatina: Transformaciones en la Familia

RESUMO

Introdução: As fissuras labiopalatais são as mais comuns dentre as malformações congênitas, sendo necessário um tratamento longo e multiprofissional, necessitando que a família seja inserida nos cuidados desde o nascimento da criança. A família desempenha um papel fundamental no manejo da criança com fissura labiopalatal, sendo necessário por vezes, adaptações da família para a melhor condução do cuidado com a sua criança **Objetivo:** conhecer as transformações da família da criança com fissuras labiopalatais. **Método:** trata-se de um estudo de abordagem qualitativa, descritiva e exploratória. Os dados foram coletados através de entrevista com 14 familiares de crianças com fissuras labiopalatais. Os participantes foram captados através do método bola de neve. **Resultados:** Por meio da análise de conteúdo foi possível encontrar 5 categorias temáticas: Esperando a criança perfeita; Dedicando-se exclusivamente a criança; Mudando sua rede de relacionamentos; Optando por não ter mais filho; Vivenciando o sofrimento por meio da esperança na fé. **Conclusão:** O manejo familiar foi voltado as necessárias provenientes da condição da criança. O cotidiano da família foi reestruturado buscando um melhor suporte para a sua criança e uma maior adaptação à nova realidade desta família. Aos profissionais de saúde faz-se necessário o conhecimento das o manejo familiar visando o fortalecimento da família, assim como a inserção da criança no contexto familiar.

DESCRITORES: Família; Relações familiares; Crianças; Fissuras labiopalatais.

ABSTRACT

Introduction: Cleft lip and palate are the most common congenital malformations and require long-term, multidisciplinary treatment, requiring the family to be involved in care from birth. The family plays a fundamental role in managing children with cleft lip and palate, and sometimes requires adaptations to better manage the care of their child. **Objective:** To understand the transformations in the families of children with cleft lip and palate. **Method:** This is a qualitative, descriptive, and exploratory study. Data were collected through interviews with 14 family members of children with cleft lip and palate. Participants were recruited using the snowball method. Results: Through content analysis, five thematic categories were identified: Waiting for the perfect child; Dedicating exclusively to the child; Changing your network relationships; Choosing not to have another child; Experiencing suffering through hope in faith. **Conclusion:** The family management was focused on the needs arising from the child's condition. The family's daily routine was restructured to provide better support for the child and better adaptation to the family's new reality. Health professionals need to understand family management to strengthen the family and integrate the child into the family context.

DESCRIPTORS: Family. Family relations. Children; Cleft lip and palate.

RESUMEN

Introducción: El labio leporino y el paladar hendido son las malformaciones congénitas más comunes y requieren un tratamiento multidisciplinario a largo plazo, lo que exige la participación de la familia en sus cuidados desde el nacimiento. La familia desempeña un papel fundamental en el manejo de los niños con labio leporino y paladar hendido, y en ocasiones es necesario realizar adaptaciones para una mejor gestión del cuidado del niño. **Objetivo:** Comprender las transformaciones en la familia de niños con labio leporino y paladar hendido. **Método:** Estudio cualitativo, descriptivo y exploratorio. Los datos se recopilaron mediante entrevistas a 14 familiares de niños con labio leporino y paladar hendido. Los participantes se reclutaron mediante el método de bola de nieve. **Resultados:** Mediante el análisis de contenido, se identificaron cinco categorías temáticas: Esperando al hijo perfecto; Dedicándose exclu-

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sivamente al hijo; Transformando la red de relaciones; Decidiendo no tener otro hijo; Experimentando el sufrimiento a través de la esperanza en la fe. **Conclusión:** El manejo familiar se centró en las necesidades derivadas de la condición del niño. Se reestructuró la rutina diaria de la familia para brindar un mejor apoyo al hijo y adaptarse mejor a la nueva realidad familiar. Los profesionales de la salud necesitan comprender la gestión familiar para fortalecer la familia e integrar al niño al contexto familiar.

DESCRIPTORS: Familia. Relaciones familiares. Niños; labio y paladar hendido.

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INTRODUCTION

Congenital malformation or congenital anomaly is defined by the World Health Organization as an alteration in the function or structure of intrauterine development that may compromise organs or a group of organs, caused by genetic, environmental, or multifactorial factors(1). They are defined as any functional or structural alteration in fetal development that may be caused by genetic, environmental, or even unknown factors. It is important to note that they may manifest immediately after birth or at any time throughout life(2).

Malformations result in anatomical, functional, and aesthetic sequelae and, in some cases, can even lead to death(2). Among craniofacial congenital anomalies, cleft lip and palate (CLP) are the most prevalent in the Brazilian population, affecting 1 in 650 live births. Due to their high complexity when left untreated, they have aesthetic, functional, and psychosocial effects. Treatment begins when the baby is still an infant and can extend into adulthood, requiring a specialized team(3).

CLP is a malformation characterized by a rupture of the lip, alveolar ridge, and/or palate, resulting in the failure of these structures to close during fetal formation and development between the fifth and twelfth week of intrauterine life(3).

During the prenatal period, cleft lip and palate can be diagnosed through ultrasound examination. This allows for the identification of cleft lip, while cleft palate is more frequently diagnosed after birth through clinical examination(4).

Treatment consists of primary reconstructive surgery, beginning with cheiloplasty in the third month of life, followed by palatoplasty at 12 months. Other types of treatment include pre-surgical maxillary orthopedics, alveolar bone grafting, surgical treatment of velopharyngeal dysfunction, and orthognathic surgery(5).

The nursing team is indispensable in assisting families with children with congenital malformations, with the aim of achieving better integration, since each family, based on their previous experiences, beliefs, and values, will react differently to the diagnosis. In this integration, family members support each other in the search for development, coping, maintenance of integrity,

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and building family health. The nursing team will work to communicate effectively about procedures and the care to be provided to the child (6).

Studies report that effective, quality care requires understanding the functioning and dynamics of the family and including the family's experience with the child in order to create appropriate interventions. In this way, the changes experienced by the family and their children help nursing and health professionals expand their knowledge to better serve and support these families. Caring for these children requires a reorganization of roles, which has an important impact on the lives of family members(7).

Therefore, studies with children with CLP are important for the reality of Brazilian nursing, as they will assist in interventions with these families.

Given this, the objective of this study was to understand the transformations in the families of children with cleft lip and palate.

METHOD

This is an exploratory, descriptive study with a qualitative approach. Exploratory research aims to provide more information about a subject under investigation, familiarize oneself with the phenomenon, or gain a new understanding of it in order to formulate a more precise research problem or create hypotheses(8). Descriptive research aims to describe characteristics of a population or phenomenon. This type of study is common in research that investigates opinions, attitudes, values, and beliefs (9).

Friedman's Structural-Functional Theory was used as a theoretical framework, which seeks to understand how the family is organized, how its components relate to each other, and what functions the family fulfills in different contexts. For Friedman, the family is a dynamic system in which the internal structure and functions performed by its members are fundamental to promoting health and preventing disease (10).

This theory provides a useful framework for working with families, highlighting the importance of systemic analysis, family structure and functions, as well as interaction with the external environment, as a basis for health promotion and comprehensive care.

This research was conducted using the snowball method, which characterized the sample as intentional and non-probabilistic, where it is not possible to determine the probability of selection of each research subject. The participants were volunteers and they themselves indicated other family members to participate in the study, in a continuous process that continued until the study objective was achieved or until saturation was reached (11).

The research subjects were families of children with cleft lip and palate who participated in support groups for families of children with CLP. The initial sampling was performed by the researchers for convenience, and this sample indicated subsequent participants in a successive process(12).

Individuals who agreed to participate in the study were informed of the study objectives and assured of the protection of their anonymity, as well as the possibility of withdrawing from the study at any stage, according to their wishes. After receiving this information, individuals who agreed to participate in this study signed an Informed Consent Form.

The inclusion criteria were: family members over 18 years of age who had a child with cleft lip and palate at least 6 months of age, who lived in the same residence, and who participated in the child's care. The exclusion criteria were people with communication difficulties.

The sample consisted of 14 family members of children with cleft lip and palate who actively cared for the child and who agreed to participate voluntarily in the study.

Participants were invited to join the study through telephone calls or electronic messages sent by the researcher. Initially, the researcher presented and explained the objectives of the study, guaranteeing anonymity and absolute confidentiality of the information, as well as the freedom to participate or not in the study. After clarification, the participants signed the informed consent form. A demographic data collection instrument was used to characterize the participants. The interviews were recorded and transcribed in full by the researchers and subsequently analyzed descriptively.

The interview was conducted at a location chosen by the participant and lasted approximately 40 to 60 minutes. The following guiding question was used for the interviews: Tell me what has changed in your life and your family's life after the birth of your child with LPL.

Bardin's content analysis was used to analyze the data, which aims to find the core meanings present in the interviews whose presence or frequency are significant and correspond to the study's objective. It is organized into phases: pre-analysis, exploration of the material, treatment of the results, and interpretation(13).

In preparing this manuscript, the criteria for qualitative research reports presented in the COREQ checklist - Consolidated criteria for reporting qualitative research(14) were taken into account. This research complied with the recommendations of Resolution No. 466, dated December 12, 2012, of the National Health Council (CNS), with approval number: 3,065,460 from the Ethics and Research Committe[e] (15).

RESULTS

Fourteen family members of children with CLP participated in the study, including thirteen mothers and one grandmother. Family income ranged from 1,200 to 6,000 Brazilian reais, with five families unable to report their income or having no income. Of the

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participants, twelve are housewives and only two are able to work outside the home full time. The children's ages ranged from 1 to 11 years, with seven having unilateral cleft lip and seven having bilateral cleft lip and palate. Of the women, seven discovered the cleft on ultrasound (before delivery) and seven at the time of delivery (after delivery). In terms of education, five have or are pursuing higher education, one has a technical degree, one did not finish high school, and seven finished high school.

The results obtained in the study were organized into five categories: Waiting for the perfect child; Devoting themselves exclusively to the child; Changing their social network; Choosing not to have more children; Experiencing suffering through hope in faith.

Waiting for the perfect child

Pregnancy is a period marked by family expectations regarding the baby that is about to arrive. However, the diagnosis of a congenital malformation represents a rupture in this ideal, especially when it comes to craniofacial anomalies, such as cleft lip and cleft palate, which directly affect the appearance and functionality of the child's face.

Waiting for the perfect child reflects the accounts of family members when faced with the diagnosis. There is always the expectation of a typical child, and in these cases, it is necessary to deconstruct the image of the ideal child, making it difficult to accept the diagnosis or even leading to possible rejection of the child, which impacts the entire family life.

Waiting for the perfect child represents the family's expectation of the birth of a healthy child, without the need for treatment. The reports demonstrate the suffering when faced with the diagnosis and the hope during pregnancy for the birth of a child without abnormalities.

So when I found out that my son would have this problem, I suffered a lot [...] I was expecting a normal child, so that's... when I started seeing the photos and saw children being born that way, I said, my God, how is this going to be, but I looked for help (P9).

But I always asked God for my baby to be born perfect and with no missing parts, but he came missing (P6).

Families who discovered that their children would be born with cleft palates during prenatal exams had difficulty accepting the malformation and hoped that the exams were wrong.

I kept thinking that it might not be true, that he could be born normal... on the ultrasound, I couldn't accept what he had, you know? My mother and my grandmother had hopes that he would be born normal [...]. I went to so many places to confirm that he had the cleft, so many different places to get ultrasounds to confirm it (P1).

After I had the 3D ultrasound, I started researching. At first, I was in shock, right? I didn't think it was right. I wanted to know why, what I had done wrong. I got my previous tests and thought the results were wrong. I didn't want to believe it (P2).

When the pregnancy tests show no changes and the malformation is discovered at birth, it has a greater impact and greater consequences for families and children. The participants reveal their rejection when they receive their children shortly after birth. Some participants revealed that they had postpartum depression and needed help to care for their child. Today, they are left with the pain of talking about this rejection.

My mother came with him to show him to me, and when I saw him, I said, "Mom, take him away, he's not my son." I just cried and cried and cried. I had postpartum depression, and I said I wasn't going to bring him home. It hurts, doesn't it? To talk about it! But, honestly, at the time I said I wasn't going to bring him [...] I rejected him, and today he treats me with love... at first I treated him with contempt, and even as a baby he was affectionate, trying to grab my finger (P6).

My daughter suffered from postpartum depression, she couldn't take care of her daughter, at first she rejected the child, she couldn't even look at my granddaughter, so I had to take care of the girl (P4).

When I found out she would have this problem, I suffered a lot. I locked myself in my room for a week and didn't go out [...] (P9).

Devoting themselves exclusively to the child

Many family members, when faced with a child with cleft lip and palate, tend to give up their lives to meet the children's needs, that is, they give up and renounce their desires and expectations for life and career for the well-being of the children.

Many mothers gave up their professional goals and chose to stay home to closely monitor their children's treatment, accompanying them to appointments, hospitalizations, and surgeries.

I stopped working when he was born [...] because when he had the surgeries, he went to the ICU, and then he had to use a feeding tube, which made it difficult for me to go back to work, because I was the only one who knew how to use it. In the beginning, only my husband and I knew how to do it, so I had to stay home (P12).

But after my daughter was born, I made an agreement with the company I worked for and decided to take care of her at home so I could give her all the care she needed (P2).

The family prioritizes the child, often putting aside their own desires and needs because they believe they are doing what is best for their children, thus changing their lives to be able to live for their children and be more present in their daily lives.

The mothers and grandmothers who participated in the study reported devoting themselves entirely to caring for their children, often to the detriment of

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their own needs and personal activities. Such behavior highlights a focus on care tailored to the specific demands arising from the child's needs.

My whole life revolves around him [...] today I live for him, if I have to go to treatment ten times a month, I go (P10).

You often have to give up some things, like trips, because of his treatment, and when he has something he needs to do (treatment), we are away for several days (P8).

I dedicate myself more to my family nowadays, my daughters, I am more present, closer to them (P2).

They also express concern about leaving their child with other people. They reveal their fear that they will not be well cared for, so they give up activities and commitments to live for the care of their child.

If I want to go out to pay a bill or make a doctor's appointment, I can't. He sticks to us like glue because he can't be with other people who don't know how to take care of him properly... he won't let me go to the market, he won't let me get my nails done, he won't let me go anywhere, he cries and cries and won't eat or drink or do anything (P3).

Changing their social network

Families of children with CP gain a new perspective on life and, as a result, seek a new social network. They try to avoid embarrassment with people who do not understand their child's situation, which leads to them distancing themselves from friends and even family members.

When we are pregnant, we expect that our child will arrive and everyone will love them and want the best for them... then suddenly you find yourself in a situation where sometimes people avoid you for things that are not the end of the world, my child is not an animal (P5).

People treated us with pity and things like that, which made us distance ourselves a little more, to avoid people asking questions (P1).

Families reported that they even avoid going out on the street to avoid questions, suggestions about possible causes, unfortunate comments, prejudiced looks at their children, possible discomfort, and when it was necessary to go out to take their children to appointments, they felt the need to hide the child's face so that they would feel more protected from other people's prejudice.

To prevent their children from being seen as victims, looked at with prejudice or pity, families choose not to interact with society.

So sometimes we would go to the doctor, or go out on the street, and I would just stare, right? I always wanted to cover his face, I always walked around with the baby carrier covering his face (P9).

When he cried, I honestly said that he looked like an anomaly, you know? She looked like a little monster, she scared me so much, I only walked with Igor covered up, I couldn't uncover Igor, because people would look and criticize and ask what he was [...] I always ended up fighting with people in the middle of the street, because people would stare with disgust... So, I'm very nervous, I'm very angry... So, I would stop in the middle of the street, you know? I would fight (P6).

Choosing not to have more children

The decision not to expand the family after the birth of a child with PLP, even if it is the firstborn, is influenced by the fear of experiencing a congenital malformation again. The suffering associated with treatment, continuous care, and multiple surgical interventions contributed to many families giving up on their plans to have a large family.

The impact of the birth of a child with CLP caused intense suffering in some mothers, often described as despairing. This trauma has repercussions on later experiences, leading them to experience fear at signs of a possible new pregnancy—such as delayed menstruation or contact with pregnant women—and thus expressing a desire to avoid another pregnancy.

I am afraid, very afraid, of being born the same way, of being born with a cleft lip again. I will tell you, my daughter... I take medicine, right? And even if I take medicine, when the medicine runs out, if a week goes by and nothing happens, you need to see me. I almost died. I get desperate, neurotic. The fear is very, very great [...] My dream as a girl was to be the mother of a girl, I dreamed of having a girl, I was going to call her Maria Eduarda, but today I gave up, I don't even want to know (P6).

After she was born with a cleft palate and cleft lip, I gave up completely, and so did the father. The father even wanted another child, but now he doesn't want one anymore [...] actually, he said he wanted two, but he ended up giving up, and yes, it's more because it's a long treatment (P8).

Experiencing suffering through hope in faith

Support in religious faith, especially in the belief in God as a sovereign and protective being, emerges in the participants' reports as a fundamental coping resource. Mothers and grandmothers attribute a central role to spirituality in the elaboration of suffering, interpreting the child's condition as part of a greater purpose and waiting on God for comfort in the face of difficulties.

That thing about being a parent, right? Welcoming me, like lifting me up, so I don't get sad, that God wanted it this way [...] God supports us and we have the strength to care [...] I am connected to God at all times (P2).

Thank God I've always had God by my side, who gave me the strength to fight and face the surgeries (P5).

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Faith proved to be a source of strength and comfort for these families, especially in moments of insecurity and despair, providing them with emotional stability and support to continue on the journey of caring for their children.

DISCUSSION

During pregnancy, it is common for families to create an image of their baby and have hopes for the birth of a healthy child without problems. However, when confronted with a diagnosis of CLP, especially when it arises unexpectedly, whether during childbirth or in previous tests, family members are faced with the need to abandon the idea of the perfect baby and accept the real baby, who was born with a congenital condition. This difference between expectation and reality causes a profound emotional impact, triggering a range of emotions such as disappointment, concern, and distress. Mothers' accounts illustrate this experience, revealing that the cleft was not expected and that its discovery triggered intense emotional reactions(16).

With advances in technology, 3D and 4D ultrasound are currently the most accurate and safe tools for detecting prenatal deformities. These findings help parents and healthcare teams plan the procedures to be performed after the child's birth.

Families report that when they discovered FLP with ultrasound, they had difficulty believing that the tests were correct, thinking that the tests must be wrong. These families were filled with hope that their babies had developed fully in the womb. However, both families who discovered the condition in utero and those who discovered it at birth experienced feelings such as fear, despair, and even momentary rejection of their children(18-19).

The diagnosis of FLP triggers a variety of emotional reactions in mothers, including feelings of denial, intense concern, surprise, crying, frustration, anxiety, insecurity, anger, and sometimes rejection, until a gradual process of acceptance of the child's condition is reached(18-19). The way families receive and process this diagnosis has a significant influence on their acceptance of the cleft and adaptation to the new reality imposed by the condition(20-21).

Some chronic conditions, such as FLP, require families to make important decisions, such as who will care for the child and who will need to stop working for this purpose. Usually, the caregiver is the mother, who must take on the dual role of mother and caregiver for her chronically ill child(22). As most mothers leave formal employment, they lose their income and become financially dependent on their husbands or other family members, which leads to feelings of helplessness and low self-esteem (22) (Pinheiro et al, 2021).

In the context of families with children with cleft lip and palate, significant decisions also need to be made, often including the resignation of one family member from their professional career in order to devote themselves fully to the care of the child. In most cases, the role of primary caregiver is assumed by a female figure—usually the mother or grandmother—whose life becomes oriented toward the child's demands and the rehabilitation process (23).

Caring for children with congenital malformations can require significant adjustments and impact the family routine in many ways, leading to physical and emotional overload for the entire family, especially the primary caregiver. This often has an impact on careers, requiring adjustments or even leaving employment to deal with the demands of care, resulting in loss of income and professional opportunities(24).

Some families facing the challenges of caring for children with FLP may benefit from support networks, such as groups of mothers, fathers, and caregivers, where they can share their experiences and obtain emotional support(25). Sharing stories of families facing these challenges can contribute to family growth and strengthening, as well as help to combat the prejudice experienced by the child and their family.

It is unfortunate that families face challenges related to prejudice and lack of understanding regarding the needs of children with LPD. Caring for a child in public places, such as restaurants, stores, public transportation, and other spaces, is an essential part of everyday life for families. However, families often face judgmental looks and negative attitudes from other people(26).

It is important to remember that caring for a child in public places is a fundamental right of families. In some situations, a direct approach may be helpful to people who are displaying prejudiced or disrespectful attitudes and educate them about the needs of children.

An important support network for parents who have a child with a congenital malformation is spirituality, which plays a significant role in people's lives and can provide support and comfort in times of crisis and difficulty(22,28). Spirituality is a fundamental dimension of the human experience, often related to the search for meaning, purpose, and connection to something greater than ourselves (29).For parents facing the challenge of coping with their child's congenital malformation, spirituality can offer solace, hope, and a way to understand and make sense of difficult circumstances(29).

When healthcare providers recognize and respect parents' spirituality, they can provide more comprehensive and personalized support. This may involve providing spiritual resources, such as religious or psychological counseling, or simply listening to and supporting parents in their search for answers and meaning. Spirituality can help parents find meaning and strength in difficult times, and healthcare teams play a valuable role in supporting this essential dimension of the human experience (30).

Nurses play a crucial role in this con-

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text, helping families cope with challenges and providing support to maintain as normal a family life as possible. Promoting effective family functioning through education, support, and adaptation to each family's specific needs contributes significantly to the physical and psychological well-being of the child and their family members, ensuring continuity of care and providing quality of life (31).

CONCLUSION

Families of children with CLP often give up various activities and aspects of their routine to care for the specific needs of the child and their treatment over the years, thus changing the habits and daily lives of their families. The child becomes the priority in family life, which makes the mother, in particular, feel overwhelmed and tired.

Professional support is essential to maintain the health of these families and children, as it is through professionals that families acquire the knowledge and support to properly care for their children with LPL. Nurses play a fundamental role in rehabilitation, as they teach proper care and guide families on how to best deal with the child's condition. Therefore, they need to organize themselves to manage the demands of the disease so that they can help restore family balance.

Therefore, this study is relevant to the field of nursing as it highlights the changes experienced by families of children with LPL, emphasizing the importance of humanizing the care and support offered to these families so that they can monitor the growth and development of their children.

The results of this study cannot be generalized. The reality of the field of study in question is unique, which is therefore a limitation of the study. We are aware that this topic requires ongoing reflection and is not exhausted in this work. Thus, new studies may be designed to continue the investigation.

As a proposal for future work, there is a need to understand the difficulties related to the care of children with FLP and the importance of nursing in the face of these difficulties.

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