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Multidisciplinary care for children with cleft lip and palate and their families: Family-Centered Care

Assistência multiprofissional às crianças com fissura labiopalatina e suas famílias: Cuidado Centrado na Família

Asistencia multidisciplinaria a niños con labio y paladar hendido y sus familias: Atención Centrada en la Familia

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ABSTRACT

Objective: To understand the multidisciplinary care provided to children with cleft lip and palate and their families.

Method: Descriptive, exploratory and qualitative study, based on the theoretical-philosophical framework of Family-Centered Care, conducted with professionals from the multidisciplinary team of an association supporting individuals with cleft lip and palate. The data were processed using the Iramuteq® software and systematized using Similarity Analysis. The study was approved by the Ethics Committee under opinion no.4,095,950.

Results: Twelve professionals participated, in which the guiding thread for the construction of the classes was the link between the words: Child, Family, Treatment and Difficulty and the alignment with the principles of the Family-Centered Care philosophy, resulting in the following classes: 1. Portrait of assistance from the multidisciplinary team in caring for children and their families (Assistance and Monitoring); 2. Challenges experienced by the team in caring for children and their families (Barriers); and 3. Exercising their (essential) role as a member of the multidisciplinary team (Impact).

Conclusion: Professionals who care for children with cleft lip and palate and their families encounter barriers during care. However, they provide support to family members and work collaboratively, from the perspective of family-centered care involving participation, dignity, respect, and information sharing.

Descriptors: Child. Cleft lip. Cleft palate. Family. Multidisciplinary team.

RESUMO

Objetivo: Conhecer a assistência multiprofissional prestada às crianças com fissura labiopalatina e suas famílias.

Método: Estudo descritivo, exploratório e qualitativo, pautado no referencial teórico-filosófico do Cuidado Centrado na Família, realizado com os profissionais da equipe multiprofissional de uma associação de apoio ao fissurado labiopalatal. Os dados foram operacionalizados por meio do software Iramuteq® e sistematizados por meio da Análise de Similitude. Estudo aprovado pelo Comitê de Ética sob parecer nº4.095.950.

Resultados: Participaram 12 profissionais, no qual o fio condutor para a construção das classes se deu pelo vínculo entre os vocábulos: Criança, Família, Tratamento e Dificuldade e a convergência com os pressupostos da filosofia Cuidado Centrado na Família, resultando nas classes: 1. Retrato da Assistência da equipe multiprofissional no atendimento das crianças e suas famílias (Assistência e Acompanhamento); 2. Desafios vivenciados pela equipe no atendimento às crianças e suas famílias (Barreiras); e 3. Exercendo seu papel (essencial) como membro da equipe multiprofissional (Impacto).

Conclusão: Os profissionais que atendem crianças com fissura labiopalatina e suas famílias encontram barreiras durante a assistência. Entretanto, proporcionam suporte aos familiares e trabalham de forma colaborativa, sob a ótica do cuidado centrado na família envolvendo a participação, dignidade, respeito, e compartilhamento de informações.

Descritores: Criança. Fenda labial. Fissura palatina. Família. Equipe multiprofissional.

RESUMEN

Objetivo: Comprender la atención multidisciplinaria brindada a niños con labio y paladar hendido y sus familias.

Método: Estudio descriptivo, exploratorio y cualitativo, basado en el marco teórico-filosófico de la Atención Centrada en la Familia, realizado con profesionales del equipo multidisciplinario de una asociación de apoyo a labio y paladar hendido. Los datos fueron operacionalizados mediante el software Iramuteq® y sistematizados mediante Análisis de Similitud. Estudio aprobado por el Comité de Ética bajo dictamen n° 4.095.950.

Resultados: Participaron 12 profesionales, en los cuales el hilo conductor para la construcción de las clases fue el vínculo entre las palabras: Niño, Familia, Tratamiento y Dificultad y la convergencia con los presupuestos de la filosofía del Cuidado Centrado en la Familia, dando como resultado las clases:1 Retrato de asistencia del equipo multidisciplinario en el cuidado de los niños y sus familias (Asistencia y Seguimiento); 2. Desafíos experimentados por el equipo en el cuidado de los niños y sus familias (Barreras); y 3. Desempeñar su rol (esencial) como miembro del equipo multidisciplinario (Impacto).

Conclusión: Los profesionales que atienden a niños con labio y paladar hendido y sus familias encuentran barreras durante la atención. Sin embargo, brindan apoyo a los familiares y trabajan en colaboración, desde la perspectiva de una atención centrada en la familia que implica participación, dignidad, respeto e intercambio de información.

Descriptores: Niño. Labio leporino. Fisura del paladar. Familia. Equipo multidisciplinario.

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INTRODUCTION

Cleft lip and palate is a type of craniofacial malformation that occurs during intrauterine life and has a complex etiology involving multiple factors such as genetic, environmental and teratogenic influences[1–2]. It is estimated that the prevalence of cleft lip and palate in Brazil is one case per 650 live births[3].

This type of cleft can compromise the development of the nose, palate, jaw and/or lip[1–2], impairing verbal communication and hearing, as well as the aesthetic appearance, oral health, adequate food intake and psychological well-being of children. Social interaction can also be impacted, since discrimination, stigma and prejudice on these children are still present, both within the family and outside the family environment[4–5].

Children with clefts are often subjected to surgical interventions during their first year of life, since early treatment is recommended to reduce complications and provide a better quality of life[4–6].

Depending on the complexity of the cleft lip and palate, its treatment involves a range of specialties. In this sense, the work of a multidisciplinary team mainly composed by professionals from the areas of dentistry, speech therapy, psychology, nutrition, nursing, social work and pedagogy becomes necessary to achieve positive outcomes in the short, medium and long term[4–5,7–8]. The work of the multidisciplinary team is collective, developed through interaction, communication and sharing of skills between individuals from different professional areas aiming to provide comprehensive care to the patient[9].

The inclusion of family members and patients in planning the necessary rehabilitation procedures has been very important for the prognosis of children, especially those with cleft lip and/or palate, due to the impact of the condition on the entire family cycle[5]. The Family-Centered Care (FCC) model is characterized by the direct participation of the family in the planning, provision and evaluation of care, together with the health team[10].

To adopt this care model, healthcare professionals must listen to and respect the choices of the patient and their family members, including their beliefs and values. Therefore, it is essential to share information in a clear and objective manner, facilitating adherence to therapeutic measures[10].

Given that treatment of cleft lip and palate is specialized, the discussion regarding multidisciplinary action is still incipient and restricted to rehabilitation centers, causing a gap in knowledge about the care necessary for comprehensive care[6,11]. In this perspective, the present study is justified by the need to understand the dynamics of care, identifying the main challenges faced by the team to enable reflections that can contribute to the care practice aimed at this population.

The objective of this study is to understand the multidisciplinary care provided to children with cleft lip and palate and their families, aiming to answer the following question: How does the multidisciplinary team provide care for children with cleft lip and palate and their families?

METHOD

This is a descriptive, exploratory, qualitative study, based on the theoretical-philosophical framework of Family-Centered Care (FCC), grounded on the theoretical assumptions: participation, collaboration, shared information, dignity, and respect[10]. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to provide greater transparency and quality of the study[12].

The study was conducted with 12 professionals who are part of the multidisciplinary team of an Association for Support of Cleft Lip and Palate Patients (*Associação de Apoio ao Fissurado Labiopalatal*) located in the northwest region of the state of Paraná. This is a civil society organization whose paid and volunteer employees provide free care to all children and adolescents with cleft lip and palate in the municipality where it is located, as well as in 79 municipalities in the region.

Nowadays, in 2023, the service attends 475 children and adolescents and has a trained multidisciplinary team. It consists of a pediatric dentist/general dentist, two orthodontists, a periodontist and a surgeon for minor oral procedures (both volunteers), a social worker, a speech therapist, two psychologists (one for monitoring babies, providing guidance to pregnant women and parents, and another for individual clinical therapeutic care), a nutritionist, a teacher and a pedagogue.

At the time of data collection for the research, some criteria for selecting professionals were established. Inclusion criteria were those who were members of the multidisciplinary team that cares for children with cleft lip and palate, as well as their families; and who had been working at the institution for at least three months, understanding that they were familiar with the service dynamics. Professionals who were on leave, vacation and/or absent from work for any reason at the time of data collection would be excluded. The collection took place between April and June 2023. The sample size was defined by convenience, and all professionals from the service participated in the study.

Initially, the coordinators responsible for the service were contacted, the research interest was explained, and the authorizations and opinion from the Ethics Committee were provided. The professionals were then approached personally, at their workplace by the main researcher. The researcher explained the study's objectives and methodology and requested the signing of the Informed Consent Form in two copies.

The interviews took place individually in a private room and to meet the objectives of the study, they were conducted only once with each participant and at appropriate times that did not interfere with patient care. A semi-structured interview was adopted, using a script with the following trigger question: "Tell me how the care for children with cleft lip and palate and their families has been with the multidisciplinary team?" Additionally, other auxiliary questions and a questionnaire involving data on the sociodemographic and professional profile developed by the authors were used. The questions were reviewed by nursing professors from the research group who work with child and family health.

The interviews were recorded on digital media, fully transcribed, and possible language errors were corrected, without, however, altering their content. In addition, field notes were taken during all interviews. To ensure greater validity and reliability, after transcription, the material was returned to the participants, made no corrections[13]. The average duration of the interviews was 20 minutes, and all interviews were conducted by the first author, a nursing undergraduate student, and a nurse in the process of completing a doctorate, both with experience in qualitative studies. The interviewers were interested in this research topic as they work with child health.

It is important to highlight that this study is part of a research project developed at the service two years ago, of which the interviewers are also part, and therefore familiar with the research field.

Initially, the speeches were organized to systematize the ideas to identify the central concept regarding care for children with cleft lip and palate and their families. A textual corpus was constructed through the frequency of the words that originated the text segments (each text segment is approximately 3.25 lines). The material produced was imported into the Iramuteq® software[14].

For this study, Similarity Analysis was used, which allowed the identification of word occurrence and the connection present between them in the textual corpus. These words were later grouped into central and peripheral zones (graphs), generating a similarity tree that helps in the identification of the structures[14]. The convergence between the words highlighted by the software and the assumptions of the FCC theoretical framework gave rise to three definitive classes: Class 1. Portrait of assistance from the multidisciplinary team in caring for children and their families (Assistance and Monitoring); Class 2. Challenges experienced by the team in caring for children and their families (Barriers); and Class 3. Exercising their (essential) role as a member of the multidisciplinary team (Impact). After the analysis, the interviewees did not provide feedback regarding the study findings.

The study was developed in compliance with the guidelines set forth by Resolution No. 466/12 of the National Health Council/Ministry of Health and approved by the Permanent Committee on Ethics in Research Involving Human Beings under opinion No.4,095,950/2020 (CAAE: 31583720,3,0000,0104). To maintain participant anonymity, their identities were coded according to their professional category (e.g., nutritionist).

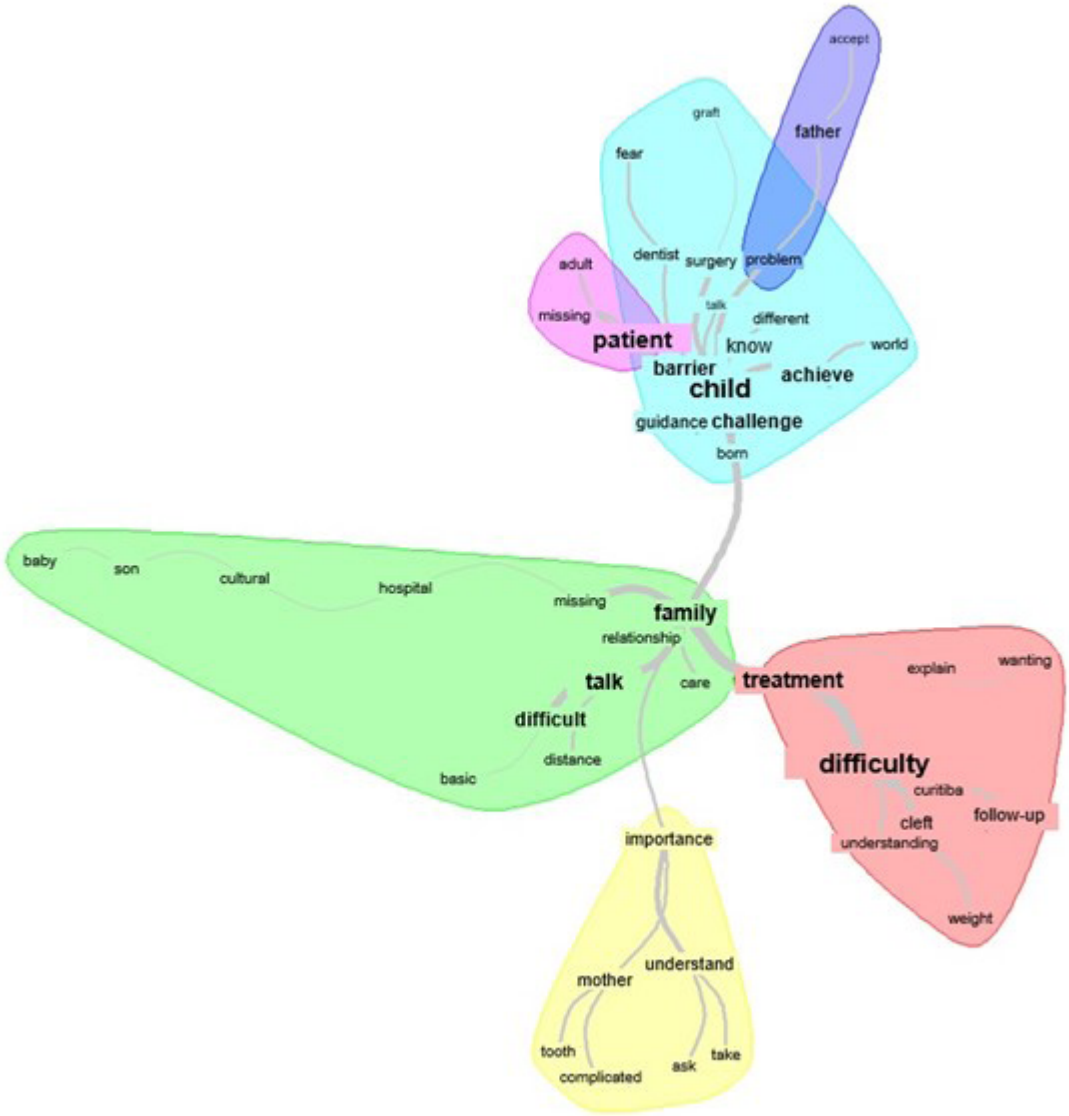
RESULTS

The study included 12 professionals from the multidisciplinary team, 11 of whom were female, one male, and aged between 20 and 40 years old. Regarding their academic background, three professionals had a *lato sensu* postgraduate degree in cleft lip and palate, three had additional training in cleft lip and palate, and four had a *lato sensu* postgraduate degree in other areas, and two had no specialization. The professionals' experience ranged from two to 10 years, and their working period at the institution, the field of this research, ranged from one to five years. At the time of data collection, ten professionals were hired and the others worked as volunteers.

A synthesis of the care provided by the multidisciplinary team in monitoring children with cleft lip and palate and their families can be understood from the similarity tree (Figure 1).

The tree presented four essential graphs. In the upper peripheral zone, the word **child** stood out, with stronger connection with the words **challenge**, **barrier** and **patient**, and complementarily, with **father**. In the central zone, the word **family** was initially linked to **talk**, **treatment**, **difficulty** and **follow-up**, and, secondarily, to **importance**, **mother** and **understand**. In this context, the link between the main words was between **Child**, **Family**, **Treatment** and **Difficulty**, from which the final classes of this study were constructed.

Figure 1 – Similarity Analysis. Maringá, PR, Brazil, 2023.



Source: Research data, 2023.

Class 1. Portrait of assistance from the multidisciplinary team in caring for children and their families (Assistance and Monitoring)

The first class refers to the representation of the assistance of the professionals presented by the multidisciplinary team in the care for children with cleft lip and palate, contemplating the assumptions of **Assistance** and **monitoring** of the FCC philosophy[10]. Despite the participants' experience not being minimal, it is possible to observe, overall, a lack of experience in the area, whether in care or in basic and complementary training.

> *I didn't have much knowledge about cleft lip and palate before I started working here, and I can see how much of an impact it has, that it's not just a cleft or a little cut on the lip, but that it impacts many aspects, such as learning, self-esteem, and relationships with other children.* (Clinical psychologist)

I didn't know about cleft lip and palate before I came to the institution. We say that it's a flaw in special education itself, in training, because we don't see this area. (Professor)

The topic wasn't addressed in college. You see in theory what it's like, but having real cases and getting to know them in college wasn't part of it. (Pediatric dentist/general dentist)

Regarding the dynamics of care for children and their families, we noticed, in the speeches, a flow that determines it. Initially, patients are welcomed and, based on the observed needs, referrals are made to specialized professionals available in the service.

Children are referred by other departments, or at the request of parents. (Clinical psychologist)

They receive a screening by the general dentist. When the doctor sees that there is a need, she has done the cleaning and given instructions, and the patient is still not following the treatment, she refers the patient to me. (Periodontist)

Upon arrival at the institution, they come to me so I can diagnose the type of cleft, then they go to the nutritionist and the psychologist. (Speech therapist)

The therapeutic plan takes considers the specificities of each child, adapting to the progression of the patient's clinical condition and the behavioral adaptations needed in the family. The multidisciplinary team works together and includes the family in the care, addressing issues that influence the child's treatment.

At first, the appointment is weekly, until I understand how the acceptance process is going. Then I move to biweekly, and monthly. Until they are three to four years old, I move to quarterly care, from three to six years old every six months, and then I follow up annually. [...] After they become adults, it is according to each person's needs. (Counseling psychologist)

We provide equal care, from the first appointment [...] we talk to the professional colleague so that we can work together a way to provide this support within this comprehensive perspective. (Social worker)

We see who has a crossbite, who has some orthodontic need [...] but in a general context, we organize so that all the teeth reach the oral cavity. (Orthodontist 1)

Class 2. Challenges experienced by the team in caring for children and their families (Barriers)

The second class encompasses the challenges faced by the multidisciplinary team in caring for children with cleft lip and palate and their families. The barriers faced were associated with the (lack of) commitment and (difficulty in) co-responsibility for treatment by family members, prejudice and stigma in society and the difficulty in coordinating with other services available in the municipality's healthcare network.

It is necessary for the family to be part of the treatment [...] Maybe they still don't understand the importance of all this monitoring and can't commit to it as ideally as needed. (Clinical psychologist)

The family is the biggest challenge. In terms of following the guidelines [...] You have to be able to make those responsible aware of the importance of caring. (Pediatric dentist/general dentist)

The mother's exhaustion is evident and makes hinders follow-up, because since they already go to Curitiba [referral center], coming here is also tiring [...] they become discouraged and end up being absent. (Speech therapist)

The family is a key element for the continuity of care. The way the family understands the cleft lip and palate can determine how the child will deal with the health-disease process, even with regard to bullying, a situation frequently experienced, especially at school.

What I notice is that some patients have a family that is very protective of their child, always wanting to take great care of them, sometimes more than they need to. (Clinical psychologist)

There are mothers who are overprotective at the beginning, and when they grow up it becomes difficult, they can't handle it. (Counseling psychologist)

There is also bullying that children suffer at school, many become closed off, and they don't like to talk. We deal with many problems here that we have to help patients and family members manage. (Orthodontist 1)

The child suffers and deals with it in different ways [...] sometimes they go through a phase of denial, difficulty in relationships, social interaction because of the cleft, and they react in different ways. (Orthodontist 2)

Childcare is expensive and often the family income is insufficient to meet the health demands of their children, which can negatively impact the evolution and improvement of the individual's clinical condition.

> *The economic challenges faced by patients, for example those who are more disadvantaged. Because it is a specialized treatment, and sometimes these patients lack basic conditions.* (Orthodontist 2)

Despite the service has a multidisciplinary team, there is a need to coordinate and include the patient in the other parts of the health care and education network. The communication, referral and counter-referral among professionals in the network are flawed, generating divergence in practices and decision-making.

> *It seems that there is no engagement [between the school and the Institution], a fear that if she goes there, I will lose her here, but no". [...] Many times we call and say that it is from the Support Institution for cleft lip and palate, and they say, where? Where is that? What do you do there? In other words, they don't even know.* (Pedagogue)

> *Our challenge is that the surgeries are done in Curitiba. We are also far from part of the multidisciplinary team. Here we have part of it, which is the clinical part, but now the surgical part is all there. This is still a barrier, because we don't have as much contact with the professionals there.* (Orthodontist 1)

> *Outdated professional guidance [...], some patients receive different guidance from what we try to provide here, at least what I try to provide at least.* (Nutritionist)

Class 3. Exercising their (essential) role as a member of the multidisciplinary team (Impact)

The third class demonstrates the relevance of the role of professionals who make up the team caring for children with cleft lip and palate, in terms of providing support and helping families to become resilient throughout the process (Impact).

> *Helping to understand the complexity of the treatment, a space where they can talk about the difficulties of such a long treatment. The issue of image acceptance, in the case of patients who have a more issue with their appearance. And finding resources to deal with these difficulties that arise from treatment, development, growth, relationships with family and friends, in the sense of having structure, being able to develop self-support to deal with these issues inherent to growth.* (Clinical psychologist)

The importance of the **health education** component in the list of activities and roles performed by the multidisciplinary team is highlighted.

> *It is through nutrition that we can further promote health. Guiding on the nutrition part, those basic behaviors of a good introduction to food. Also having breastfeeding as the main source of nutrition. I think these are small details that can make a difference. All of this will later be related to the child's quality of life.* (Nutritionist)

Finally, the speeches reiterated that collaborative work between the multidisciplinary team improves the quality of care and impacts the quality of life and well-being of children, in addition to act as bridges inserting them into the health care network and receive the necessary care.

> *The child can rehabilitate reading and writing skills, which is where they may have more difficulty. Reading aloud, adolescents beginning to present seminars, and not wanting to, even having panic attacks during class. Therefore, all aspects of language, both oral and written, need to be worked on extensively.* (Professor)

> *Orthodontics takes care of facial growth and smiles, which are expressions of joy and happiness. When you can restore a child's smile, the impact is great, and their self-esteem improves significantly, as well as on the family.* (Orthodontist 2)

> *I see my specialty as something inevitable, it is a unique pillar, it is a piece within the entire complexity of dentistry in cleft patients. I am just one step that is necessary to be able to continue the entire treatment, to improve the aesthetic and functional part of mastication.* (Dental surgeon)

> *What can have a positive impact are the connections, these interventions, mediations that we do with the entire public and private network, to provide rehabilitation for them.* (Social worker)

DISCUSSION

The multidisciplinary care provided to children with cleft lip and palate and their families is complex and relies on the collaboration and shared responsibility of all involved. Cleft lip and palate, as in other craniofacial anomalies, requires specialized treatment, with coordination between different expertise in search of better outcomes, centered on the individual and family[15].

This study demonstrates that the multidisciplinary team may not have received adequate training in the courses they took, and that its members did not have professional experience when they entered the respective service. This context points to the need for improvement in the curriculum of educational institutions concerning the care of children with cleft lip and palate, as despite its high incidence, this malformation is still insufficiently discussed during professional training[16–17]. A study conducted in Norway corroborates these findings and highlights the need to promote the approach to the topic and internships to enhance clinical practices even during undergraduate studies[16].

Furthermore, training and practice within the Unified Health System (*Sistema Único de Saúde* – SUS) need to keep up with changes in the population's epidemiological profile, as well as adopt strategies that enhance comprehensive care and collaborative practice among the various health areas. Therefore, there is a need for interprofessional and multiprofessional training that allows for the integration of actions, teamwork, and quality of care[17].

With trained and active professionals providing care in this area, it is possible to start follow-up during pregnancy, which can allow for a flow of care as parents discover the malformation, as well as establishing a relationship of trust between them[10,18]. Moreover, it is important for the healthcare team to approach the family with **dignity** and **respect**, as per the FCC assumptions, which advocate that perspectives, knowledge, values and beliefs need to be respected and included in the care plan, and that professionals must recognize that both have the knowledge to contribute to care[10]. Frequently, surgical interventions and care that are part of the treatment of clefts occur in the early years of the child's life, except in more complex cases[18].

From the initial care provided to the child with cleft lip and palate, it becomes evident that including families in the therapeutic plan is necessary, since the family is a central element in the child's life. This initiative is essential so that they can act as allies in the children's rehabilitation process, assuming the role of caregivers, and having their doubts and concerns addressed by professionals. Involving the family into the treatment increases patient satisfaction, quality of life and safety, improving clinical effectiveness and also reducing the burden on professionals[10,19–20].

The FCC, which has benefits recognized worldwide, is still viewed with resistance by some professionals. However, it is what allows both the family and the patients to collaborate in making treatment decisions, known as shared decision-making. By involving the family in the treatment, the multiprofessional team embraces the FCC principle of **participation**, which involves encouraging and supporting the patient and their family to participate in the care and decision-making regarding the treatment, allowing the family to feel empowered in the face of the situation[10,19–20].

Although the FCC model is relevant, the commitment and shared responsibility of the family for the child's care is essential and represents a significant barrier to successful rehabilitation. This is because cleft lip and palate, like other chronic health conditions, requires continuous care and availability by the family, due to the high number of appointments throughout the child's childhood. The need to dedicate oneself fully to the child's care can cause many parents to stop working, which can impact the family's financial situation. All of these issues alter the routine of the groups, resulting in an overload and fatigue of the caregivers, which can directly influence the family's quality of life, their commitment and attendance at appointments[19,21–22].

The bullying/stigma/prejudice suffered by children, especially in the school environment, were situations mentioned by professionals due to the impairment and changes that the cleft lip and palate causes, especially to the appearance of the nose, lips and teeth, as well as speech and sometimes hearing. The school, while being a social environment for discussing various issues, is also a place of provocations and dissemination of hate. All of these situations have an impact on children's mental health, causing trauma that will be experienced throughout adulthood[23]. A study conducted by the Department of Oral and Maxillofacial Surgery/Oral Pathology in Amsterdam found that in India, Nigeria, Uganda, Zimbabwe, and Ghana, children with orofacial clefts were isolated, stigmatized, and did not receive treatment. They were also rejected by their parents, who often felt ashamed of their children due to their health conditions[24]. In this sense, the multidisciplinary team plays a key role in the rehabilitation of children, supporting them in the process of acceptance and integration into society[23].

Given this reality, from the perspective of the multidisciplinary team, the professionals observed how families reframe

cleft palate and transmit these concepts to their children. The lens used by the family to view/experience the health-disease process can influence the child's perception of themselves, their role as an individual with a chronic condition, and who needs to live socially, as the child is the one most affected by stress and coping mechanisms of their family[10,25–26].

In this regard, overprotection is a common issue among families of children with cleft lip and palate and other malformations as a way of avoiding their child's suffering. By excessively protecting the child from situations perceived as **threats**, families limit the child's possibilities for developing tools and skills. A study conducted in the United Kingdom identified maternal and family situations related to behavioral problems and quality of life in children with cleft lip and palate[23]. Overprotection needs to be addressed with families from the first appointments, strengthening their choices with **dignity** and **respect**, according to the FCC, and ensuring a welcoming and safe family environment that does not minimize the child's potential[10,23].

Cleft lip and palate treatment should occur in specialized centers with the support of associations that have professionals trained to provide care. Therefore, it is necessary to include children with cleft lip and palate in health care, education and the community in general[16,27].

Due to the need for specialized treatment to correct cleft lip and palate, investments are unavoidable throughout the therapeutic itinerary. In this sense, family income is an obstacle to the success of treatment, since many families do not have sufficient financial resources to travel to rehabilitation centers and acquire the necessary materials. A qualitative study conducted in New York with professionals including surgeons, speech therapists, orthodontists, managers and nurses representing non-governmental organizations, hospitals, hospital groups and private clinics, identified that patients with cleft lip and palate living in Asia, Europe and Africa have difficulties and financial restrictions in seeking treatment, due to the costs of traveling to treatment centers[15]. The FCC allows professionals to collaborate in the development and implementation of policies and practices that provide financial and emotional support to these families[10].

Although health professionals try to include children with cleft lip and palate in other points of the care network, effective communication between professionals in the institutions is a challenge, as at other levels of care, health teams are unprepared to provide care, or are unaware of the existing services and resources[14,16]. The consolidation and strengthening of these networks expand the sharing of information, favor the construction of partnerships and help to overcome the challenges faced by individuals in different contexts, especially in managing chronic conditions[17].

Considering that a child with cleft lip and/or palate can compromise the psychological well-being of parents due to concerns, doubts and anxieties regarding treatment, it is of utmost importance that the multidisciplinary team be sensitive and offer emotional and informational support to family members, so that they become resilient in facing the treatment, handling the adversities along the way with more tranquility and wisdom[10,28]. Thus, health education and the provision of reliable information to parents of children with cleft lip and/or palate are necessary, as each family unit is different and unique, to raise awareness among families, alleviate anxiety and fear, and empower them in health care and management[10,29].

The members of the studied corpus highlighted the need for the multidisciplinary team to work collaboratively to rehabilitate children with clefts, in addition to providing health guidance to caregivers, contributing to better family functioning. **Information sharing** is one of the premises of the FCC framework, in which healthcare professionals need to communicate and share impartial information with patients and families, in a clear and objective manner, facilitating the flow of information and effective participation in care[10].

With the multidisciplinary team working together and equipping caregivers for home care, patient care can be enhanced, whether in the postoperative period, in nutritional control, or in child rehabilitation. As a result, the ability of families to make assertive decisions in therapeutic management can be strengthened, prompting reflections on their roles and co-responsibility for the health of their children[25].

Regarding the limitation of the study, it is worth highlighting the impossibility of including all professional categories due to the current structure of the service, limited to seven professional classes.

However, despite this limitation, the results of this study have the potential to strengthen multidisciplinary assistance in the care for children with cleft lip and palate and their families by understanding the dynamics of care through a dense and robust reference such as the FCC. Based on the findings, it can be inferred that collaborative care between different health expertise, identifying barriers that may compromise of long-term rehabilitation success, concomitantly with the enhancement of the family group, supported by participation in the decision-making process and shared responsibility for care, are the guiding thread for the transformation and qualification of care for these children.

FINAL CONSIDERATIONS

The multidisciplinary care provided to children with cleft lip and palate and their families is permeated by complex aspects that integrate the care of a child with a malformation. During care, the multidisciplinary team is faced with its own inexperience and the need to consider the specificities of each child to include the family as a unit of care.

Among the barriers, stands out the difficulty in family acceptance and commitment to shared responsibility for care; prejudices and stigmas within the family nucleus and among society, which is permeated by bullying, especially in the school environment; there is a need for collaboration in interprofessional care, with the integration and coordination of the different services of the healthcare and education network.

However, even in this context, the professionals on the team still provide support and assistance to the families of children with cleft lip and palate; health education actions; and can work collaboratively with each other in the service. The findings are directly and indirectly integrated with the specificities necessary for family-centered care that involve participation, dignity, respect, protecting children in the face of adversity and information sharing.

It is reiterated that for holistic and humanized care for children and their families, it is necessary to strengthen and disseminate care practices based on Family-Centered Care framework, which enables shared decision-making, respecting the specificities of each family unit, and valuing the potential and small transformations that occur for the well-being of the family.

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