Cogitare Enfermagem

ORIGINAL ARTICLE

Care for children with orofacial clefts and their families: perspectives of the multidisciplinary team

HIGHLIGHTS

1. Multiprofessional team works in an integrated way in rehabilitation.
2. Professionals value empathy and continuous updating in care.
3. Families prioritize dentistry and speech therapy.
4. There is a need for articulation between health, education and social work.

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ABSTRACT

Objective: To understand the multiprofessional team's perspective on the care of children with orofacial clefts and their families. **Method:** Qualitative study involving 12 professionals from the multidisciplinary team of an association supporting individuals with orofacial clefts, conducted through individual semi-structured interviews between February and April 2024. The data were transcribed and subjected to thematic content analysis. **Results:** Three categories emerged: the role of professionals in care, the competencies and responsibilities of professionals, and the inclusion (or exclusion) of the child in care networks. It was observed that professionals recognize the importance of a multidisciplinary approach and of seeking professional development; however, patient referral and counter-referral processes are deficient. **Final Considerations:** The study highlighted the importance of integrated team efforts in the rehabilitation of children with orofacial clefts and their families. It underscores the need for public policies and effective coordination among health, education, and social services.

DESCRIPTORS: Child; Cleft Palate; Cleft Lip; Patient Care Team; Family.

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INTRODUCTION

Orofacial cleft is a common malformation, with a global incidence of one in 1,000 to 1,500 live births[1-2]. In Brazil, the incidence is one in every 650 live births[3]. This condition may or may not be related to syndromes and genetic abnormalities, and it affects facial structures to varying degrees, involving the lip, alveolar ridge, and/or palate[1]. Its cause is not clearly defined, but genetic predisposition and environmental factors may be involved[2].

In Brazil, Senate Bill No. 385 of 2018 aims to ensure treatment and rehabilitation through the Brazilian Unified Health System (SUS) in a decentralized manner, with at least one accredited center in each state[4]. This initiative is in line with the National Policy for Comprehensive Child Health Care (PNAISC), which guides comprehensive and continuous health care efforts[5]. In the state of Paraná, the Center for Comprehensive Care of Cleft Lip and Palate (CAIF) provides free care to patients with craniofacial deformities from across the state[6].

Due to functional, aesthetic, and psychosocial changes, children with cleft lip and/or palate require complex care and should be treated by a multidisciplinary team, including specialists in plastic surgery, oral and maxillofacial surgery, dentistry, orthodontics, nutrition, speech-language pathology, social work, psychology, education, and nursing[7].

Primary surgery to correct a cleft lip is performed around three to six months of age, while cleft palate repair takes place between 12 and 18 months of age. Although treatment is tailored to each patient's specific condition, it is known that additional surgical procedures may be necessary well into adulthood[8].

In addition to the challenges that orofacial clefts pose for affected children, family members and caregivers also suffer throughout the entire journey, from diagnosis through treatment and rehabilitation. The family may experience social isolation, stress, suffering, distress, and overwhelming burdens, as well as financial hardship, all of which will affect the child's quality of life and the family-child relationship. Thus, a multidisciplinary team is essential to address all the needs of the child and their family throughout the process[7,9].

In this regard, the study is justified by the need to understand the multidisciplinary care provided to children with orofacial clefts and their families, recognizing the importance of each professional discipline in the rehabilitation process[7]. Furthermore, there is a scarcity of studies addressing the specific contributions of the different professional fields that make up the teams responsible for this care[10]. Given this, the study aims to understand the multiprofessional team's perspective on the care provided to children with orofacial clefts and their families.

METHOD

A qualitative and descriptive study, the description of which is based on the guidelines of the *Consolidated Criteria for Reporting Qualitative Research* (COREQ)[11], which used the PNAISC as its conceptual basis. The PNAISC was established in 2015 and sets forth guidelines aimed at promoting, protecting, and restoring children's health through comprehensive and continuous actions at different levels of health care[5]. The PNAISC informed the interpretation of findings related to comprehensive care for children and their families.

The study was conducted at a nonprofit support association located in northwestern Paraná, Brazil, which serves as a referral center for 80 municipalities in the multidisciplinary care of children and adolescents with orofacial clefts and their families. The institution

provides care through the Brazilian Unified Health System (SUS), functioning as a specialized service within the Health Care Network. Patients gain access through referrals from the public or private healthcare systems, or by walking in. Data were collected between February and April 2024.

The study's target population consisted of 12 professionals from the multidisciplinary team who work with children with orofacial clefts and their families. The following eligibility criteria were adopted: being a health or education professional, being a member of the multidisciplinary team, and having worked at the institution for at least three months. Professionals who were on leave from their duties during the data collection period were not included.

Sampling was based on convenience, and authorization to conduct the study was requested from the department coordinator to identify and include participants. The professionals were approached in person at their workplace by the principal investigator (a nurse and master's student in nursing), who has been participating in a research project at the institution for two years but has no professional relationship with the participants. Given the number of professionals working on the institution's multidisciplinary team, all professionals were included in the study. No one refused to participate in the study.

Participants were briefed on the study's objectives, its methodology, and the researcher's experience with this type of data collection. The semi-structured interviews were conducted in person, individually, and in a private room, once with each participant, with only the researcher and the interviewee present. No pilot study was conducted.

A script was used with the following guiding question: "Tell me how your professional field supports children with clefts and their families," along with supplementary questions such as: "How are follow-up visits for the children conducted at the clinic? How often do these visits take place? Are children referred among team members? What kind of care has been provided to the children and their families? What challenges or barriers are identified during these follow-ups? And how can your profession impact these children's rehabilitation and recovery process?" A questionnaire covering sociodemographic and professional variables was also used. The semi-structured interview guide was reviewed by nurses, master's degree holders, and PhDs affiliated with the research group focused on child, adolescent, and family health.

The interviews were audio-recorded with the participants' consent and conducted by the first author, who has experience in qualitative research; they lasted an average of fifteen minutes. Field notes were also taken during the interviews, which aided in the interpretation of the data. Data collection was concluded after all eligible professionals had participated. The interviews were transcribed in full, and to ensure reliability and validity, printed copies were provided to the participants so they could read, review, and subsequently approve the interview and its content, with the option to add, delete, or clarify any aspect. No participant made any changes.

Subsequently, thematic content analysis was employed, carried out in three phases: a) pre-analysis: review of all material to identify the central idea; thus, the material was prepared and organized, followed by data coding; b) exploration of the material: the raw data were aggregated into units of meaning (excerpts from the statements), facilitating the characterization of the content and organizing them into clusters of meaning; and c) categorization of the data: content with similar meanings was regrouped, and inferences and interpretations were made[12]. No *software* was used as an auxiliary tool in the analysis process.

In accordance with the guidelines set forth in Resolution No. 466/12 of the National Health Council/Ministry of Health, the study was approved by the Standing Committee on Ethics in Research Involving Human Subjects under Opinion No. 4.095.950/2020.

Participants were identified by their professional category in order to preserve their anonymity.

RESULTS

Of the 12 participants, two are psychologists, one is a pedagogue, one is a speech-language pathologist, one is a teacher, one is a social worker, one is a nutritionist, one is a pediatric dentist, two are orthodontists, one is a periodontist, and one is an oral and maxillofacial surgeon. The oral and maxillofacial surgeon and the periodontist are volunteers, while the other professionals are employed. According to the demographic profile, 11 participants are female, ranging in age from 28 to 62 years.

Based on the content analysis, three categories were identified: *The role of professionals in the care of children with orofacial clefts and their families*; *Competencies and responsibilities of professionals in the rehabilitation of children*; *Inclusion (or exclusion) of children with clefts in healthcare networks.*

The Role of Professionals in the Care of Children with Orofacial Clefts and Their Families

During consultations with children with orofacial clefts and their families, professionals address various needs related to the rehabilitation process, such as feeding difficulties, dental issues, and emotional challenges. In addition, guidance is provided on caring for the child: before and after surgical procedures, speech therapy, access to health services, and support for coping with physical, emotional, social, and educational challenges.

We provide educational support, seeking to address these challenges. We try to help them integrate into school so they can have as pleasant an experience as possible alongside their peers. We help them understand that everyone has their own unique qualities and differences (Pedagogue)

The main focus is guidance and referral. We fill out the family's registration information. We address all three areas—social work is part of education, health care, and social services (Social Worker)

Psychology addresses the emotional aspect, both in issues directly related to the cleft and in those involving the patients' mental health. And we provide support to the family (Clinical Psychologist)

We receive the baby; my role is to explain the cleft and also assist with feeding until surgery. After surgery, I provide guidance on how to care for the baby. And after two years, the focus shifts to more intensive speech stimulation (Speech-Language Pathologist)

Orthodontics is very helpful because patients with cleft palates are born with an abnormal dental arch. Our specialty involves expanding the arch to prepare for the graft and provides comprehensive care throughout the transition from baby teeth to permanent teeth. Many cases require orthognathic surgery, so we are also the ones who prepare the patient for that. Our field is one of the cornerstones of cleft palate treatment (Orthodontist 1)

Even though a multidisciplinary team is needed to address all the needs involved in the rehabilitation of children with orofacial clefts, family members and patients often prioritize certain types of care over others.

In rehabilitation, they focus a lot on the dentist and the speech therapist, because those are the main ones—it's what keeps you from getting a job, it's what makes you "ugly," in quotes, because you feel ugly. Among other things, that's always the parents' priority. My work is like that of an ant—talking, explaining the therapeutic process (Psychologist providing follow-up care)

The problem with clefts is that they fall more under the purview of oral and maxillofacial surgery, which is already a form of reconstruction. And we observe that they're very concerned with bone reconstruction, while the gum area tends to be somewhat neglected (Periodontist)

However, the multidisciplinary team meets regularly to discuss and explore the best courses of action, including case studies as part of our routine consultations.

We try to stay in constant communication with one another. When a more complicated case arises—one that requires closer attention and demands more from the entire team—we sit down and conduct a case study on that child (Pedagogue)

If not weekly, then every two weeks, or as the need arises, we identify which professionals are involved and conduct a case study (Social Worker)

We always try to hold a meeting and conduct a case study (Psychologist for follow-up)

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We always try to hold a meeting and conduct a case study (teacher)

Overall, it is evident that professionals provide the best possible care for children with orofacial clefts and their families, and that the entire multidisciplinary team is committed to meeting the needs involved in the rehabilitation process.

Skills and Responsibilities of Professionals in the Rehabilitation of Children

From the professionals' perspective, certain skills are necessary to work with children with orofacial clefts and their families. Among these skills, patience in dealing with people and empathy for others' feelings and experiences stand out.

Patience. I think that, generally speaking, anyone working in healthcare needs a lot of patience. You need to be a very attentive listener and have a very critical eye. You need to keep a close eye not only on the patient and the cleft, but on everything involved—where they were born, how they're doing, their cultural background, and the dynamics of their family (Psychologist providing follow-up care)

Beyond the technical aspects, we have to have that empathetic perspective. It's difficult—we see that every family receives the news and deals with it differently. Here we work with people who have a serious, often limiting problem—school-age children who are bullied because of a crooked tooth or a different way of speaking. We have to have an open heart, be loving and understanding, and do our work the best way possible (Orthodontist 1)

To have a holistic perspective, to understand that they have unique characteristics. To pay close attention to those unique characteristics, and also to be careful not to diminish them or reduce them to just that (Teacher)

You have to have dedication, empathy, and a long-term vision (Orthodontist 2)

Another essential skill for performing this role is the pursuit of knowledge and professional development, to ensure that care is provided in a qualified manner through accurate and up-to-date guidelines.

Especially when it comes to understanding the World Health Organization's growth charts and knowing the correct terminology to use. And a lot has changed recently regarding children's nutrition—we always have to stay up to date (Nutritionist)

At the very least, you need a specialization or a residency to better serve this population. Otherwise, you're too limited to what you learned in college. And since we see many gum lesions, it's also helpful to have knowledge in the field of stomatology, because you need to understand the difference between healthy gum tissue and gum tissue that already has an oral lesion (Periodontist)

Really understanding fissures—the muscles involved in this failed fusion (Speech-Language Pathologist)

Professionals need to stay up to date in their field, as treatment protocols are updated periodically. Participants viewed courses, reading scientific articles, attending conferences, and the internet as valuable resources in their search for information.

Whenever courses become available—usually online—from psychologists who work with children, such as specialization courses or training programs involving children, I'm always on the lookout. I try to read a lot of published articles, or even theses (Clinical Psychologist)

We take continuing education courses in our specialty, and we also keep up with trends within the field itself. The internet today is a good source of information (Orthodontist 1)

I took advanced training courses, completed my residency, and today social media really helps you stay up to date. Today, I think the greatest resource is scientific articles (Periodontist)

Reading articles, and occasionally attending conferences focused on the topic (Orthodontist 2)

However, the lack of up-to-date materials that integrate orofacial clefts with their respective fields of practice is a challenge faced by professionals.

It's not very easy [to find these materials]. In terms of learning, yes, but when it comes to clefts, it's really difficult (Pedagogue)

When it comes to psychology and cleft conditions, it's more difficult; I end up reading from other fields and absorbing what makes sense (Clinical Psychologist)

As for patients with cleft conditions, I honestly have never seen a course focused on cleft surgery (Dental Surgeon)

It is noteworthy that professionals who care for children with cleft lip and/or palate recognize the need for empathetic treatment and care for patients and their families. Furthermore, continuing education and training for these professionals are essential; however, this malformation is still rarely discussed.

Inclusion (or Exclusion) of Children with Cleft Palates in Care Networks

Although the treatment of orofacial clefts takes place in specialized centers, there is a need for referrals and counter-referrals to other care providers, whether in the health, education, or social services sectors. However, this coordination does not occur effectively, and those involved lack commitment.

My face already says it all—you can't see it in the audio. I'm very disappointed. Unfortunately, as I say, this exists only in theory and not in practice. It's so hard to build a sense of partnership. There's no one willing to help. I'm very frustrated with this situation. Where's the networking? You try to contact the Basic Health Unit (UBS, acronym in Portuguese) or the Department of Health, but no one knows anything; then you ask to be put in touch with the ombudsman's office, and no one can connect you (Social Worker)

Even though I have contacts, I don't have a place where I can refer the patient to a clinical network—for example, I don't have a support network. The entry point to the SUS is the health clinic, even though I make the referral to the clinic, because you have to go through a doctor to see a psychologist. I don't have that kind of network, and it's not for lack of trying (Psychologist providing follow-up care)

Even the SUS here doesn't have a doctor who specializes in cleft conditions. The only one who can issue the medical report is the doctor in Curitiba. We realize that our healthcare system here—and in other regions—is very flawed in this regard. The only thing we've found that really works is requesting infant formula (Nutritionist)

Furthermore, some professionals do not make referrals outside the institution and are unaware of how this coordination between services takes place.

I can't say. I know the social worker is always in contact with the network and other departments, but I personally have never sought it out (Clinical Psychologist)

I'll have to get back to you on that—I don't know. Since I'm in the middle of the process, patients are already screened. I think social services is the department that handles this the most (Orthodontist 1)

I can't answer that, because, at least on my end, I never refer patients to another facility-everything is handled right here (Dental Surgeon)

For some employees at the institution, high turnover and a lack of training among network staff are reasons for the lack of interaction between different locations in the network, since many are unaware of their roles.

It's hard when you lose a point of contact - someone you were already used to talking to. Staff turnover is constant; just when someone starts to get the hang of things, they're already gone. Then there are people higher up who admit there's a lack of training; they don't properly train these professionals - they're just thrown in at the deep end, expected to learn on the job (Social Worker)

Caring for these children and their families requires greater engagement and coordination among various sectors of the community, such as health care, education, and social service agencies. All professionals have a role to play in assisting these families, whether through direct care or referrals; however, many of them are ill-prepared, with high staff turnover being one of the reasons.

DISCUSSION

Understanding the multidisciplinary care provided to children with orofacial clefts and their families helps us appreciate the importance of different professionals in rehabilitation and long-term follow-up. Interventions aimed at caring for children with clefts must ensure continuous, high-quality care - not limited to the series of recommended surgeries - and require a well-prepared multidisciplinary team to minimize the harm caused by this malformation[10]. In this regard, the PNAISC reinforces the need for comprehensive care that integrates the physical, psychological, and social aspects of these children's lives[5]. The findings of this study demonstrate that professionals recognize the complexity of care for children with orofacial clefts, which also encompasses emotional, social, and educational needs. This perspective also aligns with the Sustainable Development Goals (SDGs), particularly SDG 3 on health and well-being, by highlighting the importance of comprehensive, continuous, and multidisciplinary care for children with orofacial clefts and their families[13].

Families of children with orofacial clefts are exposed to various stressors that go far beyond everyday tasks; they must cope with emotions stemming from the impact of the malformation diagnosis and the rehabilitation process, which requires support networks[14–16].

To alleviate the suffering experienced by family members and children, qualified and effective multidisciplinary care is essential throughout the entire rehabilitation process[13]. The rehabilitation of these patients is only possible by following protocols and through the commitment of each professional to ensure that the desired outcome is achieved[17].

However, the family's limited understanding of the treatment leads them to prioritize certain professional areas over others, such as speech-language therapy and dental care. This situation affects how the family follows the recommendations of other team members, as well as the frequency with which they attend appointments[13]. In this regard, the PNAISC emphasizes the family's autonomy and shared responsibility in the child's care, through the active participation of family members to ensure that treatment is even more effective[5].

Interaction and dialogue among team members are essential for planning individualized care plans. A survey conducted with teams providing care for children with orofacial clefts, approved by the American Cleft Palate-Craniofacial Association, aligns with the findings of this study, highlighting that professionals routinely discuss the findings of each case, whether in meetings, case studies, or through written or oral communication[18]. In the present study, it was observed that this coordination occurs both through meetings and case studies and informally during routine care, which strengthens shared decision-making.

The professionals interviewed believe in the importance of empathy and patience with families and children to make care more humane. This behavior is important in all settings, especially when caring for family members of children with chronic conditions, given the difficulties they face daily; it is up to professionals to adopt an approach that promotes comfort, without judging each individual's experience, and that fosters the formation of bonds between the parties[19-20].

It is essential that all professionals seek to stay up to date on the care of this population so that they can provide appropriate guidance to family members. To this end, professionals can employ various strategies, such as technology, the internet, and the use of scientific materials, conferences, and lectures[20]. However, up-to-date materials addressing this topic are still scarce, and the quality of the information remains questionable[21]. Although workforce training is one of the guidelines of the PNAISC, it

remains inadequate in the care of children with orofacial clefts, as professionals still face barriers to continuing education[5].

The treatment and rehabilitation of children with orofacial clefts take place in specialized centers, staffed by a team trained to provide this care. However, there is a need for intersectoral coordination with other health and education care centers. This referral and counter-referral process often does not occur, leading to delays in treatment and a deviation from the guidelines proposed in the PNAISC, which addresses the coordination of networked services to provide coordinated and integrated care[5]. These weaknesses also highlight challenges related to reducing inequalities in access to specialized care, in line with the SDGs, especially SDG 10[13].

It is essential to implement public policies that comprehensively serve children with orofacial clefts and their families[22]. Staff turnover can impact the quality of services if proper training is not provided[23]. In this context, the participants in this study pointed out that the frequent turnover of professionals within the network's services hinders the formation of bonds, thereby undermining the longitudinal follow-up of children and families.

The study has limitations related to its design and the fact that it was conducted in a single facility with a limited number of participants, which may limit the generalizability of the findings to other care settings. Nevertheless, the results provide insight into the practices of healthcare professionals and allow for reflection on gaps in the care provided to children and their families, as well as on the functioning of healthcare, education, and social service networks. Further research is suggested to explore multiprofessional collaboration in other contexts and at other levels of health care.

FINAL CONSIDERATIONS

This study provided insight into the importance of the roles played by various professionals in the rehabilitation of children with orofacial clefts and their families. These professionals work as part of a multidisciplinary team, addressing the physical, emotional, social, educational, and rehabilitation needs of this population.

To ensure that care is provided effectively, professionals work in an integrated and dialogue-based manner, while also dedicating themselves to their work through training and continuing education, thereby honing skills such as patience and empathy. The need for integrated action among health, education, and social assistance services is reiterated, along with the need for effective referral and counter-referral between these services; the implementation of targeted public policies is one way to contribute to improving this situation.

Furthermore, strengthening coordination among health, education, and social assistance services can help promote equity in care and contribute to achieving the Sustainable Development Goals related to health and the reduction of inequalities.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Mori MM, Piran CMG, Cargnin AVE, Martins LM, Marcon SS, Furtado MD.** Drafting the work or revising it critically for important intellectual content - **Mori MM, Piran CMG, Cargnin AVE, Martins LM, Marcon SS, Furtado MD.** Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Mori MM, Piran CMG, Cargnin AVE, Martins LM, Marcon SS, Furtado MD.** All authors approved the final version of the text.

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