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FOOD INTRODUCTION FOR CHILDREN BORN WITH CLEFT LIP AND PALATE

INTRODUÇÃO ALIMENTAR DE CRIANÇAS NASCIDAS COM FISSURA LABIOPALATAL

INTRODUCCIÓN ALIMENTARIA PARA NIÑOS NACIDOS CON LABIO/PALATAL HENDIDO

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ABSTRACT
Objective: to describe the process of introducing foods to children born with cleft lip and palate. **Method:** descriptive study with a qualitative approach, carried out in a Support Association for Patients with Cleft Lip and Palate. Data collection was carried out from May to July 2022, through audio-recorded interviews, later transcribed and analyzed according to Bardin's Content Analysis technique. The study was approved by the Permanent Ethics Committee on Research with Human Beings with opinion no. 4,095,950. **Results:** 11 mothers participated, aged between 18 and 40 years. The reports allowed the creation of two thematic categories: Food introduction: process, facilities and challenges and; Nutrition of children born with cleft lip and palate and surgical procedures. **Final considerations:** Diet is directly influenced by surgical procedures and, although these improve quality of life, they can have a negative impact on nutrition.
Descriptors: Cleft Lip; Cleft Palate; Child Nutrition.

RESUMO
Objetivo: descrever o processo de introdução alimentar de crianças nascidas com fissura labiopalatal. **Método:** estudo descritivo de abordagem qualitativa, realizado em uma Associação de Apoio ao Fisssurado Labiopalatal. A coleta de dados foi realizada no período de maio a julho de 2022, por meio de entrevistas audiogravadas, posteriormente transcritas e analisadas seguindo a técnica de Análise de Conteúdo de Bardin. O estudo foi aprovado pelo Comitê Permanente de Ética em Pesquisa com Seres Humanos com parecer nº 4.095.950. **Resultados:** participaram 11 mães, com idades entre 18 e 40 anos. Os relatos possibilitaram a criação de duas categorias temáticas: Introdução alimentar: processo, facilidades e desafios e; Alimentação da criança que nasceu com fissura labiopalatal e procedimentos cirúrgicos. **Considerações Finais:** A alimentação é diretamente influenciada pelos procedimentos cirúrgicos e que estes, ao mesmo tempo em que possibilitam melhora na qualidade de vida, podem evoluir com repercussões negativas no tangente à alimentação.
Descritores: Fenda Labial; Fissura palatina; Nutrição da Criança.

RESUMEN
Objetivo: describir el proceso de introducción de alimentos a niños nacidos con labio y paladar hendido. **Método:** estudio descriptivo con enfoque cualitativo, realizado en una Asociación de Apoyo al Enfermo de Labio y Paladar Hendido. La recolección de datos se realizó de mayo a julio de 2022, a través de entrevistas grabadas en audio, posteriormente transcritas y analizadas siguiendo la técnica de Análisis de Contenido de Bardin. El estudio fue aprobado por el Comité Permanente de Ética en Investigaciones con Seres Humanos con dictamen n° 4.095.950. **Resultados:** Participaron 11 madres, con edades entre 18 y 40 años. Los informes permitieron crear dos categorías temáticas: Introducción de alimentos: proceso, instalaciones y desafíos y; Nutrición de niños nacidos con labio y paladar hendido y procedimientos quirúrgicos. **Consideraciones finales:** La dieta está directamente influenciada por los procedimientos quirúrgicos y, si bien estos permiten mejorar la calidad de vida, pueden tener repercusiones negativas en la nutrición.
Descriptores: Labio hendido; Paladar Hendido; Nutrición Infantil.

INTRODUCTION

The World Health Organization (WHO) recommends that children should be fed exclusively with breast milk until they are six months old, as this has a positive impact on their development and adult life, acquiring greater immunity and

reducing the risk of developing chronic diseases during childhood and adulthood. After six months, the complementary feeding phase begins, when other foods are introduced to develop the child's palate. This phase is marked by changes in the family routine and for the baby himself, who begins to experience textures and flavors other than breast milk.[1]

When not done properly, the food introduction (FI) can have consequences for the body, contributing to the appearance of allergic reactions and even infections. If started too late, FI becomes disadvantageous for the child, since from the sixth month onwards, breast milk alone is unable to provide the nutritional support that the body needs.[2]

When it comes to the FI of babies born with cleft lip and palate, this becomes a challenge. Cleft lip or cleft lip results from incomplete development of the baby's lip and/or palate and is usually associated with genetic predisposition, environmental factors, syndromes or other anomalies. In Brazil, approximately one in every 650 births (1: 650) are of babies with cleft lip and palate[3] and each year, an estimated 5,800 new cases arise, accounting for 25% of all congenital malformations.[4]

In relation to both breastfeeding and FI, it is known that babies born with clefts may present some particularities. Breastfeeding (BF) for a baby with a cleft can be a challenge or even lead to early weaning due to difficulty in latching on, as the cleft can make it difficult to properly seal the nipple, impairing intraoral pressure and making breastfeeding less effective.[5] In addition to changes in sucking and swallowing, the FI phase generally coincides with surgical procedures to correct the cleft, and this is compounded by the difficulty in tolerating new textures.[6]

With the necessary monitoring and guidance, most children born with this malformation can achieve promising results in FI.[7] Given this scenario, the study is justified due to the need to survey the experiences of mothers and family members regarding the FI of their children born with cleft lip and palate, associated with the scarcity of studies on the subject, especially in the area of nursing. Few publications were found on the subject and most of them deal with areas of psychology and social work. Thus, the objective of this research was to describe how food was introduced to children born with cleft lip and palate.

METHOD

Descriptive, exploratory and qualitative study carried out at the Maringá Association for Support of Cleft Lip and Palate Patients (AFIM). AFIM is a non-profit association that provides free

specialized multidisciplinary care for people with cleft lip and palate in Maringá and 80 other municipalities in the region. At this location, care is provided in a clinical and outpatient setting, in a variety of specialties, including speech therapy, nutrition, social services, psychology, dentistry and pedagogy. The institution also acts as a link between users, specialized consultations and surgical procedures performed outside the municipality.

Mothers aged 18 years or older of children aged between seven months and five years old who were being monitored at AFIM were invited to participate in the study. This age range was limited because at seven months, most children had already had at least one month of FI and the interviewees would be able to obtain a greater amount of information on the subject. The decision to restrict the collection to children aged 5 years was made because it was considered that the mothers' memories of their child's FI would still be well preserved, since this is a significant stage for the mother, and therefore it was not considered a limitation of the study.

Data collection took place at the institution itself, from May to July 2022, on a day and place previously scheduled with the site coordinator and in a reserved place, through audio-recorded interviews with the aid of an instrument composed in its first part by a sociodemographic characterization and in a second moment by guiding questions regarding the objective of the work.

The recorded interviews were transcribed in full for later analysis using the Content Analysis technique, which advocates three stages: pre-analysis, exploration of the material and treatment of the results obtained, together with their interpretation. Initially, the transcribed data undergoes the systematization and coding phase, focusing on the objective of the study. After this, such data is aggregated into units that will describe the content, then called units of meaning.[8]

During the exploration phase, the units of meaning are categorized by grouping and associations are made between them. The third and final stage consists of content analysis, characterized by the inference of the data that was extracted in addition to other studies previously carried out.[8]

To ensure the anonymity of the participants, the recordings and transcripts were identified with the letter M for mother, followed by the Arabic number of the sequence in which the interview was conducted. All participants signed two copies of the Free and Informed Consent Form (FICF) and the study was approved by the Permanent Committee for Ethics in

Research with Human Beings (COPEP) of the State University of Maringá (UEM) with Certificate of Presentation of Ethical Appreciation (CAAE) No. 31583720.3.0000.0104 and opinion No. 4,095,950.

RESULTS

Eleven mothers aged between 18 and 40 participated in the study. Regarding marital status, seven were married and four were single. Regarding education, two had completed higher education, seven had completed high school and two had only completed elementary school. At the time of the interviews, the children were between seven months and four years old.

The family income of the participants ranged from one to five minimum wages and the municipalities of residence were Cianorte, Colorado, Paranavaí, Presidentes Castelo Branco, Rondon and Maringá. To get to AFIM, eight used their own car, two came in a van provided by the city hall of the municipality they belong to and one used public transportation.

Regarding the gestational history, eight babies were born by cesarean section and three by normal delivery, with weights ranging from 2000g to 4340g and gestational ages of 36 weeks to 41 weeks and six days, six females and five males. All participants attended prenatal care with a number of consultations between six and 10. Regarding the main complications during pregnancy, these were present in six participants, namely gestational diabetes mellitus, bleeding, uterine fibroids, polyhydramnios, hypertension and pericardial edema.

Of the 11 children, eight were hospitalized shortly after birth due to prematurity, bradycardia, dysplasia, low oxygen saturation, breastfeeding problems requiring the use of an orogastric tube, meconium aspiration, and intrauterine fetal distress. Some remained in the neonatal intensive care unit (NICU) for 40 days. Regarding surgery to correct the cleft, only one child had not yet undergone the procedure.

Regarding the history of previous pregnancies, only three women had other children; with all of them not having clefts. The family history regarding the presence of clefts was also questioned and the 11 participants reported that the child in question was the only case. Regarding the type of cleft, unilateral and bilateral transforamen, incomplete pre-foramen and incomplete and complete post-foramen were found.

The reports from the interviews allowed the formation of two thematic categories: Food introduction: process, facilities and challenges; and Feeding of

children born with cleft lip and palate and surgical procedures.

Food introduction: process, facilities and challenges

In this category, it was identified that the FI of children born with cleft lip and palate was monitored by both the AFIM nutritionist and the nutritionist at the Comprehensive Care Center for Cleft Lip and Palate (CAIF), located in Curitiba and where surgical procedures are performed:

> *[...] the first person to introduce it was the nutritionist there (CAIF), as I went there before coming here, so she explained to me very clearly [...] which foods I can introduce, what is the best way to introduce them, how, she gave me an extra supplement and took some out. (M2)*

> *I was guided by the nutritionist here, [...] I started with a mashed food, it was easy, I gave vegetables, cooked cassava, yam, I gave it mashed with olive oil, like a normal child [...]. (M6)*

> *[...] they explained everything so clearly, she told me to put him in a little chair, how I should give him things separately, she instructed me on everything I should do, about each food [...]. (M8)*

Despite having support from both AFIM and CAIF, it was evident in the reports that mothers were afraid to start the FI process:

> *[...] It started with the fruits, then I started giving them baby food, potatoes, zucchini, carrots and I mashed everything, mashed it as much as possible, they said that I could even leave some grains, but I always mashed it a lot, because I was afraid, you know, apprehensive, but they ate it well until today, they eat very well (the twins). (M9)*

> *Girl, I was desperate, there was a day when I woke up in the middle of the night, milk was coming out everywhere [...] what I suffered the most was seeing her drowning, seeing this reflux coming back up through her nose, it was really bad. (M8)*

> *[...] at first we were quite scared that he would choke and that it would come out through his nose. But, after talking to the nutritionist, we saw that it was a process. (M1)*

Another point raised in the interviews was that despite the difficulties, over time mothers and other family members already knew how to deal with the complications arising from the process of feeding a baby with a cleft lip:

> *I was advised by the nutritionist here [...] she said that because I had an open palate, it didn't mean I had to start with a liquid diet [...] so I started with a little puree, and it was easy [...] there were situations where I saw that sometimes I would stop, because the palate was open [...] you could see that sometimes some food would stop there at the back, I think the pediatrician's instruction was to wash the nose with saline solution that would then go down, when I saw that it was bothering me [...]. (M7)*

> *[...] the five times they drowned [...] I was the one who helped them out five times, at home [...] at the end of my pregnancy, I had to stay in bed for a long time, I watched a lot about this issue of drowning, first aid [...] that's what helped me, you know. One day my sister was at my house and saw it, she started crying, she wanted me to call SAMU, and take them to the hospital, I told her to calm down, that I would try and then we'll see, and that's when I managed it [...]. (M9)*

The reports also showed that despite the craving, fears and complications, the mothers claimed that FI was a calm and

pleasurable moment, and that they were happy to know that their children had advanced another stage:

> *[...] I like to watch her eat because I think it's cute, because she's very independent, [...] she already exchanges food from one hand to the other, you know, she looks, passes it from one to the other, puts it in her mouth, [...] the cleft doesn't make any difference in her life, you know, she eats, she chews everything, I never gave her things all mashed up like that, I give it the way it is, you know, I give her cabbage in her hand and she chews it, I give her potatoes and she chews it, you know [...]. (M10)*

> *[...] from six months onwards the nutritionist gave the instructions, she said it would have to be very liquid, baby food, mashed, this was a very good thing because he put the bottle aside, and started to breastfeed less, the introduction was very calm [...]. (M11)*

Even though the children were born with clefts, common sense, along with the introduction of foods that are not recommended, especially for children under six months old, and the lack of understanding about FI care on the part of other family members, was also present:

> *I started giving him water, I think he was four months old, and when he was five and a half months old I started giving him juice and tea, but he never accepted it [...]. (M5)*

> *I tried to give them some tea, but they didn't like it, to this day they don't really like tea. (M9)*

> *[..] I was really scared once, when an uncle of mine [...] gave her a whole piece of chicken and she put it in her mouth. I told him she couldn't give it to her, but he told her to stop doing that. The girl choked, and that piece stayed in her fissure [...] I told him she couldn't, but he thought I was protecting her too much, but I knew the risk, she kept that thing and I had to take it out, it was really scary. (M9)*

It was observed in this category that although FI was experienced with some moments of fear and complications, it also brought positive aspects, in the sense of seeing their baby grow and develop. The mothers, in general, showed themselves capable of dealing with possible adversities, and at the same time, there was a similarity with the FI of babies who were not born with cleft, regarding the offering of other liquids before six months of age and the interference of other family members in the child's diet.

Impact of surgical procedure on the feeding of children with cleft lip and palate

In relation to diet and surgical procedures, it was evident that despite the risks involved in the procedure, the surgery was an expected moment that brought positive changes:

> *[...] before it was just baby food blended in a blender and liquid, so we saw this change including in her weight. And they said she could lose weight post-surgery, but she gained it. (M2)*

> *His chewing became different, he would go to the roof of his mouth a lot, it would get stuck, you know, then he would try to remove it with his tongue or with his finger, he would remove it, after he had the surgery everything improved. (M5)*

> *[...] after she had the surgery, she gained immunity, gained weight, she was thinner,*

> *because everything came back, after the surgery, it was something else [...]. (M10)*

At the same time, some mothers reported that the post-operative period was a bit turbulent:

> *[...] after he had surgery, and the roof of his mouth was injured, he didn't want to eat at all for the first few days, he ended up losing 1kg, but I think he's already recovered. (M.4)*

> *[...] he didn't accept milk in a cup, he only drank broth and couldn't eat other things [...]. (M.5)*

> *The first surgery was normal, because it was just the lips, but this last time was more complicated. He went two days without eating, then he drank milk, but he couldn't breastfeed, so it was much more complicated, everything had to be liquid [...]. (M.11)*

The reports presented showed that surgery is a highly anticipated moment, both due to the aesthetic and functional impact it has on the child's life, as it influences the feeding process and weight gain. At the same time, it is not free from complications and incidents, and these can also become difficult experiences for family members.

DISCUSSION

Cleft lip and palate have different shapes and complexities, which means that each one must be assessed individually. In this process, it is extremely important that the multidisciplinary team understands these characteristics, as well as the needs of the children and their families, in order to be able to assist them appropriately.[9]

Many babies with cleft palate experience difficulties during the breastfeeding process, requiring supplementation with artificial milk and an orogastric tube. Added to this is the common sense regarding the introduction of other foods such as water, teas and juices before six months of age, as many mothers are induced to use such methods with the intention of optimizing their children's weight gain.[1]

An adequate and up-to-date support network is an important factor for the development of a healthy FI. It was observed that myths related to offering teas and water before six months of age, and later to the ingestion of only blended foods or liquids associated with juices, were also observed, corroborating the fact that common sense related to infant nutrition is also present in children with cleft palate.10

There are still myths related to the FI of children with cleft palate, which perpetuate that food should only be offered in its pureed or liquid form. However, it is now known that the provision of well-cooked and properly cut food, supervised by an adult, as in the BLW method, is recommended.[1]

The challenges related to the FI of children with cleft lip and palate make this a remarkable experience for their families.

There are several challenges faced, ranging from choking on water to something more serious, such as solid food stuck in the cleft. The fear of this phase, even with the guidance received from nutritionists, is constant, and the fear of feeding the baby, offering only liquids or blended or very mashed food, can lead to food selectivity in the future.[11]

It is known that choking can be a common occurrence, even during the breastfeeding period, so it is necessary to hold training workshops with the parents and other family members of these children so that they know how to act in a situation of complications, remembering that this does not mean that the child will not be able to feed, it only reinforces that the cleft requires some special care.[5]

A study carried out on the occurrence of foreign body aspiration in Brazil between 2009 and 2019 showed that among children between zero and nine years old, the average number of deaths due to choking was approximately 196, with the main associated cause being the ingestion of food and other solid objects, reinforcing the need to prepare families to know how to carry out the choking maneuver.[12]

Surgical procedures occur at two main moments in children's lives. Cheiloplasty is usually performed by the sixth month, a less aggressive procedure in which the baby can start sucking on the mother's breast again about an hour after surgery. In palatoplasty, which occurs at about one year and one month, recovery is more laborious, involving the provision of liquids and blended foods, preferably cold, for approximately 30 days. For babies who only ate blended foods, the process is less intense, but for those who are already accustomed to solid foods and received FI through the participatory method and BLW, going 30 days without chewing properly can be more traumatic.[13]

This restriction after surgery can result in a regression in eating habits and negatively affect the child's development. For families, it is a somewhat stressful time, as they experience several situations to ensure adequate nutrition, and when the child stops eating as a result of the procedure, it can cause intense psychological suffering.[14]

The physical and emotional stress of the perioperative period is something that is quite intense for families of children with cleft palates. Along with the uncertainty of the procedure, there is the need to travel to get the surgery done, and often this happens only with the mother and her child, with no other companions to help. The rehabilitation phase also causes suffering, as the child cannot eat as before, only drinks cold liquids most of the time, and healing takes at least 15 days to occur.[15]

The reports revealed a certain lack of knowledge on the care of babies with cleft palates on the part of nursing professionals. It is worth noting that nurses are some of the people who have the most contact with patients, including monitoring pregnancy, childbirth, puerperium and subsequent care for the child during childcare. Therefore, the study reinforces the need for nurses to be trained on the subject in order to make experiences more humanized.[16]

It is understood that the fact that the study took place in a local reality and with the methodology used, the data cannot be generalized, but it does bring to light a problem that is part of the nurse's work, as this is one of the professionals responsible for monitoring these children at different levels of care. Therefore, knowing the realities and difficulties of this process, as well as the history of these children and the work of AFIM are essential to guarantee quality care.

FINAL CONSIDERATIONS

This study allowed us to describe how the AI of children born with cleft lip and palate occurs. It was evident that this is a highly anticipated moment for families, but at the same time, it causes fear and apprehension, feelings that if not properly addressed can have a negative impact on the child's development. It was also observed that nutrition suffers a significant impact after surgical procedures to correct the cleft.

The study is innovative because it sheds light on a reality that has been little studied until now. It is suggested that more research be carried out in this area in order to optimize the monitoring of these children and enable them to receive the support they need for good development.

FINANCING

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