



# Therapeutic itinerary of children with cleft lip and palate

*Itinerário terapêutico de crianças com fissura labiopalatina*

*Itinerario terapéutico del niño con labio y paladar hendido*

Allana Martins Vitorino<sup>1</sup>

Camila Moraes Garollo Piran<sup>2</sup>

Mariana Martire Mori<sup>1</sup>

Roberta Tognollo Borotta Uema<sup>1</sup>

Maria de Fátima Garcia Lopes Merino<sup>2</sup>

Marcela Demitto Furtado<sup>2</sup>

1. Universidade Estadual de Maringá,  
Departamento de Enfermagem. Maringá, PR,  
Brasil.

2. Universidade Estadual de Maringá,  
Programa de Pós-Graduação em Enfermagem.  
Maringá, PR, Brasil.

## ABSTRACT

**Objective:** to understand the therapeutic itinerary of children with cleft lip and/or palate. **Method:** a descriptive qualitative study carried out with families of children with cleft lip and palate. Data collection took place between June and July 2022 through semi-structured interviews, and thematic content analysis was applied. **Results:** eight families participated and three categories emerged: I) Facing the unknown: diagnosis of cleft lip and palate in children – feelings of shock, fear and uncertainty were noted that permeate during early or late diagnosis; II) An arduous path: pauses and beginnings during the therapeutic itinerary – it was observed that the families followed different paths due to the specificity of the family configuration and the cleft itself; III) Weaving the support network for care – support from friends, family, professionals and health institutions proved to be extremely necessary. **Conclusions and implications for practice:** the therapeutic itinerary of children with cleft lip and palate is arduous and followed by challenges, which begin at diagnosis and continue after birth. It is hoped that the results of this study will encourage dialogue among health professionals and become familiar with the needs of this population and be able to act at different points of health care. **Keywords:** Child; Family; Lip Cleft; Cleft Palate; Health Services.

## RESUMO

**Objetivo:** conhecer o itinerário terapêutico de crianças com fissuras de lábio e/ou palato. **Método:** estudo descritivo de natureza qualitativa realizado com famílias de crianças com fissura labiopalatina. A coleta de dados ocorreu entre junho e julho de 2022 por meio de entrevistas semiestruturadas, e aplicou-se a análise de conteúdo temática. **Resultados:** participaram oito famílias e emergiram três categorias: I) Enfrentando o desconhecido: diagnóstico de fissura labiopalatina na criança – notaram-se sentimentos de choque, medo e incerteza que permeiam durante o diagnóstico precoce ou tardio; II) Um caminho árduo: pausas e recomeços durante o itinerário terapêutico – observou-se que as famílias percorreram caminhos diferentes devido à especificidade da configuração familiar e da própria fissura; III) Tecendo a rede de apoio para o cuidado – mostrou-se ser de extrema necessidade o apoio dos amigos, família, profissionais e instituições de saúde. **Conclusões e implicações para prática:** o itinerário terapêutico de crianças com fissura labiopalatina é árduo e acompanhado de desafios, que se iniciam no diagnóstico e permanecem após o nascimento. Espera-se que os resultados deste estudo suscitem o diálogo entre os profissionais de saúde e se familiarizem com as necessidades dessa população e possam atuar nos diferentes pontos de atenção à saúde.

**Palavras-chave:** Criança; Família; Fenda Labial; Fissura Palatina; Serviços de Saúde.

## RESUMEN

**Objetivo:** conocer el itinerario terapéutico de los niños con labio hendido y/o paladar hendido. **Método:** estudio cualitativo descriptivo realizado con familias de niños con labio y paladar hendido. La recolección de datos se realizó entre junio y julio de 2022 mediante entrevistas semiestructuradas, y se aplicó análisis de contenido temático. **Resultados:** participaron ocho familias y surgieron tres categorías: I) Frente a lo desconocido: diagnóstico de labio y paladar hendido en niños: se observaron sentimientos de shock, miedo e incertidumbre que permean durante el diagnóstico temprano o tardío; II) Un camino arduo: pausas e inicios durante el itinerario terapéutico – se observó que las familias siguieron caminos diferentes debido a la especificidad de la configuración familiar y de la propia hendidura; III) Tejer la red de apoyo para la atención: el apoyo de amigos, familiares, profesionales e instituciones de salud resultó ser extremadamente necesario. **Conclusiones e implicaciones para la práctica:** el itinerario terapéutico de los niños con labio y paladar hendido es arduo y está acompañado de desafíos, que comienzan desde el diagnóstico y continúan después del nacimiento. Se espera que los resultados de este estudio fomenten el diálogo entre los profesionales de la salud y conozcan las necesidades de esta población y puedan actuar en los diferentes puntos de la atención en salud.

**Palabras clave:** Niño; Familia; Labio Leporino; Fisura del Paladar; Servicios de Salud.

### Corresponding author:

Mariana Martire Mori

E-mail: mari\_mmori@hotmail.com

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## INTRODUCTION

Cleft lip and/or palate are considered congenital craniofacial malformations, whose etiology is quite complex as it involves genetic and environmental factors.<sup>1</sup> Clefts can have different locations and extensions, affecting children alone or in association with other diseases.<sup>2</sup>

It is estimated that there is one case of a newborn with cleft lip and/or cleft palate for every 700 live births worldwide.<sup>3</sup> Meanwhile, in Brazil, it is one case for every 1,000.<sup>2</sup> Based on this, a study in Brazil with birth records between 2005 and 2016 identified that the South and Southeast regions had higher average rates when compared to other states, being 0.72 and 0.54 per 1,000 live births, respectively.<sup>4</sup>

Cleft diagnosis can be made through ultrasound examination between the 28<sup>th</sup> and 33<sup>rd</sup> weeks of pregnancy.<sup>2</sup> Treatment is complex and goes through the different stages of life, presenting benefits when started early. It involves multidisciplinary monitoring with a speech therapist, nutritionist, dentist, doctor, social worker, nurse and psychologist.<sup>5</sup>

Due to anatomical distortions, not only in the lip region, but also in the nose and palate region, it has been essential to perform surgical procedures in cleft treatment. Cheiloplasty (lip repair) is generally performed around two months of age, and palatoplasty (palate repair) can occur up to two years of age.<sup>5</sup> It is noteworthy that weight is an important factor for the indication of surgery.<sup>6</sup>

It is known that, faced with a diagnosis of cleft, the family in general experiences significant suffering, as a baby's malformation causes a rupture in relation to the idealization of a perfect birth, generating feelings of despair, anxiety, questions, uncertainty, incapacity and non-acceptance.<sup>7</sup> As a way to alleviate these negative feelings, it is necessary for children and families to be accompanied by a multidisciplinary team that can provide qualified and effective assistance for both,<sup>8</sup> with the aim of reducing or preventing the emergence of sequels.<sup>9</sup> Therefore, parents must be guided about the care and possible risks involved, whether due to the functional and anatomical implications of the cleft and/or as a result of other identified anomalies and treatment to be followed.<sup>8</sup>

Knowing the different paths taken by families, the therapeutic itinerary has the function of describing the path taken by the family in search of diagnosis, health services to resolve needs, in addition to the plans and actions that are drawn up along this path to deal with the illness. Considering all the particularities involved in the search for care, it is essential that each family of children with cleft have individual health care in order to guarantee resolution within health services.<sup>10</sup>

Studies on therapeutic itineraries aimed at children with cleft lip and palate are still recent and little explored, especially when the interest is the family's perception of treatment.<sup>10</sup> Such research can help improve the quality of care offered, strengthen social and support networks as well as address the difficulties experienced by families of children with cleft lip and palate. Considering the above, the question arises:

what is the path taken in health care networks by families of children with cleft lip and/or cleft palate? Therefore, the study aims to understand the therapeutic itinerary of children with cleft lip and/or palate.

## METHOD

This is a descriptive study of a qualitative nature with families of children with cleft lip and palate. In order to provide methodological quality to the study, it was carried out in line with COnsolidated criteria for REporting Qualitative research (COREQ) recommendations.<sup>11,12</sup>

The study was carried out at the Association of Support for Cleft Lip and Palate of Maringá (AFIM - *Associação de Apoio ao Fissurado Lábio-Palatal de Maringá*), which is a non-profit civil society organization with its own headquarters, which has a multidisciplinary team. AFIM provides specialized and free monitoring so that surgical treatment can be carried out within its deadline and individuals can achieve rehabilitation. Today, it covers around 500 registered patients from Maringá and 80 municipalities in the region. Currently, the institution offers outpatient clinical care in the areas of social services, psychology, nutrition, speech therapy, dentistry and pedagogical support.<sup>13</sup>

Family members with or without blood ties<sup>14</sup> were included in the study, as long as they were responsible for accompanying children under five years of age with cleft lip and palate during appointments at AFIM. This age range of children was chosen because it is a period marked by many health demands as well as to facilitate family recall. There was no withdrawal and no need to exclude participants.

Data collection took place in June and July 2022, through prior contact by the research team with families in the waiting room in order to make them feel calmer for the interviews. Subsequently, semi-structured interviews were carried out individually in a reserved room in the institution itself, on the day that children attended consultations. All interviews were carried out by the first author, a nursing student, and by a nurse with a doctoral degree. Both had previous experience with research, however, due to the research group dynamics, the interviews were carried out by a graduate student and a professor. Before starting the interviews, the researchers introduced themselves and explained the research objectives as well as the importance of carrying out the study. The interviews were recorded after acceptance by participants and, later, transcribed in full, creating a reliable record of the reports.

For data collection, a semi-structured script was used, composed in its first part of questions focused on sociodemographic construction of children and their family member, followed by questions referring to the path taken by families in health services, about the care provided and surgeries performed, i.e., aspects that would allow us to outline the therapeutic itinerary. The guiding question of the interview was: what was and how was your child's health monitoring journey from diagnosis, treatment and up to the present day?

The end of data collection occurred when the researcher observed repetition of responses with the consequent theoretical data saturation. This occurred when no new element is found among the data and the addition of new information is not necessary, as it will not alter the understanding of the object of study.<sup>15</sup> Data analysis followed the steps indicated by content analysis, thematic modality. The proposed steps are: a) pre-analysis: in which the material is organized and prepared to identify the central idea; b) material exploration: deepening the study, using a unit of meanings (cutting of statements), aiming to identify the core meanings; c) data categorization: these will be formed by regrouping content with similar meanings, where results are treated with inferences and interpretations. Thus, the researcher will analyze the results and seek to make them valid and relevant.<sup>15</sup>

The study was developed in accordance with the guidelines set out in Resolution 466/12 of the Brazilian National Health Council/Ministry of Health, and the project was approved by the Permanent Research Ethics Committee (COPEP - *Comitê Permanente de Ética em Pesquisa com Seres Humanos*) of the signatory institution, under Opinion 4,095,950, in June 2020 (CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 31583720.3.0000.0104). All participants signed the Informed Consent Form in two copies. In order to preserve anonymity, the interviewees were identified by "F" for family and number according to the sequence of the interview.

## RESULTS

Eight mothers participated in the research, and the interviews lasted about 20 minutes. As for their place of residence, four of them lived in Maringá and the others in neighboring cities. Mothers were children's main caregivers and were between

18 and 38 years old, and one of the mothers had two children with cleft lip and palate. Furthermore, half of mothers were married (four), had completed high school (five) and had no employment relationship (five), being called housewives. Family income ranged from one to six minimum wages, which subsidizes three to six people with this income.

Nine children were included, considering twins, both with the same condition. Their ages ranged between one and four years, and five were male and four female, all born in the municipality of Maringá. Five had been born in private maternity hospitals and four in public hospitals. Regarding cleft lip and palate diagnosis, four cases were discovered during pregnancy, two shortly after birth and three a few days after birth.

Regarding cleft cases, four unilateral and bilateral transforamen, two incomplete pre-foramen and five incomplete and complete post-foramen (twins) were found. No child in the study had comorbidities. Regarding the history of surgeries, seven children had already undergone one to two surgical procedures and only one child had not undergone any procedure. Mothers' search for information and assistance in health services took place at the moment they received confirmation of cleft diagnosis. The discovery about the place of treatment (AFIM) was obtained in several ways, among them, highlighted in the interviews, by the *Hospital Universitário de Maringá, Santa Casa de Maringá*, family and friends.

From an in-depth reading of the interviews, it was identified that the therapeutic itinerary of children with cleft lip and palate has been full of positive and negative experiences, being permeated by different feelings. Chart 1 presents a synthesis of how the analytical process took place until the construction of thematic categories, which were: I) Facing the unknown: cleft lip and palate diagnosis in children; II) An arduous path: of pauses and starting over therapeutic itinerary; III) Weaving the support network for care.

**Chart 1.** Coding and construction of thematic categories during data analysis. Maringá, Paraná, Brazil, 2023.

Initial codes	Intermediate codes	Thematic categories
Ultrasound for prenatal diagnosis	Prenatal diagnosis	
Discovering the diagnosis at birth	Diagnosis at birth and late	Facing the unknown:
Late diagnosis due to cleft palate		cleft lip and palate diagnosis in children
Surprise after discovery	Feelings of fear, despair, worry and anticipation of the unknown	
First contact with cleft lip and palate		
Follow-ups with the team		
Free ticket	Facilities during the search for care	
Free treatment		An arduous path:
Need to travel		of pauses and starting over therapeutic itinerary
Time availability	Difficulties that permeate the itinerary	
Surgical procedure		
Recovery from surgery		
Difficulty latching and sucking when breastfeeding		
Family support	Family network	
Health service support	Institutional and community network	Weaving the support network for care
<i>Associação de Apoio ao Fissurado Lábio-Palatal de Maringá</i>		

## **FACING THE UNKNOWN: CLEFT LIP AND PALATE DIAGNOSIS IN CHILDREN**

It was observed that all mothers underwent ultrasound as part of routine examinations requested to monitor the fetus development in the prenatal period. Some mothers received their children's diagnosis during this period, and most of them did not know what congenital malformation, called cleft lip and palate, was until the moment of diagnosis. With this news, they had the opportunity to find out about the subject and try to prepare for the arrival of a baby who would probably need special care.

*[...] the doctor said, "Mom, I don't know if you've heard of cleft lip and palate, I can't guarantee if it's just lip or palate." She explained to me exactly what it was, so I started researching to find out what it was and the causes. [...]* (F1)

*[...] I paid for the ultrasound and went into the doctor's room. It was then that the doctor showed me. He said, "Your daughter will be born with a cleft lip and palate." At the time, I didn't know what it was, I just asked him what the baby's sex was [...]* (F2)

*[...] in prenatal care, it was a morphological ultrasound, the second important one, and it must be between 23, 24 weeks [...] I had never seen a person with a cleft, I was never aware of it [...] it was with a doctor who I didn't know her and I noticed that she started looking and I understood that something was happening. She started asking me questions, until the question came "do you know what a cleft lip is?" [...]* (F6)

*[...] so, I found out when he was already 4 months old, it was a huge shock, I really struggled to accept when he was born [...] I didn't know, I hadn't met anyone [...]* (F7)

*[...] when I discovered it, I had no idea what it was, but the doctor explained it and we were very well received [...]* (F8)

Mothers who only found out about the cleft during childbirth or shortly after, a fact (or news/information) that surprises families, had a different feeling, with no time to digest them and deal with the feelings.

*[...] I found out that he had a cleft when he was born [...] I found out in the middle of the surgery [...]* (F3)

*[...] it was a surprise for everyone [...] when she was born, we were scared, I was desperate [...]* (F4)

Some children presented a late diagnosis of cleft, i.e., when there is no cleft lip, only the palate and these have little clinical repercussion.

*[...] I discovered it after 10 days in twin 1 and in twin 2 at 1 year and 2 months more or less [...]* (F8)

*[...] when I was born, she wouldn't latch on, the speech therapist saw the cleft when she cried [...] she went to the maternity ward after she was born [...]* (F5)

Regardless of when the cleft was diagnosed, whether prenatally, shortly after birth or even a few days after birth, the presence of feelings of fear, despair, concern and anticipation about possible confrontations that are still unknown can be seen in mothers' statements.

*[...] I just worried and thought, "Oh my God, what am I going to do now?" [...] but then I felt calmer, when I found out that I was being monitored, I still didn't know it was at AFIM, I found out when we were inside the hospital, when he was born [...]* (F1)

*[...] I started looking for what the cleft was, that's when I went into despair [...] I went into panic and despair [...] in the beginning, it was a feeling of fear, a lot of fear [...]* (F2)

*[...] the biggest shock was when she talked about the palate [...] it was at that time that the hole sank, because I despaired [...] at that moment, I left and started crying [...]* (F6)

It was noted that an early diagnosis makes a difference in both the lives and feelings of families. Those who were aware of the anomaly before giving birth were better prepared and sought information on how to care for their child, clarifying any doubts. However, it is worth highlighting that the situation of having a baby different from the ideal one can evolve into feelings of shock, fear and uncertainty, as presented in the statements.

## **AN ARDUOUS PATH: OF PAUSES AND STARTING OVER THERAPEUTIC ITINERARY**

During the health monitoring journey, each child followed a path depending on the specificity of the case. However, it was noticed that, in general, the journey was quite tedious for them and their families, marked by pauses and restarts. The mothers reported that their children received multidisciplinary care in both Maringá and Curitiba, and, therefore, needed to travel more than once to the reference center, experiencing different surgical procedures.

*[...] here, follow-up is with nutritionist, speech therapist, psychologist, social worker [...] we had to return every 3 months, every 4 months [...] the first surgery was performed at 7 months, there wasn't this issue of weight, because, as it was just closing the lip, it wouldn't lose as much blood, but now, to move the palate, it loses a lot of blood [...]* (F1)

[...] she is assisted by everyone. Today, she is assisted by a dentist, nutritionist, psychologist and speech therapist. There in Curitiba, she is assisted by a pediatrician, nutritionist, speech therapist, all of them here, but there is an otorhinolaryngologist there, in genetics [...] before it was every month; due to the pandemic, now we go every 6 months, every 3 months or sometimes once a year, but in the beginning it was every month [...] the first was at 6 months, everything was fine, because it's a point that melts and it starts to fall off. Now the palate surgery was a more complicated surgery, where she already knew what food was, she already knew how to feed herself, so this surgery was more painful [...] (F2)

[...] here we last came in January, today the psychologist has already made an appointment in 3 months [...] before it was every 15 days, now it has decreased [...] here there is a dentist, speech therapist, psychologist, social worker, nutritionist. They are the same as in Curitiba, but in Curitiba there are more specialists, there are ENTs, plastic surgeons, anesthesiologists, there are many more things there [...] within 1 year, we went 13 times [...] (F3)

The units of meaning showed that the journey of the child and the family was permeated with easy and difficult moments. The facilities were free passage to the treatment center and the fact that AFIM guarantees free health monitoring.

[...] the easiest thing is that I didn't have to pay any tickets [...] (F3)

[...] so, the ease comes in, having this place for him to come, having this reference center here in Maringá and there are so many cities that don't have [...] (F6)

The main difficulties encountered during the itinerary were regarding the availability of time to travel and recovery from surgery. It is known that caring for a newborn requires a lot of availability and, when a newborn requires special care, as is the case with a child born with a cleft lip and palate, dedication is even greater.

[...] the difficulty is having to keep moving to Curitiba, it's very tiring because we arrive and want to rest [...] (F3)

[...] it's difficult to be available to travel, the time we spend is tiring, just like now, I'm here and I have two others, I left it with my family to be here with him [...] (F6)

Another difficulty raised was in relation to breastfeeding, due to changes in the oral cavity caused by the cleft:

[...] to this day, I think the most difficult thing was breastfeeding, because I pumped until I was 7 months old, I had to offer the milk, heat it, freeze it [...] (F1)

[...] the main difficulty was breastfeeding, adapting to breastfeeding while sitting, waiting for her to burp, that whole process [...] (F2)

[...] for breastfeeding, she had difficulty sucking, she sucked a little, it seemed like she didn't have the strength [...] (F5)

Breastfeeding children born with cleft lip and palate is another challenge highlighted in family reports. The struggle to maintain breast milk supply entails some extra difficulties, such as the need to express milk, be able to store it properly, freeze, thaw and provide special care due to the craving, becoming a constant in the lives of such families. Added to this is the fact that sucking was often impaired as a result of orofacial changes.

Still related to the problems experienced, carrying out a surgical procedure is never easy, regardless of the age group, as recovery is not always simple, as there may be complications arising from the process. In the case of cleft lip and palate, children generally undergo several surgeries, which are necessary to repair the cleft and other problems arising from it. With this in mind, it was reported that the post-surgery period was the period of greatest difficulty encountered during the journey:

[...] on the issue of surgery, because he suffered a lot, I think that was my biggest difficulty [...] (F7)

[...] difficulty was the surgery, which is something very difficult [...] (F8)

In this category, it was observed that families went through a whirlwind of emotions regarding the care provided by health teams, the need for frequent return visits, the suffering and specialized care resulting from surgical procedures. It was noted that families took different paths, due to the specificity of both the family configuration and children's own craving, making the itinerary full of unique feelings and experiences.

## WEAVING A SUPPORT NETWORK FOR CARE

The data showed that support from family members and health services during the coping experience of being the mother of a baby with malformations is not easy. And the family support network was identified as the most significant in the field of child care.

[...] my mother, my father, my brothers, my husband, grandparents, everyone, the girls here too, everything we needed could come here and talk, we had a very large support network, it still exists today [...] (F1)

[...] the family always, my mother-in-law helped me a lot, both with preparation and also financially, everything. I have support from my family in all aspects, but from my family [...] (F6)

*[...] yes, always, today the one who is bringing it is my father, the other time it was her father, but there is always someone willing to help [...]* (F4)

AFIM was also identified as a support network, as it guarantees social and instrumental support to children and their families. Furthermore, AFIM instructs and directs children to receive appropriate and efficient care, both in the reference municipality and in others, without making a pilgrimage to seek specialized care during the treatment journey.

*[...] the girls here too, anything we needed we could come here and talk [...]* (F1)

*[...] support started to come from the moment I discovered AFIM, because I didn't have it there. At the health center, they knew, I took the ultrasound showing it, I had two ultrasounds before she was born, and it was already stated and the center has a psychologist, and they didn't talk, they didn't help, they didn't play the role that AFIM did [...]* (F2)

The support network proved to be extremely necessary at this difficult time for the family of a child with cleft lip and palate, including friends, family, professionals and health institutions. It is also observed the lack of support from other health institutions, even at the time of birth, which in a certain way hindered the process of resilience and struggle for adequate care for children.

## DISCUSSION

Knowing the therapeutic itinerary of children with cleft lip and/or cleft palate allows us to understand how caring for this child affects family dynamics and their entire journey.

Thus, it is noted that cleft lip and palate diagnosis during prenatal care allows for better acceptance and preparation for future care for the baby. That said, by performing an ultrasound exam during prenatal care, one can visualize the nose and lips from the 15<sup>th</sup> week of intrauterine life and from the 28<sup>th</sup> and 33<sup>rd</sup> weeks to visualize the lip/palate. Therefore, it becomes possible to diagnose the children's condition, and these mothers can be referred to a reference center for complete prenatal care assessment.<sup>16</sup>

Difficulties in diagnosing cleft lip during pregnancy may be related to the impossibility of pregnant women undergoing an ultrasound examination. According to the Prenatal and Birth Humanization Program (PHPN - *Programa de Humanização no Pré-natal e Nascimento*), this exam is complementary to other prenatal exams and can only be recommended as a routine exam only in places where it is available.<sup>16</sup>

After the diagnosis, whether prenatally or later, it raises the most diverse feelings, including denial of diagnosis, concern, crying, fear and acceptance of their cleft babies, since the way diagnosis is approached directly affects the feelings of families.

Therefore, the way they experience the diagnosis is fundamental for accepting children's condition. It is worth mentioning that the lack of preparation of some health professionals when reporting cleft lip diagnosis can trigger different feelings in families.<sup>16,17</sup>

Parents' concerns are, for the most part, due to the malformation that can cause difficulties for infants related to sucking and swallowing, creating a challenge for mother and baby in relation to breastfeeding.<sup>18</sup> Furthermore, infants require longer feedings and may experience fatigue during feedings, esophageal reflux and nasal regurgitation.<sup>19</sup>

Depending on the degree of the cleft, it becomes more or less difficult to breastfeed. In the case of infants with cleft lip only, they tend to present fewer complications, since breastfeeding is only possible with the correct positioning of the latch. Infants with cleft palate generally require greater support due to the presence of the junction of the nasal and oral cavities, thus intensifying the risk of aspiration.<sup>20</sup> Therefore, support during this period is essential for continuity of breastfeeding, enabling closer ties between mother and child and a healthier life.<sup>21</sup>

Another difficulty presented was in relation to breastfeeding, making the process stressful and tiring for both the mother and the child. It has been noted that, when mothers have or will have a child with a cleft, many families are not advised on how to manage breastfeeding. Therefore, breastfeeding becomes one of the main concerns of parents both in the gestational and postnatal periods.<sup>22</sup>

During the search for treatment, families are faced with a lack of specialized centers in their city. Thus, the majority of mothers travel several times to the care locations, which are reference centers, or in some situations end up moving closer to the place of follow-up to meet children's needs.<sup>16</sup> Furthermore, it is clear that, during travel, time is lost on the road and, often, this time could be used for other activities that encourage child development, family life, leisure and even self-care for mothers.<sup>23</sup>

Therefore, when mothers have some type of help when seeking treatment for their children, difficulties decrease. Access to treatment and adequate information are essential in the treatment process, in addition to bringing comfort to parents and improving patients' quality of life.<sup>16,24</sup>

Mothers, in addition to going through difficult times in the care process, deal with conflicting and stressful feelings and situations, causing an overload for caregivers, which can continue into adulthood.<sup>25</sup> Like this study, another study on itinerary shows that families had difficulties and facilities during the treatment journey, be it access to health services, specialized assistance service, change in family routine, availability of transport through the city hall, support from family members and health professionals. In both studies, the journey of family members is seen as an arduous path permeated with anguish and uncertainty about the unknown.<sup>26</sup>

The path taken to meet the health needs of their children is permeated by difficulties that act as access barriers, making them follow repeated and unsuccessful paths many times.

Knowing this, social support networks, whether family or a specialized association with a multidisciplinary team, alleviate the suffering and stress faced by families.<sup>16</sup>

Family support is extremely important, especially in cases of illness, helping to make health decisions. Friends and even strangers become important in the process, helping to overcome the difficulties experienced. Regardless of who the support comes from, families are grateful for helping to face this arduous path.<sup>27</sup>

The fact that the interviews were carried out after a prolonged period of time since malformation diagnosis, as some children were already four years old, may contribute to the existence of a memory bias among participants, although it is believed that facts such as those presented are difficult to erase due to their relevance and impact on families' lives.

The information provided a greater understanding of the itineraries of these families when faced with cleft lip and palate diagnosis. Furthermore, they can provide health professionals with greater reflection on the importance of valuing individuals' history, causing changes in care practices, improving the quality of services available to children with cleft lip and palate and their families.

A limitation of this study is the fact that it was carried out at a single AFIM. However, it is believed that the results found can support reflections on the elements involved, as a therapeutic itinerary for families of children with cleft lip and palate.

## CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Cleft lip and palate come with several challenges, affecting physical, psychological, emotional, social and financial issues for children's families. The process of caring for children with cleft lip and palate is complex and permeated by difficult situations that demand time from families, especially mothers. Furthermore, traveling to large centers for child treatment has also been a challenge.

The study makes important contributions, as the topic is little explored within nursing. It is necessary for nurses to familiarize themselves with the needs of this population, as they work at different points of health care and may come across such families at any time in their professional lives. Therefore, the study brings to light the need for research on nursing professionals' perception, in order to assist them in caring for these children and their families.

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## AUTHOR'S CONTRIBUTIONS

Study design. Allana Martins Vitorino. Camila Moraes Garollo Piran. Marcela Demitto Furtado.

Data collection. Allana Martins Vitorino. Camila Moraes Garollo Piran. Marcela Demitto Furtado.

Data analysis. Allana Martins Vitorino. Camila Moraes Garollo Piran. Marcela Demitto Furtado. Mariana Martire Mori. Roberta Tognollo Borotta Uema. Maria de Fátima Garcia Lopes Merino.

Interpretation of results. Allana Martins Vitorino. Camila Moraes Garollo Piran. Marcela Demitto Furtado. Mariana Martire Mori. Roberta Tognollo Borotta Uema. Maria de Fátima Garcia Lopes Merino.

Manuscript writing and critical review. Allana Martins Vitorino. Camila Moraes Garollo Piran. Mariana Martire Mori. Roberta Tognollo Borotta Uema. Maria de Fátima Garcia Lopes Merino. Marcela Demitto Furtado.

Approval of the final version of the article. Allana Martins Vitorino. Camila Moraes Garollo Piran. Mariana Martire Mori. Roberta Tognollo Borotta Uema. Maria de Fátima Garcia Lopes Merino. Marcela Demitto Furtado.

Responsibility for all aspects of the content and integrity of the published article. Allana Martins Vitorino. Camila Moraes Garollo Piran. Mariana Martire Mori. Roberta Tognollo Borotta Uema. Maria de Fátima Garcia Lopes Merino. Marcela Demitto Furtado.

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Aline Cristiane Cavachilli Okido 

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