

## ORIGINAL ARTICLE

## LIP AND PALATE CLEFT: CHILD AND ADOLESCENT'S EXPERIENCE

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## ABSTRACT

The craniofacial anomaly affects social environments, influences socialization, personal development and educational progress, interfering in life's quality. Rehabilitation involves hospitalization, so has early contact with nursing that must ensure humanizes care. It's necessary involvement of a specialized interdisciplinary team, spanning the biopsychosocial aspects of cleft. We aimed to understand the experience of the child/adolescent fissured to know their needs, working in the clarification and guidance. This is a qualitative research, whose method was content analysis. Subjects were individuals from 7-18. Nine interviews were conducted. Five categories emerged from the analysis: Perception of child/adolescent about the cleft palate/lip, Difficulties in social interactions, Experience in the treatment of cleft lip/palate, Understanding the reasons for the cleft and Support networks to overcome. The emotional congenital malformation's impact on the health of children/adolescent, family and society is complex. The apparent esthetic difference compromises their psychosocial adjustment. Surgical correction/psychological maturity help to improve the resiliency. The knowledge of the experience's cleft spotlight their difficulties, as well as deficiencies in Nursing action with them and their families, important aspects to be known/used to improve the care provided.

**Keywords:** Child. Adolescent. Cleft lip. Cleft palate. Nursing.

## INTRODUCTION

The overvaluation of beauty drives people to the frantic search for the perfect shape. The facial appearance affects deeply in social environments and the relations established, since the first contact through the face. So, have a malformation is a challenging experience, not only of Excel limitations, as well as confront stigma and exclusion imposed by society in general<sup>(1)</sup>.

In Brazil, the incidence of cracks is cleft lip in 1:650 born, while in the world is of 1:1000. The frequency of cleft lip and labiopalatinas is larger in males, while those that affect only the palate occur in greater numbers, female literacy (2)

The oral clefts are associated with adverse situations for the health and well-being of affected individuals. Behavioral disorders and psychological problems can arise in children and

adolescent's cleft. The decision of a new pregnancy in mothers of cleft can also be influenced by current disease of their children (3). Individuals with oral clefts may have difficulties in feeding, speech, hearing, the social engagement (4). In this way, the influence of anomaly extended way the health and social integration, not only by the aesthetic and functional aspects; but primarily by social and emotional disorders.

The treatment beginning shortly after birth and aims at overall rehabilitation: functional morphology, and psycho-social. The first corrective plastic surgery, called cheiloplasty (lip surgery) and palatoplasty (palate surgery) happen between 2-3 and 6-12 months old respectively; however, the treatment extends throughout the growth and development of the child (4).

Understanding the complexity of labial and palatal clefts, the rehabilitation of these patients require multidisciplinary integrated, continuous

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attention and specialized. Thus, the global recovery depends on the interaction between different areas of knowledge and well trained professionals both for diagnosis and for the procedures of transdisciplinary manner, within a relationship of reciprocity and dialogue both underequips, as team-team-patients and family<sup>(5)</sup>.

Professionals should have in view the full treatment of the cleft, i.e. provide a careful covering biopsychosocial aspects of individuals, helping them in difficulties and facilities that may arise during the process of feeling and experiencing the craniofacial malformation, always aiming at their integration into society, to minimize the physical, psychological and morphological effects of the disease<sup>(6)</sup>.

Children and adolescents with cleft lip and/or palate have the difficult challenge of dealing with facial difference visible, in a society that values the appearance and enhances unattainable standards of beauty (7).

The performance of nursing staff with the patient with cleft happens throughout the rehabilitation process. She must realize/welcome the feelings demonstrated by the patient and his family and ensure a humanized assistance: approach, engage, create link, support the binomial patient/family, offer scientific and technical grant guidelines for the rehabilitation process<sup>(8)</sup>.

Shows the postoperative period as an opportunity for the further training of Nursing family or caregiver about the surgery-related care, in order to promote a safe recovery, with prevention of bleeding, pain control, food and adequate hydration, physical constraint and wound care (9).

Searching the literature, it is observed that most of the production on the subject has focus on biological aspects of malformation and focuses in the areas of speech therapy, dentistry and surgery. So it becomes necessary to study in more depth the children and adolescents experience fissuratum, meet their challenges and their perception of the treatment, as well as the participation and the nursing team work with these patients. In the literature, there is also a shortage of studies search the experiences of children and adolescents, being more common studies on the family, caregiver or another character than the own child or teenager.

Therefore, the present study has as its guiding research question "As the child or teenager cracked experience the experience of having a cleft lip and/or palate?" The goal is to understand the experience for the child and the adolescent with palatal cleft.

## METHODOLOGY

It is a qualitative research that part of the social reality of the subject, working with the universe of meanings, motives, beliefs and values(10). The identification of the participants was held at the Association of Cleft support of municipality under study. From the cadastral sheets were listed the subjects who met the selection criteria: aged between 7 and 18 years (11) with the possibility of verbal communication.

Were interviewed in their homes 9 subject. It was used the semi-structured interview, because it makes it possible to obtain data both subjective and objective in nature as it is characterized as a time of exchange between interviewer-respondent, where the respondent can digress on the subject without limitations (10).

Each interview was recorded and transcribed in its entirety before performing the following, to facilitate the process of analysis of the emerging data and also to enhance and deepen the later interview. The analysis of data happened concurrently to interviews, so it was possible to identify when the lines became recurrent. In the ninth interview understand that the responses to the guiding question were repeating, interrupting the interviews.

Sometimes, some responsible for the child or adolescent has remained present during the interview and, despite not having been subject of research at some point was element of complementary information provided by children or teenagers. Two of these lines were added to the analysis of the data collected.

In the case of this research, the trigger element of the interviews was: "tell me how you have cleft lip and palate". Along the lines, were used a few questions and places to encourage exploration, clarification and extension of relevant nuclei exposed.

Because it is a survey of human beings, were respected the ethical aspects proposed by Resolution 12/466 and regulated by the National Board of health. The research project was submitted to the Committee of ethics in research in Human Beings of the Faculdade de Medicina do Rio Preto – FAMERP (5161/2011 Protocol). Officials signed an informed consent – FICS after reading, and children and adolescents agreed through signature.

For the data from the interviews was used the categorical analysis technique of thematic Bardin<sup>(12)</sup>. On the basis of the objective proposed in this study, the following operating steps were carried out: 1. Constitution of the corpus: total of interviews; 2. composition of the units of analysis through the floating of the reading interviews and definitions of the subcategories emerging, with option for the context understood by units larger themes of the interviews that were then broken down into thematic analysis units and, later, in semantic simpler themes; 3. Categorization: subcategories were grouped in categories and subsequently analyzed.

The lines were organized so that A1 has set the first teenager interviewed, A2 the second; C1 the first child interviewed and so on. The MC3 symbol indicates the line of the mother of the third child interviewed and VC1 the grandfather of the first child interviewed.

## RESULTS AND DISCUSSION

Data analysis allowed to seize five categories and two subcategories presented in the following table:

**Table 1.** Identification of categories and subcategories defined by examining lines of respondents.

<b>CATEGORIES</b>
1) Perception of child/adolescent in relation to fissure
2) Difficulties in social interactions
3) Experience of treatment of fissure: 3.1 preoperative procedures 3.2 postoperative procedures
4) Understanding of the reasons of the fissure
5) Social support Networks front fissure

Source: final scientific report "living with the palatal fissure: the experience of children and adolescents" submitted to FAPESP.

**1) Perception of child/adolescent about fissure:** from the analysis of the data showed that the perception of the child/adolescent front fissure goes through a gradual process of "normalization". That is, individuals reported that they spent the day is learn to live with the anomaly, as an integral part of your system. As well, a factor that caused revulsion and discomfort before both for family to the cracked, began to be seen as something normal and can be overcome.

"At first I wouldn't accept it, I didn't like at all, I felt a " nothing ", others were taking the piss, I cried at home, [...] For me it was horrible, I don't even know how to explain [...] But now I accept, in day surgery couldn't eat things and I didn't like it, but now I accept well, for me everything was normal [...] We have to live and talk that this is your karma, this is mine. With the treatment gets better [...] today I am happy and accepted very well, I have no shame, I love get ready! " (A2)

The emotional and physical shock of congenital malformations is complex for both cracked and his family and for society in General. The treatment is continuous and accompany the person for a long period of his life.

The aesthetic difference in the appearance of children and adolescents with a craniofacial anomaly can jeopardize their psychosocial adjustment. The surgical correction and psychological maturation help improve the effects that the presence of the crack cause on his own acceptance, allowing a glimpse of children/adolescents more normal about themselves<sup>(13)</sup>.

The literature reveals the perception that the child or adolescent have front fissure and the problems it can bring to the self-perception of every individual cracked.<sup>(13,14)</sup> studies show that levels of self-esteem in children or adolescents with and without cleft differ. It was noticed that the Group of teenagers suffering from cleft lip and/or palate exhibited low self-esteem and social awkwardness, beyond the desire to improve the voice, communicating with other people, the appearance, the nose, and even the school, relationship with the family and groups.

Such studies, although they went against findings of this research, do not confirm the final results it obtained. Thus, should analyze that the

fact of having a cleft lip and palate is not a conditioning factor for the emergence of some emotional weakness. Some children/teenagers face well the fact of having the anomaly, when supported; others, though, end up expressing feelings of inferiority.

**2) Difficulties in social interactions:** from the analysis it was noticed that there was a constant search to interact with the fissure or overcome it, however when the interviewees were placed in situations of social interactions, often suffered some kind of bias. Although children and adolescents interviewed if they accept as they are reported to have been through any embarrassment or unpleasant situation during some period of their lives, feeling rejected by society.

On occasion, the social interactions were presented as causing stress, hassle and frustration for children/adolescents with palatal cleft respondents. In some cases, this stress was potentiated in relation to gender. This, understood as a social construct, and so permeated by stereotypes and stigmas differentiated with respect to the man and the woman carries different emotional loads when thought in terms of social roles.

" They [friends] spoke, what's that on your nose and your mouth C3? Then I told you everything, so they said that I was born. (C3)

"Before I was ashamed. Before I didn't like to talk; I was mute in school opened her mouth for nothing, others even thought I wasn't there. But, now, isn't [...] Had another boy with cleft in my room, took his only fun I think girl is worse, because girl sit there in the ' bottom '. I felt the worst person in the world [...] ". (A2)

The difficulties in the care of the labial and palatal clefts are not restricted to medical treatment and financial adversity. They transcend the biological factor and bring linked emotional marks from curiosity and looks repulsive people, factors that should also be treated as part of the rehabilitation process of the patient (15).

**3) Fissure treatment Experience:** the cracks affect feeding, speech, hearing, teething and the psychosocial and rehabilitation is a continuous process, long, difficult and that can last for many years of the life of the cleft. Through the

interviews showed that the treatment, carried out in Specialized reference center by a multidisciplinary team, required several surgical procedures, which have brought benefits both aesthetic functional but sometimes emotional difficulties.

**3.1 Preoperative processes:** Preoperative exams as video fluoroscopy, laryngoscopy, blood tests, among others, were singled out by respondents as the most difficult part of the treatment. Many children refused to make them or health professionals had extreme difficulty to make them accept to do such tests. This difficulty was smaller in the case of adolescents. Anxiety pre-surgery process was also highlighted as an element in maintaining in the preoperative period.

Through interviews, it was realized that for children the preoperative process was very painful. To teens understanding of that process was more quiet, due to age, though not necessarily less painful.

"I remember only that I did a (examination) that I'd shove a drizzle through the nose (probe) to see the roof of my mouth ... they saw also the talks, sent me to speak and move the drizzle, I don't know what's it called the exam, but it hurt." (A2)

"I get scared! I was scared when I was little, now worse [...] I'm afraid of the time they will operate, sometimes they can make mistakes where they will operate, I'm afraid they make mistakes and put the knife in my nose or somewhere else and not in the mouth. " (C2)

The treatment of cleft patients is divided into stages, surgical and post-surgical pre-surgical confirming the findings of this research. The course of pre-surgery basically through the sorting, identification of the deformity, contact with the support and analysis of the socioeconomic profile of the relatives and patients, which differed partly the results of this study, since the pre-surgery process, cited by interviewees, meant for them, mostly, preoperative exams <sup>16</sup>.

**3.2 Post-operative processes:** According to the respondents, during surgery they are anesthetized and feel no pain or any other reactions, unlike in pre-surgical, when reports that the tests are invasive, painful and continuous. Thus, the postoperative process,

although long, is less painful and stressful to the pre-op.

As for swallowing dysfunction, chewing, hearing, breathing, dental records and possible consequences for nasalized voice cracked, require the inclusion of the phonoaudiological treatment in the postoperative period. During the talk, were observed some dichotomies as to the effectiveness of the activities carried out, varying the devaluation/motivation in continuing them, the recognition of benefits, depending on the professional approach that accompanied them.

" I used to be and I don't want to do. He (audiologist) sent us do some business difficult and boring [...]. Oh, he'd send me speak, then I spoke, had to speak so "Ta-ta" is that boring, tiresome and annoying, I'm never going back! " (C3)

"I spoke well, slaking even know was bad [...] The doctor said since those accustomed sees no difference in speech, but others could not understand, you know? Ah, the speech therapist helped me a lot, my boyfriend says that even see difference in my talks. " (A2)

The stages of treatment are situations prone to stress, anxiety and suffering. The various surgical procedures are characterized as steps essential to treatment. The surgeries were pointed to as the main fact that affects the quality of life, and the satisfaction not only of the surgical results, but also the process of interaction that happens on these occasions, manifested by communication, empathy, and post-surgical care expectations<sup>(16,17)</sup>.

Understanding that the treatment of the cracks cleft lip depends on a very specialized rehabilitation process, which should start as soon as possible and that when not treated can cause severe problems both functional, emotional and social integration as, rehabilitation must be done by a multidisciplinary team through a relationship of reciprocity and dialogue<sup>(18)</sup>.

**4) Understanding on the reasons of the fissure:** The s families don't have an answer to the questions of why the occurrence of cleft lip and palate, cannot explain to his son why was born with this malformation. Sometimes the families tried to explain the reason of the disease through family stories or popular myths.

"My mother always said that when he put the key here (in the chest), the children were born like that [...]. But then we went to the Center and was told there was not this, that there was a lack of a vitamin that I needed in pregnancy [...]. And that's what explained to him ". (MC3)

"She (mother of the child) began drinking, became involved with other things at the same time, to prostitution. That's when this kid was born. The child was created inside a VAT of drugs, alcohol and so on and so forth. Maybe he's born so crappy because of his mother living like this when he was still in her belly ". (VC1)

The cause of the cracks is multifactorial and may be genetic and environmental factors. Among the environmental risk factors include, among others: smoking, alcohol, maternal and paternal age, medicines, order of parity, interpartial range, folic acid deficiencies, radiation, mechanical obstruction in utero, maternal illness during early pregnancy, gender, race, geographic location, the seasonal period and family variations<sup>(19)</sup>. The multifactorial presented in this research as a factor in maintaining, because not knowing and not how to respond to questions from your child or teen is sometimes distressing both for the child and for his family, who feel powerless in the face of this condition.

**5) Support networks to overcome:** by parsing perceive that love and creating a caring environment within the home of the children interviewed were extremely important factors to feel that there was no unconditional support, regardless of their condition and realize that with the treatment could live normal and hope for a prosperous future. During the interviews were cited several sources of support, such as family, friends and teachers.

"My grandmother helped me a lot, she was everything to me, my mother and my father not so much [...] My Mama encourages me to do a lot of things. My grandmother speaks it's not to be ashamed, that if that happened, I'm going to do what? Happened to me, I have to make right? She says stuff like that, and also this is what I put on my head and helped me ". (A2)

"It was difficult for people to get ' joke ', speak these things, so for me it was as if I was normal,

but they (family) ended up helping a little in this sense to be talking about not to call when he did of 'joking' ". (A1)

The social network "refers to the structural or institutional dimension, linked to the individual. Social support is in the personal dimension, consisting of members of the social network effectively important for families ". The network can influence emotional well-being, with the reduction of mortality, the prevention of diseases and health recovery, social, monitoring company of the person you don't feel lonely, comfort, advice, information, social adjustment, material assistance and services (20).

The network of social support that children and adolescents cleft accessed were key throughout the treatment process. Enhance the completeness of the care and greater autonomy of the cleft is important for differentiated service and construction aid in the empowerment to face the difficulties of the fissure.

## FINAL CONSIDERATIONS

Knowing the stereotypes built in society, mainly in relation to the body in a general way, be born with an abnormality becomes a difficult experience, especially in childhood and adolescence, since during this period takes place by a process of self-knowledge, self-esteem building and sometimes suffering psychosomatic.

The present work adds knowledge about the experience of being a child or teenager cracked. However, more detailed studies on the experience of one's own child/teen before the rift and the needs they face are of the utmost importance, since little is given to them.

The nursing experience of these sharing social actors and their families since its very early childhood, especially with regards to preoperative and postoperative events, including the whole process of guidance to the family, children and adolescents with regard to hygiene and curative care of surgical incisions, feeding-related care, posture to prevent aspiration, among others, specific surgical procedures. However, there is little scientific literature available in this area of knowledge, especially about such care.

We see the need for health professionals to recognize its importance as members of a support network and work in order to strengthen the coping mechanisms and adaptation in this trajectory. In addition, common practice knowing of nurses to this clientele to be placed in the discussion so that scientific evidence to consolidate the clinical practice.

Studies with preschoolers, using innovative research techniques can be developed to fill the gap of knowledge that this study leaves on an age group in which surgical procedures may not have been completed and the need to know how this small child is faced with the situation, in order to consider his family to support more effective.

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## CONVIVENDO COM A FISSURA LABIOPALATINA: A EXPERIÊNCIA DA CRIANÇA E DO ADOLESCENTE

### RESUMO

A fissura labiopalatal repercute nos ambientes sociais, interferindo na sociabilização, no desenvolvimento da personalidade, no progresso educacional, na qualidade de vida. Como a reabilitação implica hospitalizações, o fissurado tem contato precoce com a enfermagem, que deve garantir assistência humanizada. Torna-se indispensável a atuação de uma equipe interdisciplinar especializada, abrangendo aspectos biopsicossociais do fissurado. Objetivamos compreender a experiência da criança e do adolescente fissurados, conhecer suas necessidades e atuar para seu esclarecimento e orientação. Trata-se de uma pesquisa qualitativa, cujo método foi Análise de Conteúdo. Os sujeitos tinham 7-18 anos. Realizamos nove entrevistas. Apreendemos cinco categorias - Percepção da criança/adolescente frente à fissura; Dificuldades nas interações sociais; Experiência do tratamento da fissura; Entendimento sobre os motivos da fissura e Redes de apoio para superação. O choque emocional de malformações congênitas na saúde infantil/adolescência, na família e na sociedade é complexo, podendo comprometer o ajustamento psicossocial. A correção cirúrgica e o amadurecimento psicológico auxiliam na resiliência. Desvelar a experiência dos fissurados evidencia dificuldades, bem como possibilidades de atuação da Enfermagem junto a eles e suas famílias, aspectos importantes de serem conhecidos/utilizados para a melhora do cuidado prestado.

**Palavras-chave:** Criança. Adolescente. Fenda labial. Fissura palatina. Enfermagem.

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## CONVIVIENDO CON LA FISURA LABIAL: LA EXPERIENCIA DEL NIÑO Y DEL ADOLESCENTE

### RESUMEN

La fisura labial hace repercutir en los ambientes sociales, influyendo en la sociabilización, en el desarrollo de personalidad, en el proceso educativo y en la calidad de vida. Como la rehabilitación implica la hospitalización, el fisurado tiene contacto temprano con la enfermera, que debe garantizar el cuidado humanizado. Es necesaria la participación de un equipo interdisciplinario especializado, que abarque aspectos biopsicosociales del fisurado. Tuvimos el objetivo de comprender la experiencia del niño y del adolescente fisurados, conocer sus necesidades y actuar para su esclarecimiento y su orientación. Se trata de una investigación cualitativa, cuyo método fue el Análisis de Contenido; los participantes tenían entre 7 y 18 años, se llevaron a cabo nueve entrevistas y aprehendimos cinco categorías: Percepción del niño/adolescente frente de la fisura; Dificultades en la interacción social; Experiencia del tratamiento de la fisura; Comprensión de las razones de la fisura y Redes de apoyo para la superación. El impacto emocional de las malformaciones congénitas en salud infantil/adolescencia, en la familia y en la sociedad es complejo, siendo posible comprometer el ajuste psicosocial. La corrección quirúrgica y la madurez psicológica ayudan en la resiliencia. Desvelar la experiencia de los fisurados labiales trae dificultades, así como posibilidades de actuación de la Enfermería juntamente a ellos y a sus familias, aspectos, estos, importantes para que sean utilizados a la mejora de la atención prestada.

**Palabras clave:** Niño. Adolescente. Fisura labial. Labio leporino. Enfermería.

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