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SCHOOL IN HEALTH PROMOTION FOR CHILDREN WITH CLEFT LIPS AND PALATES

Cintia Magali da Silva¹, Arno Locks², Daniela Lemos Carcereri³, Denise Guerreiro Vieira da Silva⁴

¹ Ph.D. in Collective Health Dentistry. Santa Catarina, Brazil. E-mail: cintiamagali1@hotmail.com

² Ph.D. in Orthodontics. Professor of the Graduate Program in Dentistry, Federal University of Santa Catarina. Santa Catarina, Brazil. E-mail: ortoarno@gmail.com

³ Ph.D. in Production Engineering. Professor of the Graduate Program in Dentistry, Federal University of Santa Catarina. Santa Catarina, Brazil. E-mail: daniela_carcereri@hotmail.com

⁴ Ph.D. in Nursing. Professor of the Graduate Program in Nursing, Federal University of Santa Catarina. Santa Catarina, Brazil. E-mail: denise_guerreiro@hotmail.com

ABSTRACT: The aim of this study was to understand the influence of school in the life and care of the health of children with cleft lips and palates treated at a reference center in southern Brazil. This qualitative descriptive-exploratory study was performed using semi-structured interviews, conducted with 15 mothers of children and teenagers with cleft lips and palates of an oral health surveillance program. The data analysis was based on the thematic analysis, which highlights two central themes: facing and overcoming the stigma associated with the physical appearance, and the school as an influence on the oral health of children and teenagers and their development. The school provides children and teenagers with cleft lips and palates with opportunities of social integration, but it also contributes to conflicts generated by the prejudice against their physical appearance. The support of the school community is essential for proper development of quality of life.

DESCRIPTORS: Cleft lip. Cleft palate. Oral health. School health.

A ESCOLA NA PROMOÇÃO DA SAÚDE DE CRIANÇAS COM FISSURA LABIOPALATAL

RESUMO: O objetivo foi conhecer a influência da escola na vida e nos cuidados com a saúde de crianças e adolescentes com fissura labiopalatal atendidas em um centro de referência do Sul do Brasil. A pesquisa foi do tipo exploratório-descritiva, com abordagem qualitativa. Foram realizadas entrevistas semiestruturadas com 15 mães de crianças e adolescentes com fissura labiopalatal participantes de um programa de acompanhamento da saúde bucal. A análise dos dados foi fundamentada na técnica de análise temática, pertencente à análise de conteúdo, originando duas categorias temáticas centrais: enfrentando e superando o preconceito relacionado à má formação; e a escola influenciando a saúde bucal da criança e adolescente e o seu desenvolvimento. A escola traz à criança e adolescente com fissura labiopalatal possibilidades de cuidados e inclusão social, mas também pode trazer conflitos pelo preconceito gerado pela sua aparência física. O apoio da comunidade escolar é essencial para que possam ter um desenvolvimento adequado com qualidade de vida.

DESCRIPTORIOS: Fissura labial. Fissura palatina. Saúde bucal. Saúde escolar.

LA ESCOLA EN LA PROMOCIÓN DE SALUD PARA LOS NIÑOS CON FISSURA LABIOPALATINA

RESUMEN: El objetivo fue estudiar la influencia de la escuela en la vida e en el cuidado de niños y adolescentes con fisura labiopalatina atendidos en un centro de referencia en el sur de Brasil. Investigación cualitativa de tipo descriptivo-exploratorio que realizó entrevistas semiestructuradas con 15 madres de niños y adolescentes con fisura labiopalatina de un programa de vigilancia de la salud bucal. El análisis de los datos se fundamentó en el análisis temático, destacando dos temas centrales: enfrentando y superando los prejuicios relacionados con la malformación, y la escuela como influencia en la salud bucal de los niños y su desarrollo. La escuela trae a los niños y adolescentes con fisura labiopalatina posibilidades de cuidados e inserción social, pero también trae conflictos generados por los prejuicios de su apariencia física. El apoyo de la comunidad escolar es esencial para el desarrollo adecuado con calidad de vida.

DESCRIPTORES: Labio leporino. Fisura del paladar. Salud bucal. Salud escolar.

INTRODUCTION

The formation of the face and oral cavity occurs between the fourth and twelfth week of intrauterine life. This episode can be considered complex in nature, involving the development of many tissue processes, which must be united and merged in an orderly manner. During this period, possible disturbances in the development of these tissue processes or merging may lead to the formation of orofacial fissures, also referred to as cleft lip and palate (CL/P).¹ The etiology of CL/P has not yet been fully clarified; however, there are indications that genetic and environmental factors act in an associated or isolated way in its occurrence.² The CL/P are among the most common craniofacial anomalies, afflicting about 1 in every 672 live births in Brazil.³

The birth of a child with an anomaly may cause a crisis that affects the entire family, upsetting its identity, structure and operation. Sometimes, the family is unprepared to cope, as the disabled child represents breaking expectations. Family life suffers changes due to emotional demands and living with the child, causing conflicts and leading to emotional instability, changes in the couple's relationship and detachment among their members.⁴

Thus, the health team caring for children with CL/P has an important role in the child's development, in the support to the families, as well as in promoting treatment adherence.⁵ This involves a professional performance that demands the full attention to health as reference. Comprehensiveness includes the concept of humanization of care and the acceptance on the part of the team that works with such families, providing support from birth to the final process of treatment and subsequent follow-up. Successful treatment of CL/P, which involves surgical procedures at the time recommended and performance of dental and speech therapies, is directly related to proper oral health condition.

Surveys show the unfavorable situation of oral health of people with CL/P, from infancy to adulthood, particularly with regard to caries and periodontal diseases.⁶⁻⁹ In this population there are several risk factors for the development of oral diseases, including biological and psychosocial factors.

Dental changes in shape, number, structure and position contribute to the accumulation of plaque and, consequently, the activity of oral dis-

eases.¹⁰⁻¹¹ Fibrous scar resulting from cheiloplasty, surgery repairing the lip, reduces lip movement, making self-cleaning and oral hygiene difficult.¹² In addition, the presence of orthodontic braces, common at the time of mixed dentition, also contributes to plaque accumulation.¹³ Added to such factors inherent to the anomaly, the early introduction of saccharose to the child's diet, aiming at the child reaching the recommended body weight to perform the surgeries. After incorporation of this habit to the palate of the child, it becomes difficult to remove it, contributing to an unfavorable diet with respect to the development of dental caries.¹⁴

Literature shows the relationship between oral health status and quality of life in patients with CL/P.¹⁵ It is important to note that there are several factors that can influence the care of these patients' oral health, which have not yet been sufficiently investigated. One of these possible factors that might have influence relates to socialization, stimulated with the beginning of school life of children with cleft lip and palate.¹⁶

The social support provided by the environments where children with CL/P fissure live is crucial in building their health. Enabling comprehensive care and creating opportunities for more autonomy of the subjects is important for the construction of a differentiated reasoning towards health care.¹⁷

Treatment of CL/P is complex and lengthy, extending from birth to adulthood, according to the degree of severity. It is dependent on the interaction between different professional areas, and they should be well prepared both for diagnosis and to perform procedures in an interdisciplinary way. They should contribute to the integration of people with CL/P in the society promoting their social inclusion. This leads to the understanding that there should be cooperation between the professionals and services that operate in the full development of the person with a cleft, in addition to the participation of the society and themselves.¹⁸⁻¹⁹

School relations appear as a significant social network in the lives of these children. There may be difficulties of the child with anomaly to establish contact with their peers. However, good contacts can be made, provided that the child is accepted in the group of peers.⁵ School and school-mates of these children will be key throughout their development, as regards adap-

tation, socialization and integration.¹⁶ The school space can contribute to health maintenance of local students and communities.²⁰ Authors emphasize that the school can act as a social space for health promotion, with the performance of strategies in collective oral health programs for children, which would enable a positive impact on inequities in health.²⁰ School also has to do with the social inclusion paradigm and contributes to care humanization towards the child with cleft-lip and palate. Living with human diversity and valuing each human being are basic principles of social inclusion.¹⁷

Together with families, the school can act as a space conducive to individual and social development of children with CL/P. Thus, the aim of this study was to determine the influence of school life in the life and health care of children and adolescents with cleft lip and palate treated in the follow-up program of oral health of the Pediatric Dentistry Department of a reference center in Southern Brazil.

METHODS

This exploratory-descriptive study was performed with a qualitative approach, aiming to understand reality, bringing into the analysis, the subjective, the participants and the environment that surrounds them. The complexity and depth of the problems of people with lip and palate malformation in their different stages of evolution in the treatment allow qualitative studies to contribute more effectively, allowing the understanding of the experiences lived.¹⁶

An intentional sample was used, and its size was defined at the time the information attained saturation level, i.e, they presented no more new information. Thus, the study was conducted with 15 mothers of children and adolescents with cleft lip and palate, participants of the oral health follow-up program of the referred Pediatric Dentistry Department. This institution aims at providing comprehensive attention to patients with cleft lip and palate. The services offered include dental care, which is performed by trainees of the undergraduate dentistry program, under the supervision of teachers. After completion of the dental treatment, patients are invited to attend further return appointments integrating the monitoring program of oral conditions. These appointments are scheduled as needed for each child, and the possibility of

the family to return to pediatric dentistry department and the availability of openings are also considered.

Participants were selected based on the following inclusion criteria: mothers of children with cleft lip and palate with no other anomalies or associated comorbidities, aged no less than 21 years; not having CL/P and also, there should not be any other family members (spouse/partner or other children) with CL/P, to avoid that previous experience had any influence on oral health care; the children with cleft-lip and palate should be participating in the oral health follow-up program at the referred institution and have developed caries and/or periodontal diseases during some stage of the treatment. This criterion was included by questioning the reason of the children's illness, despite so much care on the part of the staff. The decision to conduct the study with mothers was due to the fact that, in most cases, they were responsible for the care and monitoring their children in the care of the various professional areas involved in the treatment. To preserve the identity of the participants, the interviewees were numbered from one to 15.

For data collection, semi-structured interviews were used, which were conducted in private rooms of the Department of Dentistry, favoring dialogue between participants and interviewer. Data were collected from August to November 2008. Prior to the beginning of the interview, the study objectives were presented and authorization was requested for participation, by signing the Informed Consent Form. After authorization, interviews were started, which were recorded with the aid of digital equipment. In compliance with Resolution 196/96, of the National Health Council, this project was approved by the Ethics Committee on Research with Human Beings, under technical opinion n. 324/07.

The analysis of the data was based on the thematic analysis technique, belonging to the content analysis.²¹ The material was transcribed and analyzed, including steps such as: repetitive readings aimed at overall understanding of the material; encoding seeking to highlight the meaningful units that emerged from the interviewees' speeches, focusing on the understanding of the school's influence on the lives and on the health care of children and adolescents with CL/P; organization and selection of codes related to school life that resulted in the construction of two categories: coping and overcoming prejudice

related to malformation; and school influencing the oral health of the child or adolescent and their development.

RESULTS

Characterization of the mothers

The mothers were aged between 25 and 55 years, belonging to families from diverse regions of the state, had income from two to seven minimum wages and, with respect to health care, were users of the Unified Health System (National Public Health System in Brazil). The age of their children ranged from five to 15 years, all had performed the primary surgeries of cheiloplasty and palatoplasty, and participated in the follow-up program of oral health of the Pediatric Dentistry Department. While all of these children and adolescents were included in the monitoring program, some developed caries and periodontal diseases, and needed to re-enter dental care routine for the performance of curative procedures. All attended a school or preschool institution.

Coping and overcoming prejudice related to malformation

Although the beginning of school activities can help children's development and health care, one of the first situations experienced relates to prejudice. The bias is expressed in relationships with other children that discriminate them aggressively or more discreetly, often approaching out of curiosity about the physical condition that is different from the others. This situation generates both in children with cleft as in their mothers, a certain sadness and discomfort. In general, the mothers interviewed already expected possible questions about the anomaly arising from children and other people in daily social life. They showed anxiety in face of the consequences and uncertainties about the future of the child.

Since the beginning of school life, children with this congenital malformation had experienced prejudice due to the presence of cleft lip and palate and their compromise in relation to physical appearance. Functional implications caused by malformation, especially with regard to the phonetic function, afforded embarrassing situations, since the 'nasal' speech became cause for mockery. Children generally did not react or did not contest the attitude of their peers, just cried

as a way to express their sadness, as reported by one of the participants:

[...] in daycare they already said, already called her...they always laughed at her because she spoke with a kind of lisp. At school, the boys and girls also tease her: crooked mouth, crippled mouth... She just cried and cried [...] (I 10).

Mothers sought different strategies to defend their children with respect to coping with the prejudice. They tried in certain situations to cheer up their children, claiming they were children just like all the other children, trying not to treat them with difference in relation to other siblings and family members. Others, in order to overcome the challenge of prejudice present in the school environment, requested help from people they knew in an attempt to relieve the sadness of the child faced with the peers' attitude.

They started saying that he had the mouth like a horse's, that he had the mouth like a calf's, and they grimaced and imitated his mouth. Then he cried and became more and more depressed... So this was informed to the teachers... And, one day, my daughter went to the bus to talk with the bus driver. And he said that anyone who said something would be forced to get off the bus and go on foot (I 5).

Reaching adolescence can be considered a time of change in behavior, which together with the presence of a labio-palatal malformation, also brings the desire to be accepted and overcome prejudice. Rebellion in adolescence was present, contesting and opposing values passed on by mothers to their children. One of the points highlighted was the need of acceptance that their children had, or even being able to participate in groups with socially unacceptable behavior.

I checked her bag and found a package full of candy and gum [...]. So I went to look at the garbage. Only junk in that garbage bag. Oh, I was in such despair, felt tightness in my heart that you cannot imagine, because she had no money to buy those things (I 11).

For mothers, some of these inappropriate attitudes on the part of the children were an attempt to win a place among colleagues, since they had low self-esteem and did not know how to deal with their different appearance. There was an interest of mothers in changing this situation and winning better social acceptance for their children. Talking to teachers and school leaders was a strategy used to further this achievement. They aimed at finding, in most cases, support and understanding.

The school influencing the oral health of children or adolescents and their development

The school can represent a strong influence on the oral care of children and adolescents with cleft lip and palate. The interviewees showed two forms of school influence on oral health and the development and socialization of their children. With respect to oral health it included the guidance of oral hygiene and the control of food available at school or in its vicinity. Regarding development and socialization, this was linked to the support they received, both related to the understanding of the specific situation of the child or adolescent and referral to specialists.

The school, while relying on the performance of dentists and dental assistants in carrying out educational-preventive activities, acted positively on useful attitudes and behaviors for the maintenance of an adequate condition of oral health. Preventive activities were conducted with children and adolescents who attended the early grades of elementary school. Mothers recognized the positive role of the oral health team at educational institutions.

On the other hand, some schools, in addition to not counting with the action of oral health teams, or developing oral hygiene activities during the period spent at the institution, presented a negative agent for health, represented by the cafeterias, where they sold unhealthy foods that could cause diseases such as dental caries.

If you give her money, she buys at school. So we do not give her money any more because she buys what she wants at school. She buys candy, gum, such things that are bad for the teeth [...] (I 6).

The concern for oral hygiene in children with cleft lips and palate had a special highlight for those mothers who had been guided in a special way since the birth of the child. They hoped that the school would support in the implementation of this hygiene, especially because it recognized the difficulty involved in such care. Most often, children and adolescents did not like to perform oral hygiene care, considering it an obligation that was not common to all children. The instructions given at school helped them realize that hygiene is important for everyone.

Obtaining the support from the school in the socialization process of their children and in care with rehabilitation was a constant concern for

mothers. The school was recognized by them as one of the available sources of support.

A long journey in search for rehabilitation required of mothers and children and adolescents numerous inquiries in various areas, including dentistry. Added to routine visits, conducting additional tests, such as x-rays, and there was also the follow-up visits relating to dental treatment and surgical procedures. Several changes in the school routine occurred over this period. In this sense, the mothers felt some anxiety about the understanding of the school, represented by leaders and teachers, due to the treatment that their children needed to have. The support and cooperation of those people involved with the child in the process of teaching and learning were considered essential.

All the teachers were good. She did a bone graft surgery, and she was thirty days away and they helped a lot. They sent things for her to do at home, tests, materials, it really helped (I 8).

It is important to emphasize that the beginning of school life can highlight the presence of a common functional problem resulting from cleft lip and palate, that is, difficulty in communication. This fact brought a major conflict for mothers and their children, which is a focus of concern. The referral to the phonetic therapy was another way of support received from the school and expressed an important advance in the social integration of these children and adolescents.

The school managed to get it, the principal. So now he started speech therapy to see if he develops more because he does not want to talk to the teacher [...]. So for him to develop further, she was going to take him to judo lessons there as well (I 1).

There were, therefore, cases of positive performance on the part of the school and people involved in the progress of rehabilitation and care necessary for its success, as reported by members of the study.

DISCUSSION

The school life of children and adolescents with cleft lip and palate is considered by mothers as an opportunity to contribute in caring for the oral health of their children. The beginning of school is a time of great importance to social integration for children and adolescents with cleft lip and palate and to the people around them, having consequences in the planning and development of treatment.¹⁶ However, the beginning of

school life brings about an important conflict to these children. Prejudice is experienced in many cases, being a source of concern to mothers. They remained involved in order to overcome embarrassment and prejudice.

Sometimes, this prejudice makes the child feel embarrassed and abashed, and support from important people in the family, at school and in the community can develop encouragement, strengthening self-confidence and well-being,²⁰ having beneficial consequences on health. The observation of prejudice demonstrates the importance of clarification on the cleft lip and palate in schools and communities, demystifying these people and contributing to their health and well-being.⁵

The need for support of the school and people involved in them, such as teachers and principals, has been highlighted in other studies as a way to contribute to the rehabilitation of children and adolescents, since this health condition requires numerous absences from school, by virtue of the attendance to doctors' offices of several specialties and the performance of additional exams belonging to the lengthy rehabilitation process.⁵

Social support is highlighted as an element of health promotion for children.²⁰ This support refers to the companionship and practical support, information and esteem derived from the interaction between individuals with their social network, which involves friends, acquaintances and relatives. Thus, social support provided by people within the different spaces where children participate is essential in building their health.

Lack of understanding by teachers may be another factor causing stress in the lives of children and their parents, and detrimental to their well-being. On the other hand, not only understanding, but also the development of practices intended to assist in the development of the child will also have a positive influence on rehabilitation and health care.

Literature reveals the presence of several biological risk factors for the development of oral diseases, in particular dental caries and periodontal disease in patients with cleft lip and palate.¹²⁻¹⁴ This implies high prevalence of these diseases in these people.⁶⁻⁹ Therefore, another positive aspect in the school life of the child with labio-palatal cleft has to do with the participation in collective

preventive activities related with oral health. The entrance of the oral health team into the Family Health Strategy in many cities led to the development of health promotion activities at schools, emphasizing the importance of activities such as acceptance and interdisciplinary work.²³⁻²⁴ On the other hand, some educational institutions still keep the access to foods unfavorable to the children's oral health, allowing trade of same at the school itself or in the neighborhood. It is worth noting that often these habits come from home, starting very early with the supply of sucrose in baby bottles by parents, in order that the child reaches body weight to perform the reconstructive surgeries of lip and/or palate.¹⁴ The taste of the child, used to saccharose, becomes difficult to change, compromising the quality of the diet, which is a risk factor not only to dental caries, but also to other changes, such as overweight and obesity, increasingly more common in children's universe.^{7,24}

Special attention was given to adolescents, since they are in a phase that by itself, is permeated by conflicts and behavior changes. The presence of cleft lip and palate can promote feelings of inferiority, which may worsen in adolescence, since it is a period with broad and deep psychosomatic changes, leading them to face more barriers to achieve satisfactory psychological development.²⁵ These barriers associated with the desire for a perfect body, image, at times, imposed by society, end up influencing self-image and self esteem. Given the complexity and the different emotions at this stage of life, it is clear the importance that the professionals involved in the rehabilitation have and that the people they live with are willing to assist the children, adolescents and families through listening and support, helping to address adverse situations such as the episodes of prejudice and school violence.

FINAL CONSIDERATIONS

The school provides the children with CL/P possibilities for care and social inclusion, but can also bring conflicts by prejudice generated by their physical appearance. Another aspect relates to the policy of health promotion which, when present, is an important element for health care. The support of the school community is essential for children to have a proper development and better acceptance of their health condition.

1. The importance of school for the children's rehabilitation and social integration shows health professionals an area of expertise, which if used properly, can effectively contribute to the treatment and rehabilitation of these children.

Furthermore, the school's role in this process becomes of great importance; because while it contributes to increasing the bias, conversely, it also contributes to social inclusion.

In this sense, people involved in school life can act as a positive partnership for the success of health promotion and rehabilitation and the well-being of children with cleft, which will also contribute to their quality of life and integration in society.

From the perspective of comprehensive care and in order to promote health, this study may contribute to the awareness of health professionals, expanding knowledge about the different living spaces that people with CL/P occupy in their quest for healthy living.

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Correspondence: Denise Guerreiro Vieira da Silva
Universidade Federal de Santa Catarina
Centro de Ciências da Saúde
Programa de Pós-Graduação em Enfermagem
Campus Reitor David Ferreira Lima
88040-970 – Trindade, Florianópolis, SC, Brazil
E-mail: denise_guerreiro@hotmail.com

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