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Original article

Mothers' experience on the therapeutic itinerary of children with orofacial cleft: a clinical-qualitative study

Experiência de mães sobre o itinerário terapêutico de crianças com fissura orofacial: um estudo clínico-qualitativo

Experiencia de las madres en el itinerario terapéutico de niños con fisura orofacial: un estudio clínico-cualitativo

Camila Moraes Garollo Piran[I], Maricy Morbin Torres[I], Mariana Martire Mori[I], Allana Martins Vitorino[I], Cremilde Aparecida Trindade Radovanovic[I], Rodrigo Almeida Bastos[II], Sonia Silva Marcon[I], Marcela Demitto Furtado[I]

[I] Universidade Estadual de Maringá, Maringá, Paraná, Brazil
[II] Universidade de São Paulo, São Paulo, São Paulo, Brazil

Abstract

Objective: to understand the experiences of mothers of children with orofacial cleft during the search for health care in the context of the Unified Health System. **Method:** qualitative study, based on the clinical-qualitative method grounded on family resilience from a systemic perspective. Mothers of children with orofacial clefts attended at an institution in southern Brazil participated. Data collection took place in August 2023, through semi-structured interviews. The narratives were submitted to qualitative content analysis. **Results:** eight mothers participated, with the construction of two categories that emerged from the data: the trajectory in the face of the diagnosis of cleft and the construction of resilience and the challenges and resilience of mothers in the therapeutic itinerary of children with orofacial cleft. **Conclusion:** the mothers revealed challenges in the therapeutic itinerary of children with orofacial clefts. Family resilience favored coping with adversity, subsidizing health practices more aligned with the principles of the Unified Health System.
Descriptors: Health Services Accessibility; Cleft Lip; Cleft Palate; Therapeutic Itinerary; Mothers

Resumo

Objetivo: compreender as experiências de mães de crianças com fissura orofacial durante a busca pelo cuidado de saúde no contexto do Sistema Único de Saúde. **Método:** estudo qualitativo, pautado no método clínico-qualitativo, fundamentado na resiliência familiar na perspectiva sistêmica. Participaram mães de crianças com fissura orofacial atendidas em instituição no Sul do Brasil. A coleta ocorreu em agosto de 2023, por meio de entrevistas semiestruturadas. As narrativas foram submetidas à análise qualitativa de conteúdo. **Resultados:** participaram oito mães, com a construção de duas categorias que emergiram dos

dados: *a trajetória diante do diagnóstico da fissura e* a *construção da resiliência* e *os desafios e a resiliência de mães no itinerário terapêutico de filhos com fissura orofacial*. **Conclusão:** as mães revelaram desafios no itinerário terapêutico de crianças com fissura orofacial. A resiliência familiar favoreceu o enfrentamento das adversidades, subsidiando práticas de saúde mais alinhadas aos princípios do Sistema Único de Saúde.
Descritores: Acessibilidade aos Serviços de Saúde; Fenda Labial; Fissura Palatina; Itinerário Terapêutico; Mães

Resumen

Objetivo: comprender las experiencias de las madres de niños con fisura orofacial durante la búsqueda del cuidado de la salud en el contexto del Sistema Único de Salud. **Método**: estudio cualitativo, basado en el método clínico-cualitativo y fundamentado en la resiliencia familiar desde una perspectiva sistémica. Participaron madres de niños con fisura orofacial atendidos en un centro del sur de Brasil. La recopilación de datos se llevó a cabo en agosto de 2023, mediante entrevistas semiestructuradas. Los relatos se sometieron a un análisis cualitativo de contenido. **Resultados**: participaron ocho madres, y se identificaron dos categorías que surgieron de los datos: la trayectoria ante el diagnóstico de la fisura y el desarrollo de la resiliencia, y los retos y la resiliencia de las madres en el itinerario terapéutico de sus hijos con fisura orofacial. **Conclusión**: las madres revelaron los retos que planteaba el itinerario terapéutico de los niños con fisura orofacial. La resiliencia familiar facilitó la superación de las adversidades, propiciando prácticas sanitarias más acordes con los principios del Sistema Único de Salud.
Descriptores: Accesibilidad a los Servicios de Salud; Labio Leporino; Fisura del Paladar; Ruta Terapéutica; Madres

Introduction

Orofacial clefts, including cleft lip, cleft palate, and/or cleft lip and palate, are congenital anomalies of multifactorial etiology that affect the human face and can vary in complexity. [1] A study conducted in China found a prevalence of orofacial clefts of 7.55 per 10,000 live births, with cleft lip at 2.34 per 10,000, cleft palate at 2.22 per 10,000, and cleft lip and palate at 2.98 per 10,000. [2] In Brazil, the prevalence is 52 per 100,000 births, corresponding to 1 per 1,924 newborns, with clefts associated with preterm birth, low birth weight, and male sex.[3]

In Brazil, the Reference Network for the Treatment of Craniofacial Deformities (RRTDCF,in Portuguese) aims to organize the provision of services and reduce inequities in access to the Unified Health System (SUS). Therefore, it is considered important to establish intersectoral coordination, incorporating effective public policies that can combat poverty and inequality, providing equal access to treatment, and improving the health and living conditions of these patients and their families.[4]

Children with orofacial clefts have specific treatment needs and require a multidisciplinary team to provide care, including surgeons, dental surgeons, nurses, and psychologists. To access personalized care, it is necessary to seek treatment at specialized centers.[5] Given this, strategies are needed to minimize the suffering of these families—especially mothers, who are primarily responsible for care and follow-up—through peer support, hope, and social support.[6-7]

That said, both healthcare professionals and services must support mothers in coping with orofacial clefts, so that the child's healthcare journey is managed effectively, directing them to specialized services. The healthcare-seeking process refers to the therapeutic pathway and seeks to describe the steps taken with the goal of resolving health problems. Furthermore, this pathway is not limited to the availability of services but also considers different personal characteristics and individual needs.[8-9]

In light of the above, there is concern regarding the experiences of mothers of children with orofacial clefts as they seek health care, as well as the increasing prevalence of newborns with this type of malformation.[10] The available literature indicates that qualitative research is still in its early stages when it comes to providing a state-of-the-art understanding of the treatment journey for children with orofacial clefts and, more specifically, the mothers' experiences during this care process. It is also worth noting that many studies focus on investigating the factors associated with clefts.[11-12]

The journey to seek care and everything associated with it can influence the physical, emotional, and social health of children with orofacial clefts, in addition to significantly affecting maternal well-being.[12] Resilience enables the mothers of these children to reorganize themselves to overcome such difficulties, despite experiencing adverse situations. The process of resilience is interactive and synergistic, in which the creation of shared meaning develops through communication; therefore, family functioning can become effective in coping with adverse conditions.[13] In light of this, identifying the experiences of mothers of children with orofacial clefts—from diagnosis and health care through post-surgical rehabilitation—can highlight the unique nature of the perceived challenges,[8] providing essential insights for improving care.

Thus, the gap to be addressed concerns understanding the therapeutic journey based on the experiences of mothers of children with orofacial clefts. It is these mothers who experience all situations within the care network and maintain relationships with professionals to ensure the best care for their children.

Given this, the objective of this study was to understand the experiences of mothers of children with orofacial clefts as they sought health care within the context of the Unified Health System.

Method

This is a qualitative study based on the Clinical-Qualitative Method (CQM)[14], which utilized the theoretical concept of family resilience,[13] a concept that emphasizes how the family system copes with challenging experiences, reorganizes itself, and overcomes adverse situations. To ensure transparency and completeness of information, the research report is presented in accordance with the criteria of the *Consolidated Criteria for Reporting Qualitative Research* (COREQ) checklist.[15]

The study was conducted at a support association for children with orofacial clefts and their caregivers, located in a municipality in the northwest of the state of Paraná. It is a nonprofit organization that serves patients from the city and neighboring municipalities and has a multidisciplinary team consisting of psychologists, dentists, a nutritionist, a speech-language pathologist, a social worker, an educator, and a teacher. The choice of location was intentional, as this service interacts with different levels of health care.

Eligible participants were mothers of children under five years of age with orofacial clefts who were attending appointments at the support center and who had already undergone some form of surgical procedure. The age range was established because this is a period when children have many health needs, making it easier to recall events. Only mothers aged 18 years or older were included. Those with cognitive impairments that might affect their understanding of the questions were to be excluded; however, there was no need for exclusion or refusal to participate in the study. A pilot test was conducted with two participants, and since no changes to the interview script were deemed necessary, the interviews were included in the final sample.

The study population was defined as mothers who accompanied their children to the selected healthcare facility, met the selection criteria, and agreed to participate after being invited and briefed about the study. In addition, the purposive sample of participants was closed upon data saturation, at which point the researchers observed recurring information, indicating that the data collected were already sufficient to address the study's research objective.[16]

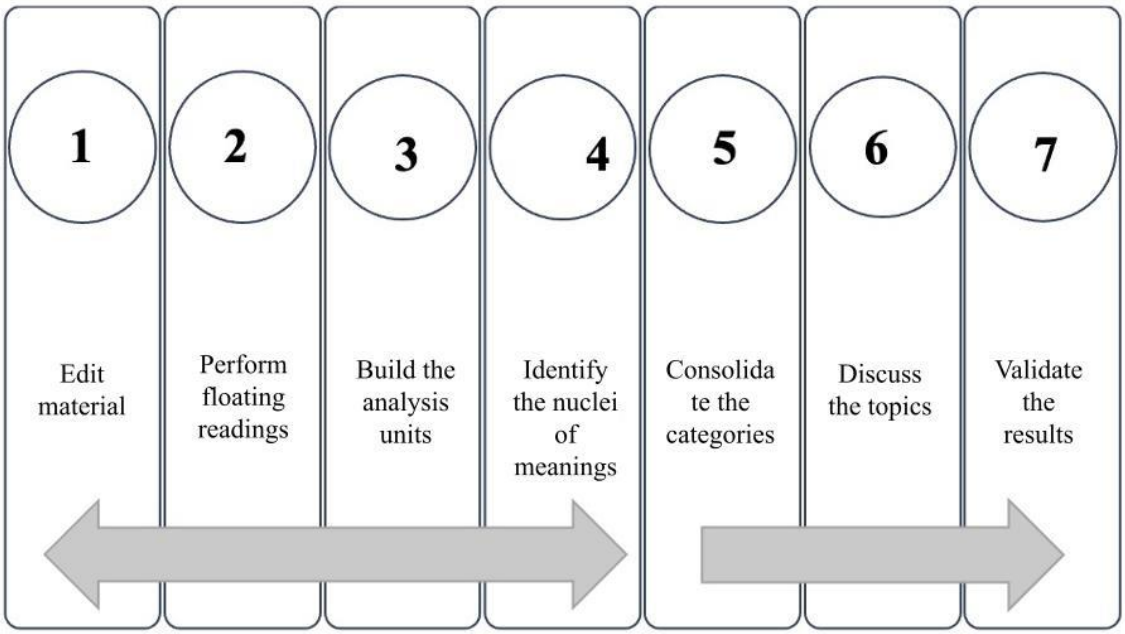
First, the researchers began the familiarization phase—that is, the research team spent some time at the clinic—and conducted acclimatization interviews with the mothers. They also worked with the clinic director to identify all cases of children under five years of age with orofacial clefts who were being treated at that facility, to contact the mothers, and invite them to participate in the study.

The researchers explained the study's objectives and how it would be conducted; thereafter, invitations were extended to the children's mothers in person at the association itself. Upon acceptance, interviews were scheduled according to the mothers' availability and preferences. All interviews were conducted in person, individually, and in a private room by two researchers who had undergone training with a research group specializing in child, adolescent, and family health. The researchers had prior experience with interviews, and both were nurses, enabling them to apply their skills—such as active listening and addressing the mothers' concerns—which are essential attributes for interviews within the CQM and contribute to the validity of the data obtained. Neither researcher had prior contact with the study participants.

That said, the in-depth, semi-structured interviews began through mutual interaction between the interviewer and the interviewee—both of whom were focused on establishing *rapport*—when the following question was posed: "Tell me about your experience seeking health care for your child." Follow-up questions were used to guide the interview, focusing on medical appointments, difficulties, and positive aspects during this care process, and field notes were taken during data collection. Participants were provided with *feedback* on the interviews; however, no interviewee requested changes to their statements. The interviews were conducted once with each participant in August 2023, lasted an average of 25 minutes, and were audio-recorded on digital media. The material was transcribed as the interviews were conducted.

The data were analyzed using Clinical-Qualitative Content Analysis, which consists of seven steps: the collected material was transcribed and organized; the material was read without relying on a theoretical framework; meanings were derived from the statements by selecting specific fragments; a second reading was conducted, and codes were assigned; the material was organized for categorization; the material was reorganized according to the adopted theoretical framework; the validity and reliability of the data were assessed. The analysis flowchart is shown below (Figure 1).[14]

Figure 1 - Flowchart of the qualitative content analysis



Source: Adapted from Faria-Schützer et al., 2021[14]

During the review and validation of the categories, the consistency of the categories and the relationship between each category's title and its respective central ideas were verified.[14] This process was carried out by the two researchers through discussions and consensus-building regarding the interpretation of the findings. Following the "seven steps," the final product yielded two categories of analysis, which were discussed by comparing them with the existing literature[14] and within the interpretive theoretical framework of family resilience from a systemic perspective.[13] No *software* was used as an auxiliary tool in the data analysis process.

The study was conducted in accordance with Resolution 466/2012 of the National Health Council and was approved by the Ethics and Research Committee for Human Subjects, under opinion No. 4,095,950, in June 2020. Participants were presented with the Informed Consent Form, which they signed in duplicate. The participants' statements were identified by the word "mother" and a number corresponding to the sequence of the interview.

Results

Eight mothers participated in the study; they were between 18 and 38 years old, four were married, five had completed high school, and five were homemakers. The children were between one and four years old, and five were male. The clefts ranged from unilateral and bilateral preforaminal clefts to incomplete and complete postforaminal clefts. None of the children in the study had comorbidities.

The Journey Following the Diagnosis of the Cleft and the Development of Resilience

The mothers reported that the diagnosis of the orofacial cleft occurred at different times, ranging from the prenatal period, birth, or the first days of the child's life. This moment was marked by reactions of surprise; even so, they demonstrated resilience and sought support for their children's care.

> *I found out about her cleft during a 3D ultrasound. (Mother 2)*
> *I saw it for the first time and found out about the cleft at birth; I was scared because we weren't expecting it—my blood pressure dropped. [...] I wondered what I should do now and where to take her to get her cared for. (Mother 4)*
> *She had trouble latching on, and then the speech-language pathologist noticed the cleft when she cried. I had seen it, but since I'd never had a baby before, I thought it was just because she was a baby—I could see her little palate was open. (Mother 5)*

The participants' statements showed that the unexpected diagnosis affects the mothers' emotional state, given their feelings of fear and worry. This situation causes emotional distress for the mothers, making it difficult for them to remain resilient as they care for their children.

> *Until I had him, I didn't receive any follow-up care; I just kept thinking, "My God, what am I going to do now? I have a child with a cleft lip and palate!" I was so worried. (Mother 1)*
> *She was all swollen, with her little mouth wide open—it was a huge shock. (Mother 4)*
> *I didn't know a person could be born with an open palate! I was in shock when I found out that her cleft was in the palate! (Mother 6)*

One mother expressed feelings of guilt due to her lack of knowledge about the causes of orofacial clefts, which underscores the importance of support in building resilience throughout this journey.

> *But it was a shock because it was my fault, you know? After I came to understand that it's genetic, anything can happen. (Mother 7)*

The testimonials highlight the difficulties experienced when breastfeeding children with orofacial clefts, which often lead to feelings of frustration for the mother.

> *She would nurse just a little; it seemed like she didn't have the strength—the difficulty was with sucking. (Mother 5)*
> *Oh! We always hope she'll be able to breastfeed. [...] Then we found out why she had trouble latching on—it was because of that; her mouth muscles were weak. (Mother 8)*

However, even with the difficulties inherent in the process, the mothers reveal a reframing of their situation, in which, through resilience, they seek to find meaning and see their child beyond the malformation.

> *I even miss that big, wide smile [cleft]. (Mother 2)*
> *Oh, come on, guys! Thank God it's not that bad—some children are born with much more serious conditions! (Mother 5)*
> *In my eyes, he's perfect! There's nothing wrong with him, you know, even though he has a cleft. (Mother 7)*

The Challenges and Resilience of Mothers in the Therapeutic Journey of Their Children with Orofacial Clefts

The journey of mothers seeking care for their children with orofacial clefts begins at the time of diagnosis. Access to specialized services plays an important role in ensuring continuity of care within the SUS system, strengthening family resilience by providing a welcoming environment and support.

> *The follow-up care is excellent, because I receive so much support both here at the Cleft Lip and Palate Support Association and in the capital as well. (Mother 5)*
> *As soon as I found out about his cleft, that same day I mentioned it to a group of friends, and someone said there's a place in town for people with clefts. (Mother 6)*
> *When I left the hospital, they referred me here to the Cleft Lip and Palate Support Association, and this was the place where I felt welcomed. (Mother 7)*

Monitoring the child is a careful process, especially with regard to the weight required for corrective surgery for orofacial clefts. Following these steps underscores the importance of ongoing support, which ensures the safety of the treatment and helps build mothers' confidence throughout their child's treatment journey.

> *When we came here and found out, we learned that the surgery has to be done at a certain time, and the child has to be at a certain weight. When she had her surgery, she weighed a little over 4 kg—4.5 kg—so she was at the right weight; she was already ready for surgery, but we just waited a few more days. (Mother 4)*
> *When he was 3 months old, we started going to Curitiba so he could begin follow-up care there in preparation for the surgery. When he was about 6 or 7 months old, they scheduled his surgery; he was gaining weight normally, within the standard range, and then, when he was 1 year old, he had his palate surgery. (Mother 3)*

The surgical rehabilitation process was also described as a delicate one, given that children with orofacial clefts undergo several procedures. Nevertheless, the mothers still highlight the quality of the care and support, as well as the attention they received from healthcare professionals during this phase.

> *My biggest challenge was his surgery; he had surgery on his lip and then to close his palate, but the recovery is very delicate. (Mother 7)*
> *Throughout this journey, I'm grateful that, back in Curitiba, the nurses working behind the scenes at the CAIF—which is our go-to center for cleft conditions there—are excellent. (Mother 6)*
> *The care is very good, provided by a nutritionist, speech-language pathologist, ENT specialist, dentist, surgeon, doctor, and nurse. (Mother 7)*

Given that the facilities in the care network for patients with orofacial clefts are located far from home, patients must travel from their homes to the treatment site. This commute requires time for the round trips to and from healthcare appointments and is tiring for both children and mothers, making it exhausting and creating obstacles to family resilience.

> *The difficulty is that we have to go through several places. (Mother 1)*
> *I'd spend the day there and come back—a round trip. (Mother 4)*
> *But the process is draining, with so many trips back and forth for the professionals to care for him. (Mother 3)*

It is clear that the mother-child pair faces many challenges during the child's health care, including society's curiosity and prejudice, which ultimately have a negative impact on these families' lives and the mothers' well-being.

> *I kept it a secret; I didn't tell anyone. Only my family knew. To other people, I said, "You'll only find out when she's born," because I was already protecting her from the prejudice I knew she would face once she was born. (Mother 2)*
> *Now it's much easier for me; what affects me most is the way people look at me. (Mother 7)*

The testimonies show that the support network provided by other family members is essential for helping caregivers face the challenges of the caregiving process. It is clear that the involvement of other family members in the child's recovery process provides a sense of security for the mothers.

> *Her father takes her, and sometimes my father does. But I always have someone to help me. (Mother 5)*
> *The support network is always the family. [...] It was my husband and me; I went every time with someone accompanying me. (Mother 6)*

However, not all mothers have the privilege of a family support network, and this situation negatively affects their resilience and can lead to caregiving overload.

> *I have to make a decision on my own, which is even harder; whatever they told me there, I have to decide on my own—I don't have anyone with me to give me a second opinion. (Mother 8)*

Mothers maintain a positive outlook on their children's rehabilitation process, which is linked to spirituality through their faith and hope that their children will be well. This optimistic outlook helps ensure continuity of care and enables them to cope with the challenges posed by the condition.

> *Thank God he's in very good health; it's just the cleft. (Mother 1)*
> *He's started treatment and is making progress; thank God, the treatment is working. (Mother 6)*

Discussion

The findings of this study have shed light on the fact that seeking health care for children with orofacial clefts within the SUS is fraught with challenges. In this study, mothers are the primary caregivers accompanying the children, and for each of them, the meaning of motherhood is different. Thus, these women, along with other family members, experience the arrival of a newborn with a congenital anomaly in their own unique way, based on their personal and family experiences.[17]

That said, when an orofacial cleft is diagnosed during pregnancy, it is important to prepare the mother to accept her child, thereby minimizing emotional distress.[17] Thus, prenatal consultations are essential for alleviating the stress associated with the diagnosis.[5] Consequently, the process of resilience influences dynamic processes over time as the family system copes with adversities, such as the stress of the diagnosis.[13] A study conducted in Germany to investigate the psychological burden on parents of children with cleft lip and palate during the first three years of life showed higher levels of psychological stress compared to parents of healthy children.[18]

Some mothers are unaware of their child's orofacial cleft before birth, so the moment of the child's birth is an embarrassing and shocking experience, leading to psychosocial consequences. [19] Given this, prenatal health education for parents about orofacial clefts can help reduce parental anxiety or depression and may improve psychological outcomes once the family actually welcomes the child.[19]

The expectations built up during the pregnancy of the idealized and dreamed-of baby, when confronted with the reality of birth and seeing the actual baby, lead to a rupture of those dreams, causing suffering and invisible scars in those who idealized the baby so much. Thus, support from the healthcare team is necessary to minimize the emotional impact.[17] This helps family members adapt to life with a baby with a cleft lip and palate,[13] while reframing their distress. This does not mean being happy all the time, but rather understanding the real challenges of caring for the child and recognizing their strengths and weaknesses as a family member.

Many mothers, in addition to dealing with accepting their child with a cleft lip and palate, also experience difficulties with breastfeeding. A study conducted in Uganda, which sought to explore mothers' perceptions of breastfeeding their children from birth to 24 months, showed that breastfeeding practices fell short of the ideal due to difficulties in handling the baby, anxiety, and social stigma. Thus, care for the mother-child dyad with a cleft should include timely support.[20]

Given parents' expectations regarding the birth and growth of their child, and faced with the reality of having a child with an orofacial cleft, many reframe this process and become resilient. Thus, it is evident that when families are exposed to stressful situations, they must draw upon the resources that will shape how they respond to these circumstances.[13]

After their child's health condition is diagnosed, they begin to navigate various situations within the healthcare system in search of care. In doing so, they encounter specialized services and/or support groups for patients with orofacial clefts, which often refer them to a specialized center. Care provided by healthcare professionals trained in cleft care has been highly valued and respected by parents. Furthermore, to ensure holistic care, cooperation is needed among teams caring for children with clefts at other pediatric centers, as these teams are responsible for sharing knowledge specific to the care of patients with clefts.[21]

Furthermore, the support provided by healthcare professionals has been a key factor in family resilience when facing adversity, from the time of diagnosis through their child's treatment. Support from outside the family enables families to cope with the crisis by providing instrumental, informational, and emotional support. Thus, the relationship between the family and healthcare professionals allows for successful family empowerment interventions.[13]

Therefore, when professionals are trained in family resilience, they work collaboratively with families. As facilitators and compassionate witnesses, they help families share their hardships and negative feelings with one another and build mutual support to overcome the challenges they face in seeking health care.[13]

The search for and wait for surgery is the families' primary concern, since, in the face of a cleft lip, the location of the deformity and the possibility of aesthetic and functional sequelae cause great distress among mothers as well as other family members.[17] Thus, treatment can lead to functional and aesthetic improvement, as well as social integration; therefore, care provided by a qualified multidisciplinary team has been indispensable.[19]

As noted, children born with clefts require treatment, which is extensive and often lifelong. Consequently, they face certain barriers to quality care before they can reach an orofacial cleft center.[22] Barriers to accessing care—such as long trips, travel distance, and the vulnerability of families—can affect treatment adherence, since these children require long-term, multidisciplinary care.[23]

Furthermore, the mother-child dyad still faces misconceptions and prejudices regarding physical deformities, even when people already have some prior knowledge of the subject. Thus, the community must practice empathy, recognizing families and children with orofacial clefts as members of society.[19]

Faced with so many adversities that arise throughout the journey to seek care, family support becomes indispensable and irreplaceable for emotional and psychological well-being. Even so, there are mothers who lack a support network, and as a result, their difficulties are further exacerbated.[17]

Family resilience is strengthened when family members support one another, collaborating and committing to one another in the face of crises encountered during the search for care. Cohesion and emotional and affective bonds within the family help them confront and overcome crisis situations.[13]

Times of difficulty and adverse events lead families to seek comfort and connect spiritually with their spiritual and religious beliefs. The practice of faith has been considered beneficial during this journey, as it helps families gain greater control over their emotions.[13]

Among the study's limitations, it is worth noting that the research was conducted at a single support association for children with orofacial clefts and their families, which does not have a nursing service. This may limit the generalizability of the findings to other care settings and restrict our understanding of the role of nursing in this care. For

future studies, we suggest conducting broader research that includes the perspectives of health professionals from all three levels of care, in order to expand upon and validate the results.

Regarding the implications for advancing scientific knowledge in the health field, the results pertain to the use of essential elements of resilience in the care process for families with orofacial clefts, assisting health professionals in recognizing and valuing family strengths during the functional (re)organization required to seek care.

Conclusion

Understanding mothers' experiences while seeking health care for children with orofacial clefts, in light of family resilience, allowed us to explore the meanings, perceptions, and attitudes of parents in the face of the complexity and adversities of having a child with an orofacial cleft. Added to this is the issue of how they are treated by healthcare professionals and systems. Despite the challenges, mothers find coping and reorganization strategies that support the continuity of care and family resilience.

Above all, these perceptions shed light on the experiences and difficulties mothers face throughout their journey in seeking health care. That said, the presented results offer the potential to inform health care evaluation practices based on the experiences of mothers who have a child with a chronic condition, thereby enabling the more effective application of the principles of the SUS in health care delivery.

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Authorship contribution

1 – Camila Moraes Garollo Piran
Corresponding author
Nurse, Master – camilagarollo@gmail.com
Research conception and/or development and/or manuscript writing; Review and approval of the final version

2 – Maricy Morbin Torres
Nurse, Doctor – mmtorres@uem.br
Research conception and/or development and/or manuscript writing; Review and approval of the final version

3 – Mariana Martire Mori
Nurse – mari_mmori@hotmail.com
Research conception and/or development and/or manuscript writing; Review and approval of the final version

4 – Allana Martins Vitorino
Nurse – allanamvitorino@hotmail.com
Research conception and/or development and/or manuscript writing; Review and approval of the final version

5 – Cremilde Aparecida Trindade Radovanovic
Nurse, Doctor – catradovanovic@uem.br
Research conception and/or development and/or manuscript writing; Review and approval of the final version

6 – Rodrigo Almeida Bastos
Nurse, Doctor – almeidabastos.rodrigo@gmail.com
Research conception and/or development and/or manuscript writing; Review and approval of the final version

7 – Sonia Silva Marcon
Nurse, Doctor – soniasilva.marcon@gmail.com
Research conception and/or development and/or manuscript writing; Review and approval of the final version

8 – Marcela Demitto Furtado
Nurse, Doctor – mdfurtado@uem.br
Research conception and/or development and/or manuscript writing; Review and approval of the final version

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