Maternal Perception of Breastfeeding in Children with Unilateral Cleft Lip and Palate: A Qualitative Research Work

Ana María Cerón-Zapata (aceron@ces.edu.co)
Universidad CES https://orcid.org/0000-0002-2021-9419
María Cecilia Martínez-Delgado
Universidad Ces
Gloria Emilia Calderón-Higuita
Universidad CES

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Maternal perception of breastfeeding in children with unilateral cleft lip and palate: a qualitative research work

Cerón-Zapata Ana María D.D.S. Pediatric Dentist, Msc Dental Science, Professor Universidad CES. E-mail: aceron@ces.edu.co

Martínez-Delgado Cecilia María D.D.S, Epidemiology Specialist, Msc University Direction. Professor Universidad CES. E-mail: cmariamar@hotmail.com

Calderón-Higuita Gloria Emilia Nutritionist, Human Nutrition Specialist. Breastfeeding certificate consultant. E-mail: gloria.calderon@hotmail.com

Corresponding author:

Address: Calle 10 A # 22-04

Medellín, Colombia, South America

E-mail: aceron@ces.edu.co

ABSTRACT

Background: Unilateral cleft lip and / or palate (UCLP) is one of the most common congenital craniofacial difference. The objective of this study was to describe maternal perception of breastfeeding in children with unilateral cleft lip and palate and to assess the role of breastfeeding counseling. **Methods**: Qualitative descriptive method and phenomenological analysis were used to analyze the narratives. 28 mothers of patients with nonsyndromic UCLP treated with nasoalveolar molding (NAM) between April 2015 and April 2018 were strategically selected and interviewed after NAM treatment. Framework analysis was conducted for qualitative data. The CES University ethical committee approved the study. **Results**: The findings resulted in six main categories: First contact with the CLP program, access to early diagnosis and timely treatment, perceptions of parents about health personnel on breastfeeding of CLP patients, perceptions of mothers toward breastfeeding, perception of advantages and disadvantages of the NAM technique regarding breastfeeding and assessment of the CLP program. The interviewed mothers, both prenatally and postnatally, stated the advantages of initiating the process prenatally. There are still difficulties for reaching a timely diagnosis. Several mothers stated that health professionals and assistants determined the hospitalization, installation of a nasogastric tube or feeding through a baby bottle or syringe, which prevented the first contact between mother and child. Even though the breastfeeding process is difficult for these mothers, they acknowledged its immense advantages. Interviewed mothers considered the use of the NAM advantageous as the obturator allowed a better bottle-feeding process. The program generates satisfaction, motivation, expectations and happiness to the mothers who initiated

this therapy with their children. **Conclusion**: The participants related difficulties with breastfeeding. Mothers acknowledged the clinical results when using the NAM obturator, as well as the support provided by the breastfeeding consultant.

Key Words: perception, experiences, breastfeeding, cleft lip and palate, presurgical orthopedics, nasoalveolar molding.

Background

Cleft lip and/or palate (CLP) is one of the most common congenital craniofacial difference and may produce in these patients' esthetic, functional and emotional disorders [1]. It shows a prevalence of one per 1000 live births [2]. This condition affects the patient and his/her family causing difficulties in emotional and social development [3], feeding [4], breathing and the development of speech [5], occlusion[6] and physical appearance [7]. Therefore, during initial orientation to parents, is important to understand and assume the fact of having a child with CLP can be difficult to cope [3].

Exclusive maternal breastfeeding is the best option to assure that the infant receives the amount of essential nutrients needed for growth and development during the first six months of life [8]. In addition, breast milk is the main choice to prevent adverse health conditions and promote intellectual and language development [9]. One of the complications exhibited by children with CLP is feeding. An inability to create seal around the nipple during breastfeeding has observed which leads to failure to generate enough negative intraoral pressure during suction [10]. This situation could lead to inadequate nutrient intake and could appear growth and development delay of the newborn [11].

Current advances in pre-surgical orthopedic treatment protocols for CLP, including nasoalveolar molding (NAM) obturators, are an alternative for improving the quality of the reparation process, since they actively improve the affected nostril and passively the alveolar segments [12–14]. However, the treatment protocol has observed that breastfeeding still presents difficulties, some of them arising from the perception of mothers, such as discomfort to the infant and the

idea that the child is still hungry [2,11]. Even though research, including quantitative approaches, has focused on the first reactions to the diagnosis and measurement of stress levels during the first years of life [15,16], qualitative investigations that assess the perception of mothers around breastfeeding and CLP are scarce.

Qualitative studies with an exploratory phenomenological approach, look to understand the social phenomena from the perspective of the interviewed person, their experience, their relationships, motivations or intentions, beliefs and the significance of their experiences in a specific situation [17].

Therefore, the purpose of this investigation is to describe maternal perception of breastfeeding in children with unilateral cleft lip and palate and to assess the role of breastfeeding counseling.

Materials and Methods

Institutional approval was obtained from the Ethics Committee of CES University, through minute number 7429 September 29, 2014. All the mothers signed the applicable informed consent before the data collection.

The study was a qualitative study with exploratory phenomenological approach; the researchers tried to understand the perspective of the interviews, their relationships, motivations and the experiences in a specific situation: breastfeeding their children with unilateral cleft lip and palate treated with NAM, after breastfeeding counseling.

Semi-structured interviews applied to 28 mothers of children with non-syndromic unilateral cleft lip and/or palate (UCLP), with prenatal (32%) and postnatal

diagnosis (68%) mothers who consult to receive early orthopedic treatment with NAM in the Clínica Noel Foundation interdisciplinary CLP program in Medellín, Colombia, between April 2015 and April 2018. All mothers were born in Colombia, as different cultures have different attitudes to CLP and the authors wished to focus on issues relating to Colombian culture.

Selection criteria

Mothers of patients between 0 and 2 months of age with either prenatal or postnatal diagnosis of non-syndromic UCLP were included. Mothers who could not attend scheduled periodic appointments were excluding because NAM requires weekly appointments.

Before the interviews, mothers received orientation by a certified international breastfeeding consultant (GECH) using a breastfeeding personal education program. The pediatric dentist (AMCZ) explained the NAM treatment and detailed oral hygiene and diet counseling. Their UCLP´s children received treatment with NAM.

Mothers were divided in two groups. The first group received prenatal information about the process of maternal breastfeeding by an international breastfeeding consultant using a personal education program. Postnatal group received information in the same way by an international breastfeeding consultant using a personal education program, since they were unable to arrive at the CPL program prenatally.

Data collection

Two field worker training sessions covered research ethics, obtained informed consent and data collection, with the strongest focus being on developing

qualitative interview skills. Fieldworkers underwent extensive practice conducting interviews using role-plays and applying the pilot test. Four pilot interviews were carried out before the interviewer could strive to vary the focus of the phenomena under study. During data collection, researchers listened to interviews on an ongoing basis to monitor quality of interview skills, and feedback given to fieldworkers as necessary. The participants were encouraged to describe their feelings and experiences as fully and as deeply as possible. During the interview, they were asking to give examples and to clarify ideas.

The interviews last between 60 to 90 minutes and were digitize and transcript. The preliminary and emerging categories were analyzed in order to compare results.

Baseline data was collect using a structured quantitative questionnaire, which included information about participants' sociodemographic characteristics and their infant feeding plans.

Data analysis

Mothers were requested in-depth interview guides to state whether they planned to feed their baby breastmilk only, formula milk only, or both breast and formula milk.

Two investigators carried out independent data analyses to establish their consistency and reliability. Results were compared and minor variations discussed, reviewed and resolved.

To preserve anonymity, codes were assigned to each participant based on the group. Audio recordings and transcripts were stored at University CES in a

password protected file. In accordance with the methodology, transcripts were code according to preliminary categories. Emerging categories were analyzed in order to compare results and reach conclusions (Table 1).

Information collected reached saturation categories meaning that the information did not reply and did not provide a new topic or intensify it [17].

Analysis of the interview data was based on predetermined research themes (drawn from the interview guide), as well as inductive themes that emerged from the interview data [18]. The data was grouped into analytical categories in order to organize the information, and finally contribute to the writing the findings.

Framework analysis comprised five stages, beginning with a process of familiarization with the transcripts to gain an overview of the content. This was followed by the development of an analytical framework based on identified research questions, as well as on themes that emerged. This framework was then applied to the individual transcripts and data charted into categories based on these identified themes. Finally, a process of mapping and interpretation was undertaken.

Results

Data presented in Table 2 indicates participants' sociodemographic characteristics.

The findings resulted in six main categories: i) first contact with the CLP program; ii) access to early diagnosis and timely treatment; iii) perceptions of parents about health personnel on breastfeeding of CLP patients; iv) perceptions of mothers

toward breastfeeding; v) perception of advantages and disadvantages of the NAM technique regarding breastfeeding and vi) assessment of the CLP program.

First contact with the CLP program

The specialist who detected the anomaly during the second trimester ultrasound referred prenatally diagnosed patients and their parents to the program. The patients who received the diagnosis after birth were referred by friends, family members or the medical staff that worked in the hospital were the patient was born.

The interviewed mothers, both prenatally and postnatally, stated the advantages of initiating the process prenatally: tranquility from the counseling of the interdisciplinary team, psychological support, information about the procedures that the child would endure and better acceptance of the infant's condition by the parents:

> *"I think it was very important because I now assimilate things better, especially the risks and benefits of the whole treatment." [E16]*

> *"We prepared ourselves psychologically so the impact would not be too high, right? That helped us understand the feeding procedure and the process with the obturator." [E27]*

Access to early diagnosis and timely treatment

There are still difficulties for reaching a timely diagnosis, especially for those people who live in rural areas or for pregnant women who access the hospital only at the time of delivery. These factors make early diagnosis difficult.

“I was referred but I had already had the baby.” [E14]

“I was referred here but the baby had already been born, he was around 3 months old.” [E20]

Perceptions of parents about health personnel on breastfeeding of CLP patients

Several mothers stated that health professionals and assistants determined the hospitalization, installation of a nasogastric tube or feeding through a baby bottle or syringe, which prevented the first contact between mother and child.

“The problem with the baby was that he was in the hospital and the process stopped, it was suspended and the baby was fed through a tube.” [E2]

“To be honest, I did not breastfeed her because the cleft was wide open when she was born. She was taken to the ICU, received the tube and was left in the hospital for 10 days. I had missed the opportunity to breastfeed her, I had no milk left.” [E17]

The interviewed mothers stated that it seemed as if health professionals considered breastfeeding impossible for these patients, which made the promotion of breastfeeding difficult, despite the recommendations of the World Health Organization (WHO) to breastfeed exclusively up to the six months of age [19].

“Well, a nurse told me that the baby had to be fed with a syringe and a baby bottle so I told her that I wanted to feed him myself and she told me that I was incapable of doing so.” [E11]

Perceptions of mothers toward breastfeeding

Mothers deal with difficulties when they initiate the breastfeeding process since children cannot perform adequate suction. Bottle-feeding from an early age, using breast milk from the mother can be used [10]. Mothers revealed the efforts to perform this process, their frustrations, sadness and despair that caused them the inability to breastfeed their children.

"Hard, it was very, very hard." [E16], [E18]

"Well, sometimes you feel frustrated because you really want to breastfeed her exclusively, both for her sake and for economic reasons." [E27]

Mothers who could start breastfeeding, performed it only for a short period of time. Complications arose quickly for different reasons, which led them to make the decision to abandon breastfeeding altogether.

"I did not have enough breast milk to feed him, although a little came out." [E11]

"There was a time when he was malnourished or so they told me." [E11]

"I feel like nothing comes out. I take a look at his mouth and it is dry, like he does not have enough strength to suction milk." [E1]

Mothers stated other problems, such as inability to suction, how babies hold the nipple, pressure by family members, fear of breastfeeding and even comparisons with previous healthy children who were able to be breastfed for periods of up to six months. The breastfeeding consultant (GECH). gave-personal education

when parents need. They had consultant phone number and could call when they need help.

> *"My baby boy could not hold my breast and I did not produce enough breast milk to feed him." [E13]*

> *"I was able to breastfeed my two other children, one up to two years of life and the other up to four." [E16]*

> *"He loved breast milk, but I had to extract it because he was in the hospital for 8 days and they always fed him through a baby bottle, so I extracted it and gave it to him using the bottle." [E23]*

Hospitalization of mothers is also difficult for the breastfeeding practice as the mother-baby bond is broken. In addition, ignorance of this process, especially in new mothers, led to the suspension of breastfeeding.

From the economic standpoint, the access to supplementary milk is an additional cost to mothers of low income and consumption increases as the child grows, which raises such expenses:

> "*We always prepared the baby bottle with the milk they recommended, but then we could not afford it anymore." [E16]*

Despite such difficulties, mothers expressed and recalled the breastfeeding process as a special connection with their children and communicated their sadness because they wanted the process to last longer and be less difficult.

Even though the breastfeeding process is difficult for these mothers, they acknowledged its immense advantages:

“Babies develop better with breast milk, their mental development, their hearing and vision, everything.” [E25]

“Everything, I do not know…their growth, the defense system, they are healthier.”

“Everything, every vitamin, everything.” [E16], [E26]

Perception of advantages and disadvantages of the nasoalveolar molding (NAM) technique regarding breastfeeding

Interviewed mothers considered the use of the NAM advantageous as the obturator allowed a better bottle-feeding process; the palatal cleft was narrower, a nasal molding occurred and weight was gained.

“Now, my baby uses the baby bottle more. It is less difficult and he does not congest as much.” [E8]

“My boy has the wing of the nose uplifted, the palatal cleft is almost non-existent, which helps him a lot.” [E5]

“From the moment he received the obturator, he has gained weight and is chubbier.” [E11]

The use of the obturator for 24 hours showed no complications for any of the mothers. They did not perceive mood changes or sleep disorders. The cleaning process and its use, in general, were not difficult.

A few mothers, who continued with the breastfeeding process while using the obturator, manifested discomfort and lacerations as the main disadvantage of the

obturator. Dermatitis in the child was another disadvantage, but adhesives are necessary to keep the tissues in place and improve the position of the columella.

"When I tried to feed him using the obturator, the little wire poked me, so I decided to remove the device." [E11]

"I was breastfeeding him before using the obturator; once he started using it, I could not feed him anymore. I had to just use the baby bottle." [E12]

"He developed an allergy and it was horrible for him." [E21]

The correct use of the NAM obturator at home was always concerning as it was a new procedure for the mothers and they wanted to perform it correctly for the well-being of their children. One of the interviewed mothers stated:

"As a suggestion, when they give you the obturator, they should include not only general information, but also recommendations on the product for us to be able to handle the obturator correctly at home." [E15]

Assessment of the CLP program

The program generates satisfaction, motivation, expectations and happiness to the mothers who initiated this therapy with their children. All of them reported that their children made great progress.

"Wonderful! It has been a beautiful experience because when I realized that my baby was coming with this condition, I never thought that there could be a solution." [E10]

"I am super happy. It is a great happiness because my baby has improved a lot with the obturator." [E28]

Breastfeeding counseling provided by the program was valued as effective but difficult to apply on a daily basis. The mothers receive additional counseling from the breastfeeding consultan (GECH) when they encountered complications.

"It was effective but it was really a fallacy because there is nothing you can do when the baby is still in the womb. You have to wait until you have the baby, and what you expect is quite different from the real situation." [E15]

Positive comments were also generated from close family members as they witnessed the progress and acceptance of the child's condition:

"Well, they say everything is ok for the baby." [E6]

"Everybody encourages me a lot. [E20]

Discussion

A few qualitative studies permitted establishing similarities and differences with the results of the present investigation. The Cartesian approach is still predominant, even though available qualitative data allows further inquiry into the experiences of individuals in specific situations, such as the condition in the current study.

This study revealed difficulties regarding maternal breastfeeding in a sample of UCLP Colombian children who were treated at Clínica Noel Foundation in Medellín. Mothers positively valued the information provided by the breastfeeding consultant. However, daily application was difficult. These results are in agreement with those of Lindberg and Berglund and Madhoun [20,21] .

Some factors that discouraged maternal breastfeeding in children younger than 6 months of age included inadequate breastfeeding techniques, frequent use of the baby bottle and early introduction of complementary foods. These factors could create difficulties producing breast milk [4].

The mothers showed efforts to breastfeed their children, a product of what they learned during lactation counseling, however, they privilege the use of the feeding bottle and other techniques over maternal breastfeeding. This was due to suction problems, sensation of low levels of milk in their breasts, milk coming out of the baby's nose, social and family pressure, fear that the baby would lose weight and early hospitalization, which do not ease the mother to child bonding. Several of the reasons mentioned coincide with a quantitative study carried out in Porto Alegre, Brazil [22] and the qualitative study by Lindberg and Berglund [20].

Garcez and Giugliani found that, in spite of the diverse difficulties reported and the lack of professional support after discharge from the maternity wards, the initiation rate and the duration of breastfeeding of children with cleft lip and palate is compatible with successful breastfeeding [22].

Lindberg and Berglund [20] reported that, despite the difficulties, mothers were aware of the importance of breast milk, which is in agreement with the results of the current investigation, such as Colombian mothers. Owens described the feeling of failure manifested by mothers when trying to breastfeed their babies. Mothers found breastfeeding challenging so they needed support, especially when babies showed additional feeding deficiencies [23]. A similar finding was reported in our study, where mothers were deal with difficulties during the breastfeeding process.

Amstalden Mendes *et al.* analyzed counseling to parents during the postnatal period and identified resources used to feed their babies and concluded a lack of attention to UCLP patients by health professionals [24]. This study showed that health system factors and maternal-baby factors were the main precipitating reasons why mothers failed to breastfeed.

Regarding the NAM, Goyal reported a breastfeeding frequency between 44% and 100%. Mothers who received counseling were more willing to breastfeed compared to mothers who did not receive it (72% vs 44%). The results of this study showed that treatment with the NAM reduced the breastfeeding practice. In addition, some complications were evident when using the obturator, such as the difficulty of approaching the baby to the breast [25].

Difficult situations with the health personnel due to a negative attitude toward breastfeeding of UCLP children at birth, were reported by Lindberg and Berglund. The Colombian mothers felt low medical support and lack of breastfeeding information [20].

The breastfeeding of siblings without UCLP was easier in the Scandinavian study [11]. In this study, the mothers valued the breastfeeding counseling but they thought that their siblings were easier to feed than the child with CLP was.

Conclusions

In this study, breastfeeding children with CLP was a difficult process, though it was vital and necessary. Thus, efforts should be directed toward a breastfeeding program implementation with pregnancy CLP mothers, so they will have tools that allow them to deal with the expected difficulties during early breastfeeding.

In addition, it revealed that health professionals must not become an obstacle in the mother-child bonding. They should act based on attention protocols formulated according to context and culture. They must provide knowledge and support for mothers to make optimal feeding choices, increase mothers' self-efficacy and facilitate breastfeeding success.

Professionals trained in breastfeeding are a very valuable resource for mothers of children with CLP, as they support them and resolve breastfeeding concerns and complications.

Another practical implication would be the encouragement to mothers who have undergone this intervention to support either in person or through video, group, or other modality new CLP mothers prenatal and postnatal. Forming a peer-peer support group may help mothers cope with the complications of feeding their infants.

The design of educational strategies help mothers cope with feeding difficulties, using personal counseling, sending videos by email or WhatsApp or calling by phone. An interdisciplinary approach is mandatory, especially during pregnancy, since mothers can feel better prepared to receive their children. Finally, the researchers suggest further investigation on improving accessibility to the program and/or providing in-home breastfeeding support.

Limitations

Results of qualitative research cannot be inferred from the general population of mothers with CLP children. Nevertheless, they provide useful information to generate hypotheses of future investigations, for example, related to accessibility to early prenatal diagnosis and access barriers to the health system.

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Conflicts of interest

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Availability of data and materials

The dataset or transcripts are available from the corresponding author on reasonable request.

Authors' contributions

AMCZ and CMMD conceptualized the study and designed data collection methods. GECH did breastfeeding support and consultancy. AMCZ supervised collected data and CMMD performed qualitative analysis of the study and performed statistical analysis of the data. AMCZ and CMMD contributed to writing the manuscript. All authors critically reviewed and approved of the final manuscript.

Ethics approval and consent to participate

Ethics approval for this study was obtained from the Biomedical Research Ethics Committee at CES University # 7429, 2014. All participants signed a consent form before the study began and voluntarily participating in the study. For participants who were younger than 18 years, written consent was obtained from a parent or legal guardian and assent from the participant. To preserve anonymity, codes were assigned to each participant based on the area, type of participant and number of the visit. Audio recordings and transcripts were stored at CES University in a password protected file.

Consent for publication

Not applicable

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