Cleft team members' views on breastfeeding of infants with cleft lip and/or palate

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PLAGIARISM DECLARATION

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Title of article: **Cleft team members' views on breastfeeding of infants with Cleft lip and/or palate**

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Abstract

Background: Breastfeeding of infants with cleft lip and/or palate is a constantly evolving area of research with varying opinions, beliefs and practices. Local CL/P team members' views on this topic are yet to be explored**.**

Aim: This study aimed to investigate South African cleft lip and/or palate (CL/P) team members' views on breastfeeding of infants with CL/P.

Setting: A South African electronic survey study created and distributed using Qualtrics XM Software

Methods: An electronic survey was distributed via QualtricsXM rendering mostly quantitative data. Permission was granted before posting an infographic on social media and networking sites. Stratified, non-probability sampling methods were used to recruit qualified healthcare professionals working with infants with CL/P. Eighteen South African CL/P team members across different disciplines, from four provinces, responded. Data were analysed descriptively**.**

Results: Eighteen participants (100%) viewed anatomical limitations associated with the type and extent of the CL/P as the main barrier to breastfeeding for infants under their care. Many participants (n=16) recommend breastfeeding as the desired outcome for infants with CL/P; however, it is not attempted due to knowledge or systemic limitations. Although infants' health is the main priority for team members, most professionals report a lack of adaptive breastfeeding support for mothers of infants with CL/P (n=13; 76.5%).

Conclusion: South African CL/P team members perceive breastfeeding as an important but challenging feeding option. Breastfeeding outcomes are often dependent on a combination of the individual infant's physiology, healthcare context, and maternal motivation as decision-making variables.

Contribution: The findings of this study emphasise the multifactorial nature of breastfeeding challenges in infants with CL/P and highlight the need for consistent, team-based approaches by medical and allied healthcare professionals.

Keywords: Cleft lip and/or palate**;** breastfeeding; speech-language therapists; maxillofacial surgeons; lactation consultants; plastic surgeons; otolaryngologists (ENTs); infants; survey

List of abbreviations:

ACPA: American Cleft Palate-Craniofacial Association

ACPCA: American Cleft Palate and Craniofacial Association

CL/P: Cleft Lip and/or Palate

EBM: Expressed breastmilk *(as mentioned by participants in results section)*

IP: Internet Protocol *(appears in ethics section re: IP addresses)*

SACLC: South African Certified Lactation Consultant

WHO: World Health Organization

1. Introduction

One of the most prevalent congenital abnormalities globally is cleft lip and/or palate (CL/P) (World Health Organisation [WHO], 2023). CL/P contributes notably to South Africa's burden of disease despite initiatives to increase awareness and advocate for multidisciplinary approaches (Liu et al., 2024), emphasising the need for early diagnosis (Erasmus et al., 2023), feeding support, and effective long-term monitoring to reduce potential later socioeconomic and psychological impact (Liu et al., 2024).

Clefting results from abnormal fusing of the lips, oral cavity, and pharyngeal structures during embryological development in the first trimester of pregnancy, which is caused by endogenous, exogenous, or multifactorial inheritance with varying degrees of severity (Kummer, 2020). These structural abnormalities and related comorbid conditions pose a myriad of challenges for both parents and infants, especially during feeding (Campbell et al., 2019; Kadir et al., 2020; Namchaitaharn et al., 2021). The ability to breastfeed their infant safely and effectively is often one of the most highlighted concerns for mothers of infants with CL/P (Kummer, 2020; World Health Organisation [WHO], 2021).

Medical and allied healthcare professionals regard breastfeeding exclusively during the first six months as the gold standard for infants and babies to receive optimal nutrition (Nabatanzi, 2021). Breast milk provides infants with essential nutrients and antibodies for immune protection (World Health Organization [WHO], 2021). Breastfeeding offers long-term cognitive, emotional, and physiological benefits and promotes language development and the prevention of acute otitis media. (Centre for Disease Control and Prevention, 2021).

One of the key benefits of breastfeeding is its role in promoting mother-infant attachment (American Cleft Lip and Palate Association, 2024). This process stimulates the release of oxytocin, often referred to as the bonding hormone, which reduces maternal stress and strengthens the emotional connection between mother and child. Oxytocin facilitates eye contact and skin-to-skin contact, both of which are essential for establishing a secure attachment and fostering infant development." (Namchaitaharn et al., 2021; Tahmasebifard et al., 2021).

Infants with CL/P, however, present with severe early feeding difficulties, specifically in creating and maintaining intraoral pressure for proper suction necessary for sufficient milk extraction (Nabatanzi et al., 2021). Infants also struggle to latch properly onto the breast to gather both the nipple and alveolar tissue (Genna, 2011).

The infant must resort to compensatory strategies such as excessive tongue protrusion and jaw movements. Although breastfeeding difficulties are cleft-specific (Zajac & Vallino-Napoli, 2024), such compensatory strategies are often exhaustive for the infant (Genna, 2013). To varying extents, infants with CL/P are at an increased risk for aspiration and nasal regurgitation and thus poor weight gain due to insufficient milk intake compared to typical infants (Kummer, 2020; Genna, 2013; Zajac & Vallino-Napoli, 2024).

Breastfeeding infants with CL/P thus becomes ineffective and, in some cases, impossible for some dyads and uncomfortable for mothers (Erasmus et al., 2023; Kummer, 2020; Marwa Ashour Ragab et al., 2023; Nagel et al., 2022). Inadequate milk intake and prolonged feeding times increase the risk of insufficient weight gain, crucial for surgical candidacy and support of typical maturation (Liu et al., 2024). Infants with CL/P may also swallow excessive air during feeding, which can cause abdominal discomfort and contribute to negative feeding experiences (Wilde, 2021).

Moreover, the reported discomfort, frustration, and emotional stress of feeding complications resulting from CL/P, as well as the physiological effects of the diagnosis of CL/P, further exacerbate poor milk expression and adherence to feeding management strategies (Marwa Ashour Ragab et al., 2023; Nagel et al., 2022; Namchaitaharn et al., 2021).

To ensure appropriate growth and development of the neonate, specialised feeding methods is needed, such as expressed breast milk, formula using specialised bottles and one-way valve nipples (American Cleft Lip and Palate Association [ACPCA], 2024 n.d.) is often used should oral intake be insufficient. These recommendations compensate for poor suction or labial seal and prevent nasal regurgitation (Kummer 2020; WHO, 2021).In addition to the above mentioned, techniques such as non-nutritive sucking is used to stimulate and build the suck-swallow-breathe synchrony (American Cleft Lip and Palate Association [ACPCA], 2024 n.d.).

Given the complexities of CL/P management, a holistic and dynamic approach is essential. An interdisciplinary team model is widely regarded as the most effective strategy, addressing not only feeding and nutritional concerns but also physical, aesthetic, functional, and speech-related needs (Alfonso et al., 2019; Smarius et al., 2020). This approach also prioritises psychosocial and developmental support, enhancing overall patient and family well-being (Namchaitaharn et al., 2021). Each team member—including psychologists and social workers—plays a critical role in providing individualised counselling and managing carer expectations (ACPA, 2024; Erasmus, 2023; Padovano et al., 2020).

Despite the known benefits of breastfeeding, its feasibility in cases of CL/P remains debated (Liu et al., 2024). A quantitative survey of interdisciplinary team members can provide insights into current knowledge gaps, regional healthcare barriers, and discrepancies in adherence to international standards, such as those outlined by the ACPA parameters of care (2024).

In South Africa, systemic disparities—including limited access to specialised feeding tools, speech therapists, and lactation consultants—hinder optimal care (Erasmus, 2023; Hlongwa & Rispel, 2018). Additional challenges in Cleft Lip/Palate (CL/P) care include inconsistent patient follow-up protocols and the impact of variable pressures within the South African healthcare system on treatment timelines and resource allocation. (Volmink, 2018; Hlongwa & Rispel, 2021). The influence of cultural beliefs and power dynamics between healthcare professionals may also have an impact on collaborative clinical decision-making (Hlongwa et al., 2019; Bow et al., 2025).

Multidisciplinary care is further complicated by regional stigma, particularly regarding visible clefts, insufficient clinician training, and a lack of standardised protocols for family education and support (Erasmus, 2023; Hlongwa et al., 2019; Schlome et al., 2025; Liu et al., 2024). A broader spectrum of CL/P team member perspectives should be understood, given the perspective of the hierarchical decision-making power to prioritise team members, such as surgeons and nurses, above allied health professionals (Hlongwa & Rsipel, 2021; Hollingsworth et al., 2024), to investigate potential gaps in collaboration and role education in the South African healthcare

context to ensure continuity and comprehensive care for CL/P infants and their families.

By analysing interdisciplinary perspectives across geographical and clinical settings, this study aims to identify barriers and facilitators to breastfeeding in CL/P cases. The findings will inform evidence-based strategies to improve feeding management and carer support in South Africa, aligning clinical practice with global standards.

2. Method

2.1 Aim

To determine the cleft team members' views on breastfeeding of infants with CL/P.

2.2 Study design

A quantitative, descriptive survey design was employed, yielding predominantly quantitative data with an element of qualitative data. A self-compiled electronic survey was designed to gather the relevant data pertaining to the topic (Schlome et al., 2025).

2.3 Study population and sampling strategy

A stratified, non-probability sampling method was used in this study (Leedy & Ormrod, 2019). To ensure recall accuracy (Erasmus et al., 2023), the study was open to healthcare professionals currently working with or who have worked regularly with infants with cleft lip and/or palate and their families within the past three years in a time-limited sampling approach (Leedy & Ormrod, 2015). English-proficient professionals who have access to an electronic device were targeted, including maxillofacial and oral surgeons, orthodontists, ear-nose and throat specialists, medical doctors, plastic surgeons, neonatologists, dentists, chiropractors, nursing practitioners, dieticians, and lactation consultants. Participants were also allowed to type in another profession as "other" as an option in the demographic section of the survey. Participants were recruited via an electronic survey linked to an advertisement circulated via various social media platforms (see Appendix D). Twenty-one responses were obtained in total. After incomplete responses were deleted, the final sample size was 18 participants.

Table 1. Professional roles and demographic characteristics of participants (n = 18)

Variable	Category	n(%)
Primary Role in CL/P Team	Speech therapists (including one South African Certified lactation consultant)	9 (50%)
	Maxillo-facial and oral surgeons	3 (17%)
	Neonatologists	2 (11%)
	Nursing practitioner	2 (11%)
	Prosthodontist	1 (5%)
	Orthodontist	1 (5%)
Years of experience with CL/P infants	5-10 years	6 (28%)
	11-20 years	7 (39%)
	≥ 20 years	8 (33%)
Primary Sector of work	Private sector	10 (47%)
	Public health	9 (42%)
	Academic institutions	2 (10%)
Province	Gauteng	15 (83%)
	Mpumalanga	1 (5%)
	Western Cape	2 (11%)
Multidisciplinary team involvement (n=18)	Yes	14 (78%)

Table 1 summarises the professional roles and demographic characteristics of the sample. Half of the professionals were speech therapists, while maxillo-facial and oral surgeons, neonatologists, and nursing practitioners accounted for smaller proportions. Participants demonstrated a broad range of experience, with 72% (n=12) reporting more than 10 years of practice with CL/P infants. Almost equal

numbers were employed in private (n=8) and public health sectors (n=9), One participant mainly works in training speech therapy students in an academic institution. The majority of participants were located in Gauteng Province, and most reported involvement in multidisciplinary cleft lip and palate teams.

2.4 Materials

Full disclosure regarding the purpose for and use of the data collected was given to potential respondents in the survey cover letter (Appendix B). The survey questions were adapted from similar, recent qualitative research studies such as Cloete et al. (2019), Nash et al. (2021) and Erasmus et al. (2023) (Appendix F). The original survey questions (Appendix E) were used to compile a pre-test survey.

2.5 Survey design and pretesting

The survey instrument was designed to collect both quantitative and qualitative data relevant to the study objectives. It consisted of 18 questions, including 14 closed-ended questions and 4 open-ended questions (Appendix E). The closed-ended items included a combination of multiple-choice, single-response, yes/no, and Likert-scale formats, primarily focused on demographic information and participants' perceptions and practices (Questions 1–14). The open-ended questions (Questions 15–18) were designed to elicit more detailed, reflective responses on participant experiences and views.

The survey was initially pretested by an independent faculty member not directly involved in the study. Based on their feedback, revisions were made to improve clarity, survey flow, and formatting to enhance respondent understanding and engagement. For example, questions such as "What prognostic factors influence your recommendation of breastfeeding?" and the question to rate their perceived feasibility of CL/P breastfeeding success combined to ask respondents to comment on the open-ended question, "Breastfeeding is possible for infants with cleft lip and/or palate." To avoid the suggested survey ambiguity, closed-ended questions such as "What is your role in the cleft lip/palate team?" were reworded as "What is your primary profession?"

The question, “What are the most common challenges you encounter….”) was expanded to include choice selection of aspiration, difficulty sucking, excessive maternal stress, reflux, poor milk transfer, weight gain, maternal breast or nipple pain, dehydration and excessive wind or cramps to reflect a wider range of professional experiences and perspectives as guided by Erasmus et al. (2023). Lastly, questions asking respondents to rate their satisfaction with current CL/P standards of care and accessibility of healthcare elicited responses outside the scope of this study’s core objectives.

Lastly, questions asking respondents to rate their satisfaction with current CL/P standards of care and accessibility of healthcare elicited responses outside of the scope of this study’s core objectives. The study’s response options for years of professional experience were also revised from the original range (less than 1 year to more than 10 years) to “Less than 5 years” to “More than 30 years” to appeal to a wider distribution of respondents.

Several items were self-developed, while others were adapted from previously validated (Appendix F). The demographic section for this study’s survey was adapted from Cloete et. al, (2020) for reliance on the CL/P professional population. This includes questions regarding the respondent’s primary province of work, years of experience and role within the healthcare team.

For example, the question and corresponding options to the Cloete et al., 2020 survey question, “Where do you work with people with aphasia?” were selected to suit the typical CL/P team member’s treatment contexts (namely private or public healthcare settings). The inclusion of questions on experienced challenges in the management and decision-making factors relevant to the CL/P population and, lastly, the respondent’s estimation of their case load currently breastfeeding was referenced from the Nash et al.(2021) survey study.

2.6 Data collection

The survey was circulated using an active Qualtrics link on the infographic disseminated on various social media platforms and researchers' and supervisors' personal networks. Reminders were sent to ensure that all eligible participants could access the survey for six weeks after initial distribution. Respondents could choose to withdraw their participation at any point by exiting the survey. The average response time was approximately 15 to 20 minutes. Open-ended questions and free-text response content were thematically analysed to deduce recurring or similar patterns in the participants' responses regarding breastfeeding of CL/P infants with the aim of understanding different perspectives within the participants' context as gained from the initial closed-ended questions.

2.7 Data analysis

A manual, thematic, content-based analysis of the gathered data was conducted (Field, 2009). The Quantitative data were manually analysed using descriptive statistics (Brink et al., 2018). The electronic survey was fully completed by 18 respondents. Three incomplete responses were ethically discarded.

3. Ethical considerations

Institutional ethical clearance was obtained from the Research Committee of the Department of Speech-Language Pathology and Audiology at the University of Pretoria prior to the commencement of data collection on 20 February 2025 (Appendix B). Informed consent was obtained from all participants at the beginning of the survey in line with the University of Pretoria's code of ethics for research (University of Pretoria, n.d., p. 12). Participation in the survey was entirely voluntary, and they were made aware of their right to withdraw from the study at any point.

To ensure anonymity and mitigate self-reporting bias, no answers were made compulsory to proceed (American Psychological Association [APA], 2017). Participants' identities remained anonymous, as the Qualtrics survey software only reports the participants' responses, the date of their response, and the time it took to complete the survey. No identifying information can be accessed via the Qualtrics XM software, excluding IP addresses, which were deleted before proceeding with data collection (Qualtrics security statement, 2024). The survey data were accessible solely to the researchers and research supervisors via a double-authentication protection factor.

The responses were not distributed to any third parties nor used for any other means outside of research data collection. The informed consent document was included in the survey to ensure participants were informed of their rights, as presented as a condition before continuing on to complete the aforementioned survey. The survey was distributed via a link and/or QR code provided on the infographic (see Appendix D). To ensure the validity of the data collected, the survey was pretested to ensure clarity of questions, the time taken to complete the survey, and the effectiveness of the Qualtrics link. Analysis of contrary data, feedback from other professionals, and respondent validation were conducted. (Leedy & Ormrod, 2016).

In accordance with the institutional ethical standards as set by the Department of Speech-Language Pathology and Audiology Research Committee at the University of Pretoria, the following ethical principles were adhered to throughout the duration of the study:

3.1. Beneficence and Non-maleficence

Beneficence refers to acting in the best interests of participants, ensuring freedom from harm and protection from exploitation. Researchers considered this principle by safeguarding participants' well-being. A well-set-out and carefully curated survey questionnaire was distributed to ensure that the questions would not distress the participants. The use of an online survey also aligns with ethical research standards by minimising environmental impact.

Participants were informed that participation in the study poses no risks and will not cause any stress or discomfort. The survey was pretested and reportedly took approximately 15-20 minutes to complete. Participants were informed of their right to withdraw from the study at any time, without consequences.

3.2. Autonomy and Informed Consent

Participants were asked to provide informed consent via a digital form, which clearly discloses the study's purpose, aim, objectives, and procedures. The disclosure emphasised that participation is completely voluntary, with no coercion, incentives, or penalties for withdrawing at any time.

According to the Declaration of Helsinki 1964, the study's purpose should not override participants' best interests. Therefore, participants ' dignity, integrity, privacy, and right to self-determination were respected through the informed consent process

3.3. Justice

All eligible participants meeting the inclusion criteria have an equal opportunity to participate in the study. Exclusion only occurred for reasons directly relevant to the study, ensuring fairness in participation selection.

3.4. Confidentiality

Data will be stored in a password-protected folder within the University of Pretoria's repository and then deleted in 10 years in compliance with the university's data management policy. The survey software will maintain participant anonymity, increasing the likelihood of honest and reflective responses. If any personal contact details or identifiable information are collected, they will be kept strictly confidential.

3.5. Reliability, validity, and trustworthiness

A systematic, detail-orientated, and consistent data collection process and method was used until a valid conclusion was reached, ensuring that the collected data is objective, dependable, and consistent (Brink et al., 2018).

Internal validity was controlled by the researchers to ensure the data were not influenced or manipulated in a manner that affected the study's outcomes (Brink et al., 2018). It should be noted that the contextual nature of the study and the social disparity in the contexts where participants practice present confounding variables that threaten internal validity (Leedy & Ormrod, 2016).

Neutral language used in the survey, along with the assurance of confidentiality, safeguarded against skewed answers and potential research or participant bias. As this study deals with personal experiences, participants may interpret questions through the lens of their lived experiences, influencing their responses. This was taken into consideration during data collection (Skelly et al., 2012). The retrospective research design of this study also controls the attrition and maturation of participant responses over time (Brink et al., 2018).

To ensure the validity of the data collected, we implemented triangulation of sources, analysis of contrary data, feedback from other professionals, and respondent validation (Leedy & Ormrod, 2016). The design of an online survey improves the external validity of this study and allows for easy republication and generalisation of findings. Although a random stratified sampling technique aimed to achieve depth of knowledge rather than a broad population representation, sampling bias was avoided by collecting a rich understanding of experiences.

The survey included consistent, clear, and relevant questions to achieve a specific aim and the subsequent objectives of the study. No leading questions that may skew the data towards a particular perspective were asked. Once collected, data will be securely stored in line with ethical principles for data management (Brink et al., 2018).

Results:

Demographic respondent description

Eighteen professionals participated in the study. The team members represented were Maxillo-facial and oral surgeons (n=3; 17%) and Neonatologists (n=3;17%), A nursing practitioner (n=1;5%), a prosthodontist (n=1;5%) and an orthopaedist (n=1;5%).

The majority of the sample were qualified speech-language therapists (n=9;47%), one of whom is also a South African certified lactation consultant (n=1). Most respondents had between eleven and twenty years of experience (n=7;39%) in working with infants with CL/P. All participants met the minimum inclusion criteria of having worked with the CL/P population for at least five to 10 years (n=6;28%) .

The participants were or are currently employed in the private sector (n=10;47%) in the Gauteng province (n=16;84%) or report having worked in various settings, mainly the public health sector (n=9;42%) and including academic institutions (n=2;10%) as optionally specified in the survey. Most of the adjusted sample (n=14;78%) reported current or past experience working within a CL/P multidisciplinary team.

Perceived facilitators to successful breastfeeding

Participants identified several facilitators that could improve breastfeeding feasibility. Tailored adaptations were the most frequently suggested strategies, including specialised positioning techniques (n=8;47%), feeding plates or equipment (n=5; 29%), and alternative feeding with expressed breast milk, such as cup feeding (n=6; 35%). These strategies were often described as successful when combined with *“counselling” (*50%); “continuous *support”* (n=6;33%), by maxillofacial surgeons and nurses with 5+ years of experience in the public health sector and *“confidence-building for mothers through evidence-based education” by* 2 public health care nurses and an SLT with 30 + years of experience in both private and public healthcare.

Perceived decision-making barriers to successful breastfeeding

The majority of participants (n=16;94.1%) reported that the most significant barrier to breastfeeding infants with cleft lip and/or palate (CL/P) was the presence of physiological limitations. The type and severity of the cleft were perceived as determinants of feeding outcomes. Cleft palate, in particular, was linked to *"nasal regurgitation," "poor milk transfer", "intraoral pressure deficits",* and *"infant fatigue"* by most professionals (n=10;55.5%). Participants shared that challenges were compounded when comorbid conditions were present.

Congenital conditions which result in anatomical malformations, namely Pierre Robin Sequence (PRS), were mentioned twice. One participant explained that *"PRS micrognathia, glossoptosis, and a cleft palate compromise make successful breastfeeding impossible"* (Participant < 30 years of experience, private healthcare setting). Similarly, a participant described that *"sucking is often a problem depending on the extent of the cleft palate, with milk going into the nasal passage"* (< 11 years of experience, public maternity ward).

Beyond anatomical barriers, systemic and knowledge-related constraints emerged (n=13;76.5%). Several SLT participants raised concerns about gaps in team members' feeding intervention skills, noting that *"another barrier may be a lack of breastfeeding intervention skills on the part of the team"* (21–30 years of experience, public healthcare). Misinformation and assumptions about breastfeeding feasibility were also described, sometimes resulting in mothers being discouraged from attempting breastfeeding. As one SLT highlighted, *"Public knowledge of the value of breastfeeding for child survival has been eroded to a large extent, resulting in families not giving sufficient breastfeeding support to mothers." (11+ years experience in private health care)*

Psychosocial and maternal factors were viewed as further limiting breastfeeding success. Participants consistently described *"maternal fear," "low confidence,"*

"excessive stress," and *"shock of CL/P"* as key influences, often resulting in reduced milk supply and shortened breastfeeding duration.

While over half of participants (n=9;52.9%) reported that they "often" recommend breastfeeding, the majority (n=14;82%) estimated that less than half of infants with CL/P under their care actually receive breastfeeding, as summarised in *Figure 1*.

Professional beliefs and approaches

When appropriate structures were in place, some respondents believed breastfeeding was achievable (n=6;35%). As one SLT explained, *"Yes, [breastfeeding is possible] with support and early identification, the correct methods (mixed breast and bottle feeding or positioning)... and equipment (e.g., feeding plate) added to support families." (20+ years' experience in a public health setting).*

Specialised disciplines such as surgeons and prosthodontists were generally conservative, emphasising the need to determine cleft type and extent before predicting feeding outcomes (n=4;24%). For example, one prosthodontist stated, *"Breastmilk is more important than the act of breastfeeding, and breastfeeding can be considered if a suitable plate has been made"* (21+ years of experience, public healthcare). Similarly, several maxillofacial surgeons noted that while an isolated cleft lip was associated with positive outcomes, *"Cleft lip and cleft palate will do badly, and PRS will do worse,"* which may highlight practice-related variables in breastfeeding recommendations (Figure 2).

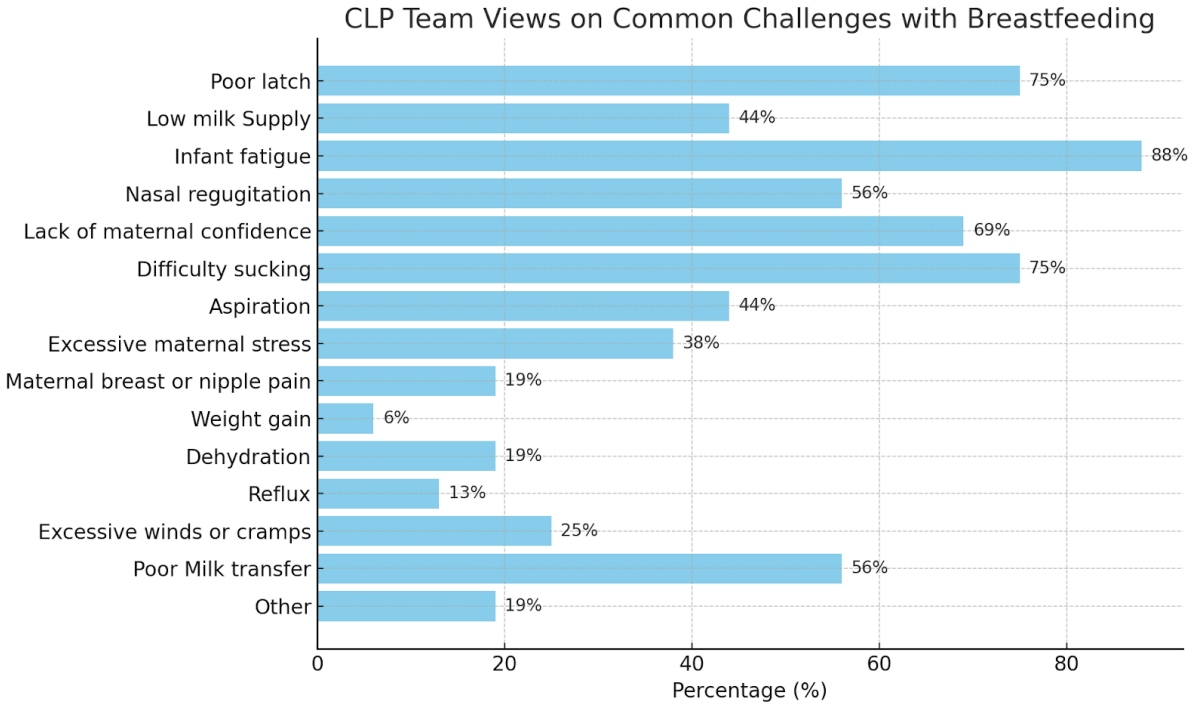
Specific infant and maternal challenges encountered

The most commonly reported challenges (n=16;94.1%) perceived across disciplines were consistent and clustered into two domains: Infant-related challenges such as poor latch (n=12;75%), infant fatigue (n=14;88%), nasal regurgitation (n=9;56%), aspiration (n=7, 44%), and sucking difficulties (n=12;75%). Maternal challenges that most frequently factor into breastfeeding success reportedly include low milk supply (n=7;44%), lack of maternal confidence (n=11;69%), and excessive stress, which further exacerbates poor lactation (n=6;38%). These led to poor breastfeeding

outcomes according to the respondents' professional experience. Consequent poor weight gain (n=7;44%) and milk transfer (n=9;56%), and excessive air intake (n=4;25%) are among the most prevalent challenges reported (Figure 1).

Figure 1:

Perceived Challenges in Supporting Breastfeeding of Infants with CL/P.



Multidisciplinary involvement and systemic barriers

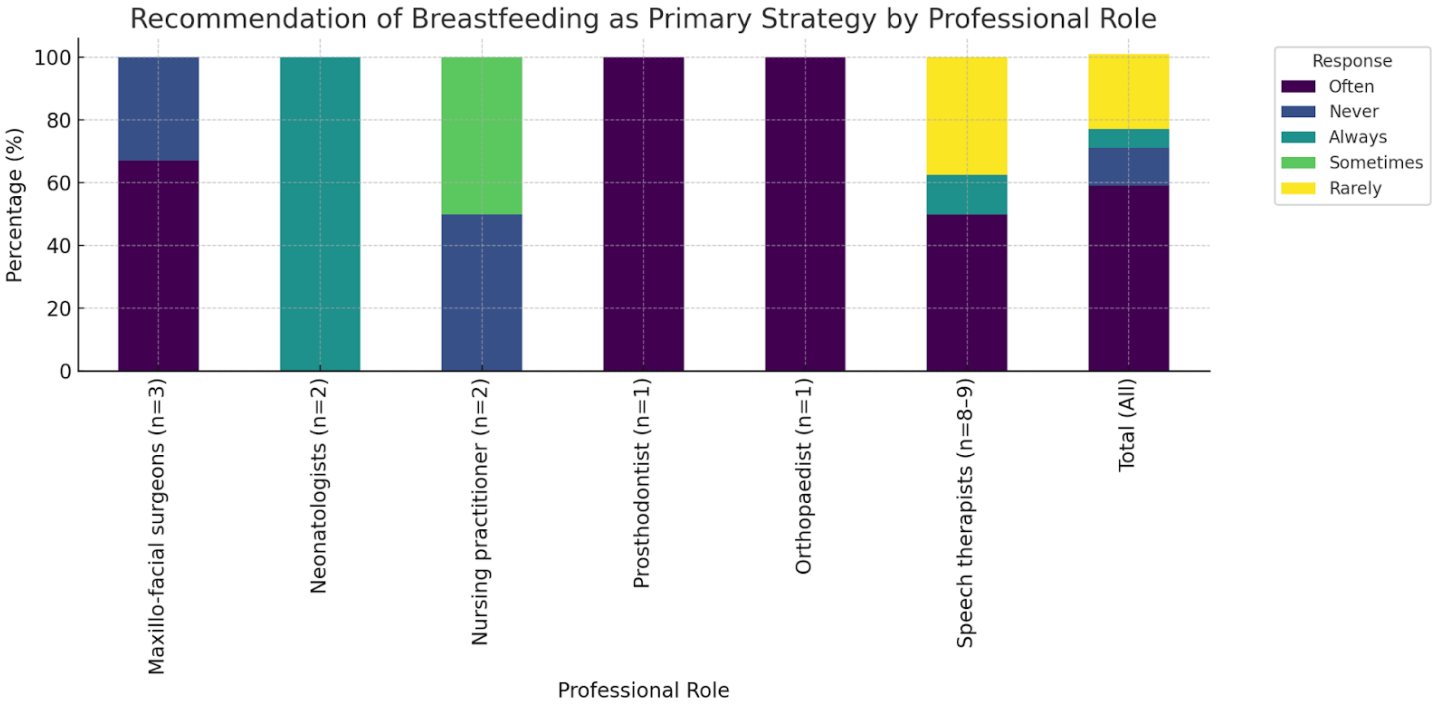
As represented in Figure 2, although most respondents (n=5;83%) acknowledged the role of multidisciplinary team involvement, explicit referral to other team members was only reported in three responses (18%). Importantly, breastfeeding was described as a desirable outcome by many professionals (n=7;39%). Actual success, however, was perceived to be by the multifactorial nature of CL/P feeding challenges (n=16;89%), constrained by maternal motivation (n=13;72%) and healthcare system limitations (n=9;50%),

Overall, there was strong recognition that outcomes remain suboptimal (n=14; 78%), largely due to systemic barriers and inconsistent clinical guidance. Differences in

professional beliefs and approaches often reflected varying levels of training, experience, and disciplinary focus.

Figure 2:

Likelihood of recommending breastfeeding as the primary feeding strategy for CL/P infants.



Discussion

This study explored views of South African CL/P team members regarding breastfeeding. The results highlighted that feeding outcomes are influenced by infant-related, maternal, professional, and systemic factors.

The majority of respondents were experienced speech-language therapists (SLTs), reflecting their central role in early feeding management and the increasing recognition of their expertise in this domain (Kritzinger et al., 2024). Their strong representation suggests that SLTs' perceptions may strongly shape family guidance and high-risk infant oral-feeding interventions (Dludla et al., 2025). Conversely,

relatively few surgical and medical specialists participated, which may have limited the diversity of perspectives captured.

Almost all participants identified physiological limitations, particularly the type and severity of cleft, as the most significant barriers to breastfeeding. Cleft palate was frequently associated with nasal regurgitation, reduced intra-oral suction, infant fatigue, and poor milk transfer, while co-morbidities such as Pierre Robin Sequence (PRS) compounded these difficulties. These findings mirror reports by Kummer (2020) and Liu et al. (2024), who highlight that anatomical restrictions remain the primary determinant of feeding success.

Maternal confidence, stress, and adjustment to the CL/P diagnosis were described as central determinants of breastfeeding outcomes in this study, aligning with Erasmus et al. (2023), who identified maternal psychological state as a key predictor of breastfeeding sustainability despite anatomical barriers. Additionally, the respondents in a study by Intiful et al. (2025) consistently reported that maternal anxiety and stress contributed to reduced milk supply and early transition to expressed breast milk or formula. For CL/P team members, these psychological barriers reinforce the need for active multidisciplinary collaboration to integrate maternal counselling, reassurance, and confidence-building into feeding interventions.

Systemic and knowledge-related barriers were also frequently reported, with nurses and SLTs highlighting gaps in feeding intervention skills across disciplines; this includes reporting reduced breastfeeding attempts and premature reliance on formula feeding by CL/P mothers in their caseload. Some respondents also

expressed concern that families were discouraged from breastfeeding due to misinformation or professional assumptions about feasibility. Similar sentiments were reported by South African SLTs in the recent study by Schlome et al. (2025), who emphasised that when direct breastfeeding is not feasible, practical alternatives must be given through clear and comprehensive counselling.

Such guidance may promote informed carer decision-making and establish realistic expectations regarding their infant's feeding outcomes. This echoes Nabatanzi et al. (2022), who found that professional guidance can strongly influence maternal decision-making and confidence to breastfeed.

Findings further encourage the urgent need for training across the CL/P team to ensure consistent, evidence-based support through early identification of feeding difficulties, followed by ongoing, detailed support (McGrattan et al., 2023). This includes CL/P-specific breastfeeding guidance to reduce caregiver reliance on self-directed feeding solutions for their CL/P infants, as suggested by Erasmus et al. (2023).

Although most respondents acknowledged breastfeeding as an achievable and desirable outcome, only a minority believed it was consistently feasible without adaptations. Facilitators included positioning techniques, feeding equipment, and the provision of expressed breast milk. These strategies align with international recommendations (Kummer, 2020; ACPA, 2024) and demonstrate that, with appropriate support, breastfeeding may be possible for some infants with less severe clefts.

However, specialist respondents, such as surgeons and prosthodontists, generally held more conservative views, emphasising cleft type and extent as determinants of feeding outcomes. In the case of cleft palate, the professionals emphasise that infants with CL/P must receive specialised feeding equipment prior to or as an alternative to breastfeeding. However, the reported limited access to such resources in South African public health sectors further exacerbated breastfeeding challenges.

In such cases, the need for stronger referral pathways and systemic advocacy to improve access to resources is highlighted, as found by Hollingsworth et al. (2024). (Hlongwa & Risper, 2021).However, while most respondents acknowledged the theoretical importance of multidisciplinary team involvement, explicit referrals to other professionals were rarely reported. This finding aligns with Hlongwa and Risper's (2021) evaluation of CL/P care in South Africa to suggest suboptimal interprofessional collaboration despite the presence of multidisciplinary structures, leading to weak health system responsiveness to the CL/P population.

Hlongwa and Rispel's 2021 Ekhaya Lethu Model also identifies that parents must be equal partners in CL/P care. However, the current study's findings further reveal limited mention of involving the infant's mothers as valued CL/P team members, which may explain reported reduced multidisciplinary involvement to provide adequate breastfeeding support.

This result is similar to that of Schlome et al. (2025) and Bow et al. (2025) studies on local breastfeeding management and international CL/P multidisciplinary team dynamics, which suggests that although collaborative care is valued, its implementation remains inconsistent or ineffective in ensuring continuity of care for

CL/P infants and their families. This further highlights the gap between evidence-based ideals and clinical realities in resource-limited contexts.

Clinical implications

The findings of this study emphasise the multifactorial nature of breastfeeding challenges in infants with CL/P and highlight the need for consistent, team-based approaches. For medical and allied healthcare team members, this means providing direct feeding intervention while playing a central role in caregiver counselling, interdisciplinary training, and advocacy for resource allocation in the South African context.

For parents, it underlines the importance of receiving practical, consistent, and supportive guidance tailored to both infant needs and maternal wellbeing. This may be achieved by increased cross-disciplinary role knowledge as a part of structured team meetings (Hollingsworth et al., 2024; Hlongwa et al., 2024) or by creating opportunities for postgraduate subspeciality training in CL/P management, as theorised by Ghabrial et al. (2024), to potentially enhance professional collaboration and quality of care through interdisciplinary role-sharing.

Study limitations

The study had several limitations. The sample size was relatively small and skewed toward SLTs, which may limit the generalisability of findings across all CL/P professionals. In addition, the majority of respondents were based in Gauteng, suggesting limited geographic representation of the South African healthcare system. Self-reported data may also have introduced response bias.

Recommendations for future research

Future studies should aim to include a more balanced representation of CL/P professionals, particularly surgeons, nurses, and lactation consultants, across diverse provinces and healthcare sectors. Further investigation into parental perspectives would provide valuable insight into how multidisciplinary professional guidance is perceived and implemented in practice.

Additionally, research exploring structured practical implementation of multidisciplinary training interventions may help address gaps in team alignment and skill-sharing to improve breastfeeding outcomes in this population. According to Hlongwa and Rispel (2021), this may involve moving beyond siloed communications by creating channels for role education and dynamic, genuine bidirectional collaboration between all CL/P team members to ensure CL/P breastfeeding management is a holistic, family-centred process from which parents and infants can benefit.

Conclusion

The results of this study show that South African CL/P team members regard breastfeeding as an important, but challenging, feeding approach. Breastfeeding outcomes were often dependent on a combination of the individual infant's physiology, their healthcare context, and maternal motivation as decision-making variables. The findings underscore the variability in care and the compounding influence of professional experience and disciplinary perspectives on feeding recommendations, including multidisciplinary collaborations.

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Appendix A: Ethical clearance

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100. Since 1919

Department of Speech- Language Pathology and Audiology

20 February 2025

Dear Researchers,

Project:	Cleft team members' views on breastfeeding of infants with cleft lip and palate
Researchers:	Justine Naude (u22527372) , Kristen Patrick (u22756800) , Aaliyah Saloojee (u22718517)
Supervisors:	Prof E Krüger, Ms B Pillay
Department:	Department of Speech-Language Pathology and Audiology
Reference Number:	SLPA2025/09

Thank you for the application submitted to the Research Committee of the Department of Speech-Pathology and Audiology, Faculty of Humanities. We have the pleasure of informing you that the above application was approved on 20 February 2025.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal.

We wish you success with the project.

Sincerely

Prof Lidia Pottas
Chair: Departmental Research Committee

Prof J van der Linde
HEAD: DEPARTMENT OF SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY
UNIVERSITY OF PRETORIA

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Appendix B: Survey cover letter

UNIVERSITEIT VAN PRETORIA
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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100. Since 1919

Department of Speech- Language Pathology and Audiology

We are final year Speech therapy students at the University of Pretoria. We are currently conducting research on the topic, *Cleft team members views on breastfeeding infants with Cleft Lip and/ Palate (CL/P)*. Your experience and expertise are crucial and valuable for understanding the challenges and best practices surrounding breastfeeding infants with CL/P and your responses will contribute to important insights in this field.

To achieve this, we kindly invite you to participate in an online survey which aims to explore your views and experiences on the support and management of breastfeeding infants with CL/P. The online survey should take about 15-20 minutes complete and consists of short and longer type of questions.

The purpose of this survey is to:

- Understand the perspectives and challenges faced by cleft team members in supporting breastfeeding for infants with CLP in the South Africa healthcare context.
- Identify strategies that can improve outcomes for both the infants and their families.
- Contribute to the development of evidence-based guidelines that could enhance clinical practice and improve feeding support and cleft care strategies in South Africa.

Confidentiality and Consent

Please note that your participation is entirely voluntary, and all responses will be kept confidential. The data collected will be anonymized and used solely for research purposes. By completing the survey, you are providing consent to participate in this study. Should you decide at any point to withdraw from the survey, you may do so without any consequences.

How to Participate

To participate, please follow this link to the survey:

If you have any questions or concerns about the study, please do not hesitate to contact us or our supervisors.

Research Supervisors

Dr E. Kruger: esedra.kruger@up.ac.za

Mrs B. Pillay: bhavani.pillay@up.ac.za

Student Researchers

Kristen Patrick: u22756800@tuks.co.za

Justine Naude: u22527372@tuks.co.za

Aaliyah Saloojee: u22718517@tuks.co.za

Thank you very much for your time and contribution to this important work. Your expertise is greatly appreciated!

Appendix C: Permission letter to post on social media groups

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

To Whom It May Concern,

We are undergraduate Speech-Language Therapy students at the University of Pretoria pursuing research regarding the views of cleft lip and palate (CL/P) team members on breastfeeding of infants with CL/P. We would like to request to post an infographic with a link to an electronic survey as a means to collect data for this research on your social media group.

This study will be submitted to receive ethical clearance by the Faculty of Humanities at the University of Pretoria. Our supervisors are Dr Esedra Krüger and Mrs. Bhavani Pillay. The electronic survey will specifically target South African Speech-Language Therapists, Maxillofacial and Oral surgeons, Lactation Consultants, Ear, Nose and Throat specialists (ENTs) and any other qualified CL/P support staff with the necessary experience to provide their views on breastfeeding of infants with CL/P.

The questionnaire should take no longer than 10 to 15 minutes to complete and all responses will be anonymous. Your permission would be greatly appreciated.

Should you have any questions, please contact Dr Krüger at esedra.kruger@up.ac.za or Mrs Pillay at bhavani.pillay@up.ac.za

Kind regards
Justine Naude, Kristen Patrick and Aaliyah Saloojee – Researchers

Dr Esedra Krüger
Supervisor

Mrs Bhavani Pillay
Supervisor

Appendix D: survey infographic

Appendix E: Pre-test survey

Breastfeeding of infants with CLP: Cleft team members' views

1. What is your role in the cleft team?
   - Maxillofacial surgeon
   - Pediatrician
   - Orthodontist
   - ENT (otolaryngologist)
   - Speech therapist
   - Lactation consultant
   - Other (please specify) _____

2. How many years of experience do you have working with infants with CL/P?
   - Less than 6 months
   - 6 months to 1 year
   - 1-5 years
   - More than 5 years
   - More than 10 years

3. In which type of healthcare sector do you work?
   - Public healthcare setting (hospitals or community health centers)
   - Private healthcare setting
   - NGO clinic or organization
   - Other (please specify) _____

4. In which province of South Africa do you work?
   - Eastern Cape
   - Free state
   - Gauteng

- KwaZulu Natal
- Limpopo
- Mpumalanga
- Northern Cape
- North West
- Western Cape

5. Do you, or have you worked in a multidisciplinary CL/P team?

- Yes
- No

6. Do you encourage breastfeeding as a treatment strategy in the management of infants with CL/P

- Yes
- No

7. Do you believe breastfeeding is feasible for infants with cleft lip and or palate?

- Yes
- No
- Unsure

8. On a scale of 1-5, how effective do you think breastfeeding is compared to alternative feeding methods (eg. Bottle feeding) for infants with CL/P in a South African context?

- 1
- 2
- 3
- 4
- 5

9. How often do you recommend breastfeeding as the primary feeding strategy for infants with CL/P?

- Always

- Often
- Rarely
- Never

10. How many of the infants with cleft lip and/or palate under your care are exclusively breastfed?

- None
- Less than half
- Half
- More than half

11. How would you rate the overall support for breastfeeding infants with cleft lip and/or palate in your healthcare setting?

- Very effective
- Effective
- Neutral
- Ineffective
- Very ineffective

12. What are the most common challenges you encounter when supporting breastfeeding in infants with cleft lip and/or palate?

- Poor latch
- Low milk supply
- Infant fatigue
- Nasal regurgitation
- Lack of maternal confidence
- Other (please specify)

13. Rate your level of satisfaction with the current standards for breastfeeding management of infants with CL/P

- Non- satisfactory
- Satisfactory
- Very satisfactory

14. In your experience, what are the most significant barriers to breastfeeding infants with CLP? _____
_____
_____
_____
_____

15. Which feeding strategies are most effective (in terms of health markers such as sufficient weight gain) for infants with CL/P under your care?_____
_____
_____
_____
_____

16. What role do you think cleft team members play in encouraging or discouraging breastfeeding of infants with cleft lip and/or palate?_____
_____
_____
_____
_____

17. Do you think that healthcare professionals are easily accessible in the South African healthcare setting to support the breastfeeding of infants with CL/P?

- Yes
- No
- Unsure

18. In your professional opinion, what prognostic factors influence your decision when recommending breastfeeding for infants with cleft lip and/or palate?_____
_____

Appendix F: Table of survey question adaptations:

Table of proposed survey questions and adaptions

Original question (Cloete, 2017; Nash, 2021)	The question used in the current research survey	Rationale
Team members involved in your clinical or professional team (n = 318)‡ • Dietician • Speech-language therapist • Physiotherapist • Nurse • Physician • Occupational therapist • Social worker • Neurologist • Psychologist	1. What is your role in the cleft team? • Maxillofacial surgeon • Pediatrician • Orthodontist • ENT (otolaryngologist) • Speech therapist • Lactation consultant • Other (please specify)_____	The target research population is those professionals who would potentially be a member of a CL/P care team with the option to specify a profession not listed to accurately represent diverse team members.
Graduated (n = 47)‡ **< 5 years ago** **6–10 years ago** **11–15 years ago** > 16 years ago	2. How many years of experience do you have working with infants with CL/P? • Less than 6 months • 6 months to 1 year • 1-5 years • More than 5 years • More than 10 years	Participants should fall under the inclusion criteria of having had experience working with infants with CL/P for at least 3-5 years to account for recent research whilst ensuring the necessary level of expertise and credibility to provide the insights needed for the prospective findings. The answer options have been narrowed down to smaller intervals for quicker response times.
Where do you work with people with aphasia? (Please select all that apply) • Acute care • Sub-acute • care facility - • Inpatient • rehabilitation • Primary • healthcare • setting • Public hospital • setting	3. In which type of healthcare sector do you work? • Public healthcare setting (hospitals or community health centers) • Private healthcare setting • NGO clinic or organization • Other (please specify) _____	This will provide valuable information in regard to different working environments which may have varying resources available, breastfeeding practices as well as patient populations which may affect the efficacy of services provided. The number of options has been reduced for relevance to our target population and to

• Outpatient • rehabilitation • Early • supported **discharge** • Community • Long-term • care • Nursing homes • Private • practice • University • Other (please specify)		shorten the answering time required of participants.
Province where service is rendered (n = ~~43~~)† • Eastern Cape • Free State • Gauteng • KwaZulu-Natal • Mpumalanga • Northwest • Western Cape	4. In which province of South Africa do you work? • Eastern Cape • Free state • Gauteng • KwaZulu Natal • Limpopo • Mpumalanga • Northern Cape • North West • Western Cape	The target population is South African healthcare professionals to understand the distribution of relevant professionals in these areas which may shape their views on breastfeeding of infants with CL/P as well as to ensure reliability and validity by obtaining a representative sample, adding Limpopo as an option.
Are you a part of the multidisciplinary team (MDT) involved in decision-making for care and intervention for PWD?	5. Do you, or have you worked in a multidisciplinary CL/P team? • Yes • No	Whether or not the target professionals have worked in a multidisciplinary team may affect their experiences and views to those who have not and may influence their attuited towards working with the population. The question has been shortened for brevity.
Your regulatory body stipulates the role of feeding and swallowing (n = ~~47~~)† • Yes • No	6. Do you encourage breastfeeding as a treatment strategy in the management of infants with CL/P • Yes • No	This question from Cloete, 2017 is specific to the role of speech-language therapists. We have changed
	7. Do you believe breastfeeding is feasible for	Allow to analyze comparing views and attitudes of

	infants with cleft lip and or palate? • Yes • No • Unsure	professionals to identify similarities and differences which varying opinions in CLP management and identify patterns and draw potential conclusions or correlations between circumstance and implementation as set by the demographic collection. Which is a mixture of similar questions in an even distribution
Considerations guiding decision-making (n = 101)± Age and cognitive level of functioning • Severity and progression of the dementia • Quality of life of and level of support and/or post-tube insertion • Family's wishes and cultural beliefs • Swallowing abilities	8. On a scale of 1-5, how effective do you think breastfeeding is compared to alternative feeding methods (eg. Bottle feeding) for infants with CL/P in a South African context?	Question adapted to suit the needs of the research topic with the use of a rating scale for increased response efficiency
	9. How often do you recommend breastfeeding as the primary feeding strategy for infants with CL/P? • Always • Often • Rarely • Never	
How many people with aphasia on your caseload are experiencing psychological difficulties? • None • Less than half • Half • More than half • All	10. How many of the infants with cleft lip and/or palate under your care are exclusively breastfed? • None • Less than half • Half • More than half	The answers to these questions are also on a Likert scale as used in Nash,2021 for response efficiency as well as to account for the unlikelihood that professionals would know the exact percentage of breastfed infants. All

		have been removed as it is not feasible for all infants to be exclusively breastfed.
	11. How would you rate the overall support for breastfeeding infants with cleft lip and/or palate in your healthcare setting? • Very effective • Effective • Neutral • Ineffective • Very ineffective •	Gauging the perceived level of support will assist in gaining valuable insight into how their experiences in the healthcare setting have influenced the previous question regarding their belief in the feasibility of breastfeeding CL/P infants. This can also highlight gaps in available support in the professional's context.
Challenges often experienced in decision-making regarding tube feeding (n = ~~57~~)‡ • Family members' insight, perception, and cultural values • SLT's personal beliefs system and bio-ethical concerns • Lack of support from other healthcare professionals	12. What are the most common challenges you encounter when supporting breastfeeding in infants with cleft lip and/or palate? • Poor latch • Low milk supply • Infant fatigue • Nasal regurgitation • Lack of maternal confidence • Other (please specify)	This question has been altered for relevance to challenges specific to breastfeeding challenges often faced regarding the feeding of infants with CL/P
	13. Rate your level of satisfaction with the current standards for breastfeeding management of infants with CL/P • Not satisfactory • Satisfactory • Very satisfactory	This question ties back to contextualizing participant responses and determining factors that may influence a cleft team member's view on CL/P breastfeeding. A Likert scale has once again been used for respondent ease which may assist in reducing possible non-response errors
	14. In your experience, what are the most significant barriers to breastfeeding infants with CLP?	