Breastfeeding experiences of mothers of infants with cleft lip and palate

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Student-author biography

At the time of publication, Tania Erasmus, Benita Jordan and Corine Wildenboer are currently completing their community service year as qualified speech-language therapists and considering post-graduate studies. Jané Vermaak has pursued a MA degree in Speech-Language Pathology at the University of Pretoria and will be commencing with community service as a speech-language therapist in 2024.

Background. Infants with cleft lip and/or palate (CL/P) have difficulty breastfeeding owing to impaired anatomical structures. Assessing mothers' breastfeeding experiences and the factors influencing decision-making may improve services and patient-centred care.

Objective. To describe the breastfeeding experiences of a group of South African (SA) mothers of infants with CL/P.

Methods. A descriptive quantitative research design was used to collect quantitative and qualitative data through an electronic survey. Purposive sampling was used to recruit 14 mothers of infants with CL/P aged <3 years old. The survey was conducted in SA, where the prevalence of CL/P is 0.3 per 1 000 live births.

Results. Thirteen participants (92.85%) breastfed or expressed breastmilk after birth, with only one mother opting to not provide any breastmilk. Despite their eagerness to attempt breastfeeding, many participants encountered active discouragement by family and cleft teams. Moreover, they reported limited breastfeeding encouragement or lactation support.

Conclusion. Healthcare professionals are encouraged to prioritise person-centred care, advocating for parents to make informed decisions regarding the best feeding options for their infant. Our findings may be valuable to cleft teams and allied health professionals interested in effective breastfeeding management of infants with clefts.

Key words. Breastfeeding, breast milk, cleft lip and/or palate, experiences, mothers, infants, survey.

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Cleft lip and/or palate (CL/P) is the fourth most common congenital disability in South Africa (SA), affecting 0.3 per 1 000 live births.[1] Individuals with CL/P face multiple challenges, including underlying anatomic anomalies and comorbid conditions that result in various difficulties with oral feeding and growth.[2] In cases where the secondary palate exhibits a complete cleft with hard and soft palate involvement, infants may struggle to draw liquids into the oral cavity, leading to difficulties in bottle-feeding and often making breastfeeding impossible.[2,3] Oral motor dysfunction, nasal regurgitation and poor feeding efficiency may occur.[4] In instances of an isolated cleft lip, the soft breast tissue may fill the gap, enabling the infant to latch and create effective suction on the nipple. However, in cases of a cleft palate where suction is not possible, infants may have an inadequate latch, resulting in limited milk transfer necessitating supplementation.[5] Structural anomalies deprive many infants and mothers of the valuable and important act of breastfeeding. Breastfeeding provides crucial nutrients to newborns, and triggers the release of oxytocin, fostering mother-child attachment and decreasing stress levels.[6,7] The use of human milk strengthens infants' immune systems and imparts long-term health benefits, which protect against infections, such as gastrointestinal and respiratory infections, otitis media and food allergies.[8-10] Owing to various benefits, the American Academy of Pediatrics (AAP) recommends exclusive breastfeeding for the first 6 months of life for all infants, with continued breastfeeding encouraged until the infant reaches 24 months while introducing solid foods.[11]

Breastfeeding is frequently discouraged in infants with CL/P as infants often have feeding difficulties impacting the success of breastfeeding. Breastfeeding challenges include difficulty latching on, long periods of sucking at the breast with limited milk transfer, nasal regurgitation, inadequate intake of milk and ineffective intraoral suction.[4]

The priority for infants with CL/P should be appropriate nutrition, especially those who are candidates for future surgery.[12] A major contributor to insufficient nutrition is inadequate breastfeeding and nutrition counselling to mothers of infants with CL/P.[5] Owing to the compelling benefits of breastfeeding and the complicated feeding

profile that infants with CL/P have, mothers should be adequately educated and counselled on available feeding options. Parents should ideally receive guidance during pregnancy and postpartum periods, whilst regular professional counselling services should be offered by healthcare professionals, including speech-language therapists (SLTs), paediatricians and psychologists who have clinical expertise in infants with CL/P's feeding requirements.[13] A lack of support from healthcare providers can hinder successful breastfeeding outcomes, and mothers have identified that lactation support from healthcare providers is a critical part of the intervention process.[14]

A mother's breastfeeding habits may be affected by a lack of knowledge and information about maintaining lactation and problem-solving strategies to schedule breastfeeding into their routine.[5,15] A lack of informational counselling might also impede their understanding of the structural deficits associated with CL/P.[1] This may lead to mothers viewing breastfeeding as impossible, prompting heavy reliance on formula milk and bottle feeding, with no attempt at breastfeeding. The financial and health concerns related to formula milk in low- to middle-income settings are an important consideration.[16]

The presence of a cleft palate (CP), with or without cleft lip (CL), leads to more frequent breastfeeding difficulty than CL with or without cleft alveolus (A).[17] Infants with CL/P should ideally be individually assessed on the severity of their feeding difficulty, to formulate adequate recommendations for possible breastfeeding, despite the presence of craniofacial anomalies.[14] Alternative feeding methods may include supplementation of breastmilk with formula milk for intake of sufficient calories, specialised bottles with venting systems and cup-feeding.[18] This can provide traction on the palate for normal spreading and normalising tongue movements.[19] Attachment to the breast is possible for some infants with CL/P if they are positioned well, while the mother holds her breast in the infant's mouth and occludes the cleft with her finger.[13,19]

The first step to improving early feeding intervention for mothers with infants with CL/P involves assessing local breastfeeding experiences. This may assist SLTs and other healthcare professionals in anticipating the necessary feeding support required to prolong breastfeeding for infants with CL/P.

Objective

This study aimed to describe the breastfeeding experiences of a cohort of SA mothers of infants with CL/P.

Methods

This study employed a survey design, primarily gathering quantitative data with supplementary qualitative data through a few open-ended questions. The survey was distributed via an electronic link shared on social media platforms. Institutional ethical clearance (GW20160203HS) was obtained before data collection commenced. English-speaking SA mothers aged 18 years or older, with infants diagnosed with CL/P, were invited to participate. To minimise recall bias, infants had to be younger than 3 years old. Participants were required to have internet connectivity and access to a device for survey completion. Written permission was obtained from administrators of existing WhatsApp and Facebook groups dedicated to mothers of infants with CL/P to share the survey link within their groups. Fourteen responses were obtained, with all participants identified as mothers of infants with CL/P. The distribution of cleft types among these participants was as follows: two CL (14.3%), six CP (42.9%) and six CL/P (42.9%).

Results

All participants (n=14) were mothers in stable relationships. While half of the infants were born full term, 13 infants had a NICU stay. Isolated CL was the least frequent cleft type (Table 1). Thirteen participants (92.85%) breastfed or provided expressed breast milk after birth (Fig. 1). Eight participants (57.14%) supplemented breast milk feeding with formula, four (28.5%) indicated a planned transition to formula milk, two (14.2%) indicated poor lactation or milk supply and one (7.14%) provided supplementation for improved infant weight gain.

Participants who provided breast milk gave sufficient reasoning, showing knowledge of breastfeeding benefits:

> '... to make sure that he got the best milk there is - liquid gold. The benefits of breastmilk for any baby is just amazing ...' (Participant 6)
>
> 'It was important to me. I am a breastfeeding advocate and it is possible to do direct feeding with a cleft lip.' (Participant 8)

Only one participant reported choosing not to provide any breast milk at all, seeing as the 'feeding attempt was too complicated' and that formula milk was 'more practical'. One participant transitioned to formula after 4 days of attempts at expression, as it was easier to 'monitor the amount of milk' her infant consumed.

The experiences of participants (n=13; 92.85%) who provided breast milk are presented in Table 2. One mother chose not to respond to all the questions, resulting in one missing value. Four participants (30.0%) reported being actively discouraged from breastfeeding by family and cleft teams.

Eight mothers ultimately felt supported in their final decision about the feeding method they selected. The majority of the sample

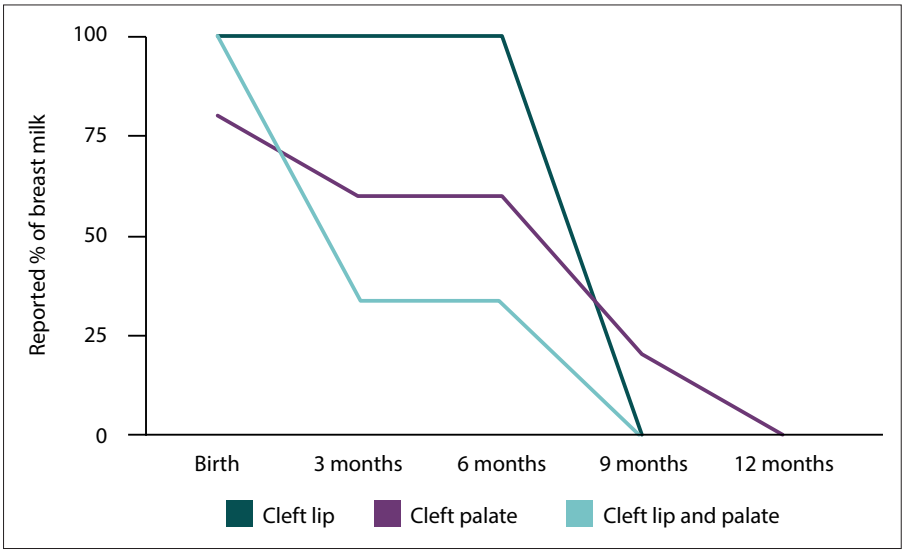

Fig. 1. Reported percentage of breastmilk feeding by cleft type between 0-12 months (n = *14).*

Table 1. Participant and infant characteristics (*N*= 14)

	N (%)	Providing BM, *n* (%)	Number of months providing BM (median)
Infant characteristics			
Cleft type			
CL	2 (14.2)	2 (14.2)	7
CP	6 (42.8)	5 (35.7)	6.50
CL/P	6 (42.8)	6 (42.8)	2.24
Sex			
Female	6 (42.8)	5 (35.7)	2.24
Male	8 (57.1)	8 (57.1)	7
Gestational age			
≤38 weeks	7 (50.0)	7 (50.0)	2.24
>38 weeks	7 (50.0)	6 (42.8)	7
NICU Stay	13 (92.8)	12 (85.7)	6
Syndrome	1 (7.1)	1 (7.1)	-
Pierre Robin Sequence	1 (7.1)	1 (7.1)	6
Prenatal diagnosis and counselling received	5 (35.7)	5 (35.7)	7
Maternal characteristics			
Mother's current age (years)			
20 - 29	5 (35.7)	5 (35.7)	2.37
30 - 39	8 (57.1)	7 (50.0)	6.5
40 - 49	1 (7.1)	1 (7.1)	2
First-time mother	7 (50)	6 (42.8)	4.19
Working mother	3 (21.4)	3 (21.4)	6
Child in daycare	3 (21.4)	3 (21.4)	8
Distance from hospital			
<1 hour	9 (64.2)	9 (64.2)	7
≥1 hour	5 (35.7)	4 (28.5)	2

BM = Breastmilk; CL = cleft lip; CP = cleft palate; CL/P = cleft lip and/or palate; NICU = neonatal intensive care unit.

(*n*=8; 61.5%) reported positive experiences and success in open-ended questions:

'It's a joyful journey and makes me proud of myself and my baby.'

Two mothers expressed disappointment upon learning that breastfeeding will not be possible:

'It was a shame that I was not able to breastfeed my cleft lip/palate baby ...' (Participant 3)

'I was very negative during my pregnancy knowing that my baby won't be able to breastfeed.' (Participant 5)

Participants had a positive regard for breastfeeding or providing breast milk, with optimism, but acknowledging the challenges:

'The whole experience was rewarding because I could help my child get the best nutrients to recover from surgery and stay healthy. It was very exhausting though because I had to spend time expressing and preparing bottles when my baby was sleeping, but I'm glad I did it for him.' (Participant 1)

'Breastfeeding wasn't much of a challenge. I have extensive knowledge on breastfeeding and wasn't afraid that I wouldn't be able to nurse him when I saw it was only the lip ...' (Participant 8)

'I loved breastfeeding even though it was difficult for my son ...' (Participant 12)

Negative experiences and perspectives were also expressed. Two mothers alluded to their emotional state and mental health improving when they decided to formula feed:

'It was the most difficult time for me. The day I decided to start giving formula, the weight was dropped from my shoulders, and I could care for my baby with improved mental health.' (Participant 9)

'... pumping would've put more emotional pressure on me and I wanted to be in my best emotional state for the sake of our baby.' (Participant 4)

Participants' challenges in breastfeeding and pumping are shown in Fig. 2. Three participants (23.0%) did not experience any problems. The most common problems reported were: breast pain or mastitis (*n*=5; 35.7%), feeding being too complicated (*n*=4; 30.7%), poor latching (*n*=4; 30.7%), and poor sucking (*n*=4; 30.7%).

Three participants successfully breastfed directly at the breast without using a breast pump. The remaining participants reported using a breast pump either in conjunction with direct breastfeeding or exclusively to

Table 2. Experiences of participants who provided breast milk (*n*=13)

Experiences	*n* (%)	Number of months of BM (median)
Prior lactation experience (*n*=4)		
Yes	1 (25.0)	1
No	3 (75.0)	7
Challenges with lactation (*n*=4)		
Yes	1 (25.0)	0.03
No	3 (75.0)	7
Mothers discouraged from BM feeding (*n*=11)		
Yes	7 (63.64)	2.1
No	4 (36.36)	6.53
Lactation support (*n*=4)		
Yes	0 (0.0)	N/A
No	4 (100)	7
Exclusive use of breast pump (*n*=13)		
Yes	8 (61.54)	4.185
No	5 (38.46)	7
Challenges with expression (*n*=10)		
Yes	6 (60.0)	2.235
No	4 (40.0)	6.5
Expression support (*n*=11)		
Yes	5 (45.45)	2.36
No	6 (54.55)	6
Formula supplementation (*n*=11)		
Yes	8 (72.73)	4.05
No	3 (27.27)	7

BM = breastmilk.

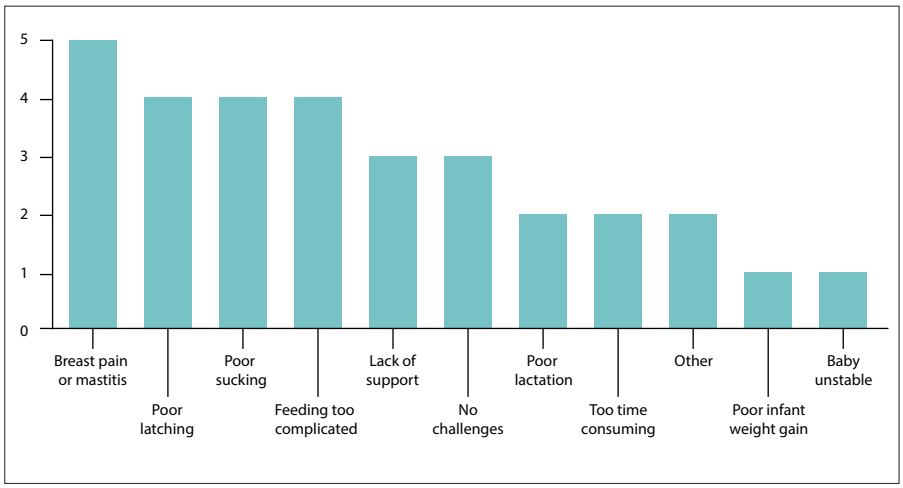

*Fig. 2. Participants' reported breastfeeding and pumping challenges (*n*=14).*

express breast milk for bottle feeding. Five mothers were actively discouraged from expressing breastmilk by either the family or the cleft team. Participants mentioned that exclusively expressing was demanding, but they continued providing breast milk as evidenced in the following statements:

'Exclusively pumping is exhausting, especially for a baby that takes long to drink and who needs to be kept upright for at least half an hour after drinking due to reflux..' (Participant 2)

'Not a traumatic experience, just had to adapt and find the perfect pump ...' (Participant 10)

NICU and obstetrics staff, along with delivery nurses were identified as sources of encouragement for breastfeeding. Two mothers reported having no assistance or any source of breastfeeding encouragement or lactation support. Participants in this study generally expressed unhappy feelings in open-ended questions regarding the assistance they received during attempts at breastfeeding:

'It was extremely irritating how everyone was questioning the breastfeeding constantly, even though the health of the child was very clearly good ... It has become clear to me that the lack of breastfeeding in the cleft community is not a cleft problem but a care provider and support problem ... Lactation specialists are also not being consulted because mothers are not being referred to them.' (Participant 8)

'Many family members have urged me to rather go to formula since it will be easier ...' (Participant 2)

Participants were asked for suggestions to improve breastfeeding experiences. The need for staff members such as nurses to be equipped with specialised knowledge to support mothers, access to feeding expertise such as SLTs and physical resources such as breast pumps, were mentioned:

'... the training of nurses in the maternity ward. As well as providing hospital pumps for mothers to borrow until they have another alternative.' (Participant 5)

'More support from the hospital staff; they had minimal idea of how to support ...' (Participant 14)

'... send a professional like a speech therapist to assist. Not merely an ICU nurse who occasionally assists cleft babies ...' (Participant 9)

Discussion

Thirteen of the 14 mothers who participated in tshe survey provided breastmilk to their infants directly after birth. The majority of participants breastfed or provided expressed breast milk, at times in combination with formula supplementation. This finding aligns with that of a Nigerian study where the majority of mothers initiated breastfeeding.[20] The study by Kaye *et al.*[14] shows contradictory results, revealing that only 33.9% of mothers in their study provided breast milk after birth to their infant with CL/P.

Tungotyo *et al.*[21] found that infants with CL received human milk for a longer duration compared to those with CL/P, aligning with the results of our study. A CP introduces numerous difficulties to feeding compared to a CL, such as insufficient negative intraoral pressure when sucking, resulting in inadequate milk transfer,[22] which explains this finding.

Reported use of a breast pump by mothers in this study either in conjunction with direct breastfeeding or exclusively to express milk showed mothers' resilience. Mothers' knowledge about the benefits of breastmilk for recovery from surgery, bonding and benefits for infants' health is shown to significantly increase rates of breast milk provision. Consistent with a previous study, participants in this study expressed concern about feeding and insight into the value of breast milk.[4]

Four participants reported being actively discouraged from breastfeeding by family and cleft teams, whereas NICU and obstetrics staff, along with delivery nurses were identified as sources of support for breastfeeding. One mother commented that she views the lack of breastfeeding in the cleft community as a 'care provider and support problem' rather than a 'cleft problem' and that lactation support professionals are not referred to regularly. This is in line with findings by Eltayeb *et al.*,[23] who found that in Sudan, only 11% of their sample received any advice regarding feeding strategies and techniques, and many participants stated that they would have wanted to breastfeed, but did not receive adequate support and information regarding breastfeeding their infant with a CL/P.

The Academy of Breastfeeding has compiled guidelines on the breastfeeding of infants with CL/P and advocates for parents to be educated about breastfeeding benefits.[13] In cases where direct breastfeeding is likely impossible, parents should be supported to use cups or syringes to provide breast milk.[13] Social support, especially from close family, was of great importance to mothers when coping with challenges related to feeding.[4] The implication is that SLTs and other healthcare providers in cleft teams have the responsibility to provide mothers with adequate information and support to encourage informed decisions. Mothers may want to attempt breastfeeding, and support services should therefore be available.

The most commonly reported reasons for discontinuing breastfeeding included breast pain and mastitis, infants having a poor latch and infants' sucking difficulty. Additionally, the feeding attempt was perceived to be too complicated. Sucking difficulties were also cited as the main reason for discontinuation of breastfeeding in other studies.[20,21] The presence of CP in infants is associated with reduced breastfeeding, whereas infants with CL and A encounter fewer breastfeeding difficulties, possibly due to the supportive nature of the mothers' breast tissue facilitating the infant's ability to latch on.[6,17]

While most participants reported positive views of breastfeeding, some also reported negative experiences, including difficulties with feeding, exhaustion, breast pain and anxiety. This is in accordance with a study by Madhoun *et al.*[2] where mothers reported symptoms of anxiety and postpartum depression after birth. Mothers' mental health during breastfeeding should be a concern for healthcare providers, considering that mothers with infants with CL/P are at higher risk for psychological affliction.[17] Inconsistent information from healthcare professionals regarding feeding could increase maternal anxiety.[4] Participants in this study emphasised the need for professionals with specialised feeding knowledge for support. They expressed the importance of access to feeding expertise from SLTs and lactation support providers, as well as physical resources such as breast pumps in the early days after delivery. One mother referred to a 'lack of knowledge of breastfeeding by care providers in general' as being a part of the difficulty in establishing breastfeeding. SLTs and nurses have critical roles in supporting parents and advocating for mothers' mental well-being when feeding decisions are made. Psycho-social and emotional support from family members and healthcare providers can help mothers cope better.[21] Another way to improve mothers' experiences is to provide prenatal counselling, providing parents with opportunities to find resources on feeding techniques and arrange appointments with lactation support providers prior to delivery.[24] Mothers who received a prenatal cleft diagnosis and counselling would be better prepared to provide breast milk for longer durations.[24]

The findings provide a valuable perspective for healthcare professionals in feeding and cleft teams, emphasising the importance of informational counselling and parent education on breastfeeding benefits and human milk provision through other methods. Findings show that parents may want to attempt to breastfeed their infants with CL/P, but often experience a lack of continued assistance and encouragement from healthcare teams, especially their specialist cleft team. Allied health professionals, such as SLTs, are called to build interprofessional collaborative relationships. This approach creates opportunities for team education and awareness about breastfeeding infants with CL/P to other members of the cleft team, such as maxillo-facial surgeons, dieticians and lactation support providers. SLTs are not always present as the first point of contact once a diagnosis of CL/P is made prenatally, or when an infant is born, and surgeons or paediatricians are often the initial source of information following diagnosis. Healthcare professionals working with infants with clefts should strive for optimal patient-centred care, keeping parents' wishes and infants' well-being central to feeding decisions.

Study limitations and future research

This small sample provides a preliminary indication of maternal experiences in SA. It could be viewed as a prospective pilot study for

future large-scale research projects. Qualitative studies, using interviews, may create an opportunity for mothers to express complex emotions. The potential recall bias of participants is also a limitation. The distribution of the online survey via social media limited mothers' access to the survey, especially within a lower- to middle-income country, and therefore, this perspective is provided from the private healthcare sector only.

Conclusion

While most participants provided breast milk to infants following delivery, many mothers reported active discouragement of breastfeeding from family and cleft teams. Healthcare professionals are encouraged to strive for person-centred care and to help families make informed decisions about the best feeding options for infants. Findings may be valuable to cleft teams and allied health professionals interested in breastfeeding management for infants with clefts.

Declaration. This study was completed in partial fulfilment of the requirements for an undergraduate degree for the first four authors.

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Author contributions. EK conceptualised the study and analysed the data. TE, BJ, JV and CW collected and analysed the data, and drafted the manuscript. EK, BP and CM supervised the study and drafted the manuscript.

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