

# Case Study



Journal of Human Lactation 2021, Vol. 37(2) 419-424 **Assisted Nursing: A Case Study of An** © The Author(s) 2020 Article reuse guidelines: Infant With a Complete Unilateral sagepub.com/journals-permissions DOI: 10.1177/0890334420964159 journals.sagepub.com/home/jhl **Cleft Lip and Palate** 

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### **Abstract**

Background: This case presents a mother's feeding experience of an infant born with a complete unilateral cleft lip and palate from birth until both were repaired. She fed him directly at the breast with assistance, controlling the delivery of the mother's own milk. The infant received only his mother's own milk, no bottles, and the excess expressed milk was donated to a milk bank.

Main issue: The Cleft Team supported the mother's wish to breastfeed but expressed realism that cleft lip and palate infants could not create suction. Success had never been observed in the unit. Instead, the team suggested expressing to deliver as much of the mother's own milk. The mother had previously breastfed her three children and was keen on finding innovative ways to breastfeed.

Management: Several techniques were trialed with the help of an International Board Certified Lactation Consultant. The most sustainable and successful was the use of a nipple shield applied to the maternal nipple areola complex to cover the lip palate. Underneath, a nasogastric tube connected to a syringe delivered the mother's own milk. Exclusive expressing protected maternal supply, the infant's nutrition and growth were monitored carefully and this technique reinforced mother-infant bonding.

Conclusion: Feeding with the modifications was challenging at times. However, maternal satisfaction was high because the mother had achieved her goal of breastfeeding without assistance post cheiloplasty and palatoplasty. This case adds to the limited body of research about feeding infants with cleft lips and palates directly at the breast.

## **Keywords**

breastfeeding, breastfeeding difficulties, cheiloplasty, cleft lip and cleft palate, human milk, International Board Certified Lactation consultant, palatoplasty, supplementation

# Lactancia asistida: Un estudio de caso de un bebé con labio y paladar hendido unilateral y completo

### Resumen

Introducción: Este caso presenta la experiencia de una madre que amamantó a su bebé, nacido con labio y paladar hendido unilateral y completo, hasta que dichos defectos fueron operados. La madre pudo amamantar a su bebé directamente al pecho con asistencia, controlando el flujo de su leche. El bebé recibió únicamente leche materna, directamente del pecho y sin necesidad de usar biberones. El exceso de leche que la madre extrajo fue donada a un banco de leche.

Problema principal: El equipo de especialistas de labio y paladar hendido apoyó a la madre en su deseo de amamantar a su bebé. Pero enfatizó que debían de ser realistas teniendo en cuenta que estos bebés no siempre logran el sello y la succión adecuados debido al defecto anatómico. En la unidad de especialistas no se habían presenciado antes casos exitosos de lactancia. En un inicio, sugirieron a la madre que se extrajera la leche y se la diera a su bebé de otra manera. Sin embargo, ésta madre había amamantado a tres hijos, y quería encontrar maneras innovadoras de amamantar a su bebé.

Manejo clínico: Se probaron diferentes técnicas con la ayuda de una Consultora Certificada de Lactancia Materna (IBCLC). La técnica que resultó más sostenible y exitosa fue la del uso de una pezonera en la areola para cubrir el defecto del labio hendido. Debajo de la pezonera se colocó un tubo nasogástrico que proporcionaba la leche extraída de la madre a través de una jeringa. La madre extrajo su leche exclusivamente para mantener su producción. El peso y la nutrición del lactante fueron monitoreados, y esta técnica reforzó el apego entre la madre y su bebé.

**Conclusión**: Amamantar en estas condiciones fue en ocasiones un reto. Aún así, la madre quedó muy satisfecha - pudo alcanzar su meta de amamantar sin asistencia después de la queiloplastia y la palatoplastia. Este caso se suma a los escasos estudios de investigación que existen sobre como amamantar directamente al pecho a bebés con labio y paladar hendido. This abstract was verified through a back translation by Lourdes García, MD.

# **Background**

Craniofacial anomalies (CFA) are considered a common anatomical malformation that affect the craniofacial region and present either as cleft lip (CL), cleft palate (CP), or cleft lip and palate (CL/P; El-Abd et al., 2017). The incidence is 1 per 500–700 births and the ratio depends on the population's ethnicity and geography (World Health Organization, 2020).

CL/P infants experience difficulties while feeding (breast-feeding/bottle feeding) because the suck, swallow, breathe triad is impaired. Oral motor dysfunction can lead to nasal regurgitation, choking, and aerophagia (Adekunle, et al., 2020; Duarte et al., 2016). Usually, they cannot generate the intra oral vacuum needed to transfer milk efficiently (Boyce et al., 2019). They tire easily, tend to feed less, and transfer less volume. If nutrition is not adequate their growth measured by anthropometry indices can falter. Growth and adequate weight gain are indispensable to arrange both cheiloplasty (lip repair) and palatoplasty (palate reconstructive surgery) (Duarte et al., 2016).

Numerous risks are associated with not breastfeeding or providing human milk for all infants, particularly those with CL/P. The incidence of secretory and acute otitis media infections of the upper digestive track and nasal mucosa inflammation due to milk reflux (Boyce et al., 2019; Raheem et al., 2017) are all reduced through the properties of human milk. Dental caries, periodontal diseases, and occlusion problems happen less frequently in CL/P infants that receive human milk (Boyce et al., 2019). Breastfeeding facilitates normal physiological muscular involvement and may play a role in speech development (Oyetunji & Chandra, 2020). Suction serves as a comforting factor and promotes bonding (Duarte et al., 2016), while developing motor skills.

This case presents a mother who fed her infant at the breast from birth with a complete unilateral CL/P. Under the guidance of an International Board Certified Lactation Consultant (IBCLC), she successfully used an NG tube under a nipple shield with the mother delivering her milk from a large volume syringe (defined as assisted nursing in this case). The infant received no bottles or formula. After

palatoplasty, she transferred her infant fully to the breast (Table 1). Written permission and consent to share her story and the pictures was granted before publication.

# History

# Antenatal Background

Originally from South Africa, living in the suburbs of London, the mother was from a middle class socio-economic background. She was a 35-year-old multipara expecting her fourth child in a family with no history of cleft anomalies. A routine antenatal scan at 20 weeks confirmed a unilateral CL/P. She had breastfed her first three children, exclusively for 6 months and beyond. The Cleft Team (CT) were supportive of her wish to breastfeed but expressed realism that CL/P infants could not create suction. Success had not previously been observed in the unit. Instead, they encouraged her to express to provide as much mother's own milk (MOM) and she was handed specialized bottles. Later, a hospital grade pump and a nursing supplemental system (NSS) were given.

The parents requested an antenatal session at 36 weeks' gestation with the author. During that antenatal session, they watched the DVD *Mauro—Yes, he can!* (Herzog & Herzog-Ilser, 2010). Finger feeding, syringe feeding and the use of an NSS with an CL/P infant were described in the video. Antenatal harvesting of colostrum was taught. The parents described this session as "a big eye opener."

The mother was highly motivated given her breastfeeding history and intention to breastfeed exclusively for the first 6 months and beyond. She emphasized that she could not imagine any other way of feeding other than how she had fed her other children; it was crucial for bonding and core to her mothering technique.

## After the Birth

At 41 weeks + 2 days' gestation, after induction, the mother had a vaginal delivery. Her infant was born with a

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Table 1. Chronology of the Case Study.

Chronology	Care Level	Healthcare Interventions	Feeding Details
Birth	Hospital	Vaginal birth after induction. Complete unilateral cleft lip and palate. Gag reflex confirmed by CNS. Suggestion that at discharge from hospital infant would be required to be bottle fed	Infant put to the breast despite lack of suction.  Colostrum expressed into mouth with use of syringes. Parents declined use of bottles to avoid nipple confusion
	Home	Expressing initiated with hospital grade pump given by CT	Feeding = syringe, finger feeding, and hand expression into infant's mouth
I week		CNS concerned about finger feeding because she had never observed it in an CL/P infant	Mother reported difficulty with her first MER due to high levels of stress
2 weeks	IBCLC	Observation of a feed. Suggestion: use a nipple shield on maternal nipple to cover the cleft lip then place NG tube under the shield	Feeding sequence initiated with first MER at naked breast with breast compressions. Followed by NG/syringe mechanism
4 weeks		Counselling on donation of excess expressed milk	Total expressing output = 1600 ml. Daily excess of 900 ml
20 weeks	Hospital	Cheiloplasty: 4 hr long, successful outcome	Feeding without a nipple shield directly at the breast with NG achieved after wound healed
10 months		Palatoplasty	Post-surgery, finger feeding and NG/syringe mechanism used. Suction developed
I week post-op	Home	Development of a small fistula in the alveolar area	"Squeaky sounds" heard by mother and then loss of suction 3 days later
3 weeks post-op	•	Spontaneous fistula closure CT expressed admiration and acknowledged having never seen a mother of a CL/P infant breastfeed without assistance	Suction regained, breastfeeding with no assistance achieved. Infant fed for comfort and fell asleep at the breast for the first time. During the 1st year, infant had no upper respiratory tract infections, otitis or tonsillitis

Note. CNS = cleft nurse specialist, MOM = mother's own milk, MER = milk ejection reflex, NG = nasogastric, op = operation, CL = cleft lip, CT = cleft team.

non-syndromic left-sided complete CL/P (Figure 1). Skin-to-skin contact was initiated post-delivery in a Baby-Friendly accredited hospital. The cleft nurse (CN) confirmed the presence of a gag reflex; the mother was allowed to offer the breast and then to harvest colostrum in syringes.

Upon hospital discharge, the mother attempted to breastfeed but was encouraged to bottle feed MOM with specialized bottles provided by the CT. Lactogenesis 2 happened on Day of Life (DOL) 2. At home, several feeding techniques



Figure 1. Infant's Complete Left-Sided Unilateral Cleft of the Lip and Palate.

were attempted. The mother started by placing the infant directly at the breast and hand expressed her first milk ejection reflex (MER) into the infant's mouth. The father then finger fed the infant using the MOM. The mother felt that her MER was delayed and acknowledged high levels of stress. She was feeling extremely anxious, as she was new to these feeding techniques and was feeling a lot of pressure about needing to feed with a bottle if this failed.

# Observations, Assessments, and Management

On DOL 16, during the first home consultation, the IBCLC and the mother experimented with feeding and devised a system that involved the mother delivering MOM from a large volume syringe connected to an NG tube inserted under the nipple shield, a solution that required no suction (Figure 2). The infant was able to feed at the breast, and he appeared more organized and coordinated; there was less spilling and leaking.

On DOL 23, the mother shared her doubts about whether this was the right decision. The session provided reassurance and emotional support, centering around the redefinition of "breastfeeding." The mother stated:

"I am breastfeeding my baby. I know it is not in the classical way. But we have managed to find a way where he gets all my



**Figure 2.** Assisted Nursing—Feeding at the Breast with an NG Tube Under a Nipple Shield, Delivering MOM from a Large Volume Syringe.

milk delivered directly at my breast. This has helped me bond. If I had to think of a term, I would call this assisted nursing."

CL/P infants can have slow growth due to the feeding challenges. Figure 3 shows how this infant was no exception. His birth weight of 4.42 kg was regained on DOL 23. He was born on the 97th centile and his weight decelerated through several centiles up to Week 25, reaching the 15th centile. To qualify for cheiloplasty the infant needed to weigh 6 kg and be tracking on a sustained, healthy trajectory. Despite the CN recommendation to supplement with formula at 16 weeks, this infant demonstrated consistent and steady weight gain receiving MOM at the breast. In addition, the infant did not tolerate solids when introduced at 6 months but started to take them regularly at around 9 months.

## Post Surgeries Outcomes

At 20 weeks, cheiloplasty took place. In the following 3 weeks, the infant did not feed much, was on heavy pain medication, and seemed sore. As a result of the operation, the mother was able to offer the breast without the nipple shield. She carried on delivering her milk at the breast with the NG tube and a large volume

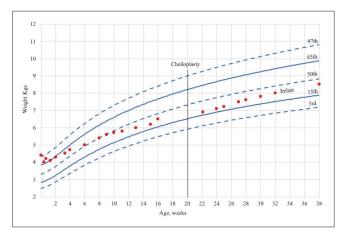


Figure 3. Infant's Weight Plotted Against WHO Child Growth Standards.

syringe as he could not yet create suction. She reported less spilling and more oral coordination.

At 10 months, palatoplasty took place. The mother started to feel some generation of suction. However, the infant developed a micro-fistula (a common complication at the surgical wound) which grew gradually to around 1 mm. He lost the acquired suction. At 11 months, the mother suspected a spontaneous closure of the fistula. She breastfed with no assistance and felt the generation of suction again.

### **Discussion**

With maternal determination, encouragement from her partner and family and the support of the IBCLC, assisted nursing was possible. When an infant has always fed at the breast, transitioning to breastfeeding will be less difficult, because there is an ingrained association of the breast being a source of nutrition and comfort. The type and severity of clefting will determine how difficult it will be to feed a CL/P infant (Alperovich, et al., 2017) The infant's complete CL/P made feeding very challenging, as he could not generate any suction. Even though the CL/P population is not a homogenous group, breastfeeding is usually not possible (Madhoun et al., 2020; Miller, 2011). "Feeding at the breast may be an option but will require supplementation" (Bannister, 2008, p. 59).

This case defied the common assumption that formula supplementation is always required. This mother who was expressing eight times in 24 hr had a daily surplus of around 900 ml. As a result, the IBCLC discussed milk donation and the mother contacted the Hearts Milk Bank. During the first year, she not only fed her infant MOM, but in addition she donated a total of 42 L (Figure 4).

Feeding a CL/P infant can be time consuming and it can lead to maternal/parental stress and anxiety (Snyder & Ruscello, 2019), as well as communication, emotional, and social problems (Nelson et al., 2012). But mother-infant bonding is enhanced (Gailey, 2016) by the proximity of feeding at the breast. A more positive psychological postnatal adaptation can happen, given elevated maternal oxytocin (Niwayama et al., 2017; Stuebe et al., 2013; Uvnäs-Moberg & Prime, 2013) and prolactin serum levels (Torner, 2016). Under the current Coronavirus disease (COVID-19) pandemic, protecting breastfeeding in CL/P infants is crucial as it provides passive and active immunity (Hassiotou & Geddes, 2015; Praveen et al., 2015) and diminishes the incidence of respiratory tract infections (Raheem et al., 2017). Mothers of CL/P infants who cannot feed at the breast or provide MOM, will miss out on many of the nutritive and non-nutritive benefits.

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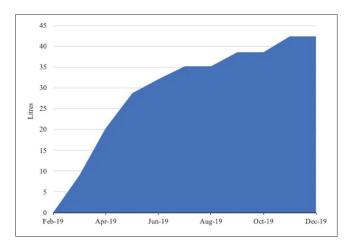


Figure 4. Milk Donated by the Mother, Liters, Cumulative.

Parents with CL/P may not be aware of the possibility of accomplishing breastfeeding (Burianova et al., 2017) or assisted nursing. Peer support groups for mothers with CL/P who have experience breastfeeding are essential (Santos et al., 2019), but lacking. Parents have reported gaps in health care providers' (HCP) knowledge (Snyder & Ruscello, 2019). HCP who do not have enough breastfeeding clinical experience will provide inaccurate information to mothers (Lindberg & Berglund, 2013). Inconsistent information and support have been reported in many countries (Adekunle, et al., 2020; Baylis et al., 2018). The common assumption is that feeding at the breast is impossible. Expressing and feeding via specialized bottles is instead encouraged. If the weight falters, formula or early introduction of solids might be recommended. Sometimes, these will be medically indicated. However, exploring how the provision of MOM can be ameliorated should take place first.

Each dyad should be evaluated individually (Miller, 2011) and different feeding resources should be trialed to determine the optimal one (Snyder & Ruscello, 2019). Anticipatory counseling offered during pregnancy could explore all feeding options at the breast and/or the provision of MOM. The mother's own breastfeeding goals should be supported (Bannister, 2008). As the Academy of Breastfeeding Medicine's *Clinical Protocol #17* (Boyce et al., 2019) suggested directing parents to the right HCP, including IBCLCs who have clinical competency in this field, is crucial.

IBCLCs play a crucial role in aiding the CL/P population and in the past have not been consistently integrated in the HCP team (Madhoun et al., 2020). Integrated teamwork (Khanchezar et al., 2019) that includes IBCLCs is needed. Team efforts could translate into a mother-centered feeding plan; elaborated, accessed, and reviewed by those involved in the provision of care. In addition, IBCLCs could share

awareness, evidence-based breastfeeding resources, and their clinical knowledge with peer HCP.

## Conclusion

Feeding CL/P infants is challenging. This case illustrated the need for more team collaboration among HCP, including IBCLCs, involved in the care of these dyads. Through evidence-based lactation care, it is important to find ways to protect and promote the possibility of feeding CL/P infants at the breast or provide as much MOM as possible. In doing so, we would be redefining and fostering a much needed "humanized policy for clefts babies" (Gil-da-Silva-Lopes et al., 2013, p. 581) around the world.

#### **Author's Note**

All photography is the property of the author; permission for publication in this journal was granted by the family.

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