Research Article

# Prevalence of Breastfeeding in Infants with Cleft of Lip / Palate and Challenges Faced by Mothers in Pakistan

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## Abstract

**Background:** Cleft lip and cleft palate is congenital abnormality in which problem of feeding occurs immediately after birth, especially if the mother has first child and there is no family or expert medical support. Epidemiological data on prevalence of breastfeeding and its barriers among these children is significantly lacking. Our primary aim was to estimate the prevalence of breastfeeding among infants with cleft lip and/or palate in the city of third world country like Pakistan. Our secondary aims were to determine the challenges faced by mothers when breastfeeding these infants, and the extent of education/support they received.

**Methodology:** We conducted questionnaire-oriented interviews with mothers of infants born with oral clefts. All patients who presented to the cleft clinic in the study period were interviewed. Infants with co-morbid conditions were excluded to limit confounders. Data was compiled into and analysed using Statistical Package for Social Sciences Version 23.0

**Results:** We recruited 336 participants in our study. Mean age of children was 10.5 months (standard deviation ± 7.6), and their age at the time of surgery ranged from 3 month to 3 years. 97.3% of mothers had the intention of breastfeeding their child before birth but only 75.9% could do so while 13% of these children were exclusively breastfed. 63.7% of mothers reported receiving feeding advice.

**Conclusion:** Prevalence of breast feeding was poor. One mother out of four was not able to feed their children due to various reasons. Mothers face inadequate guidance and lack of financial and moral support from families.

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## Introduction

Oral clefts are one of the most common craniofacial birth defects.[1] The mean incidence of orofacial clefts in Pakistan is 1.91 per 1000 births (one per 523 births).[2]

The first problem which parents encounter is to how to feed a child with cleft lip and cleft palate (CLP).[3] Breastfeeding is a major challenge in the immediate antenatal period for an infant with CLP. This requires significant guidance for the parents, and certain adjustments and accommodations to meet the nutritional and hydration needs of the infant.[4,5]

Due to their altered anatomy, infants with CLP cannot suck properly, generating a plethora of problems such as choking, nasal regurgitation and prolonged feeding time.[6]

Very few studies have been carried out globally and no study in Pakistan to assess the perception and behavior of mothers concerning breastfeeding for infants with CLP.[7]

The primary aim of our study was to estimate the prevalence of breastfeeding among infants with cleft lip

and/or palate in Pakistan. Our secondary aims were to determine the challenges faced by mothers when breastfeeding these infants, and the extent of education/ support they received.

## Methodology

A cross-sectional study was designed, which was carried out using questionnaire-based interviews. This was deemed to be the most appropriate study design to obtain data from the all study participants in a systematic and consistent manner, while eliminating interviewer bias by using a standard questionnaire as our tool. The study protocol was reviewed by the Institutional Review Board at Al-Mustafa Hospital, and deemed exempt.

Our study was conducted at the Al-Mustafa Hospital in Karachi, Pakistan over a period of eight months from April 2021 to December 2021. Karachi is the largest city of Pakistan with a population of more than 30 million people, comprising of a mixture of all the major ethnic groups found in Pakistan.[8] The public healthcare system is severely underfunded, and the bulk of medical services are provided by smaller private hospitals that may be for-profit, or supported by charitable donations. Our study site is a hospital that is predominantly supported by charity, and caters to all patients regardless of their financial background.

We utilized convenience sampling by recruiting mothers of CLP children aged 3 years and younger presenting to the cleft clinic during the study period. To limit effect of confounders, we excluded mothers of children suffering from comorbid conditions or congenital disorders such as congenital heart disease or chromosomal disorders as these can be independently associated with breastfeeding challenges. We did not offer compensation for study participation, and recruited a total of mothers of 336 children during the 8-month study period.

We divided the type of orofacial clefts encountered into 4 categories as per described by Kernahan.[9]

Unilateral cleft lip (incomplete or complete), bilateral cleft lip (incomplete or complete), unilateral cleft lip with cleft palate (anterior or full cleft palate), bilateral cleft lip with cleft palate (anterior or full cleft palate) and isolated cleft palate (unilateral, bilateral or median). Cleft lip can be complete or incomplete based on the extent of the cleft through the lip and into the nasal floor. When associated with cleft lip, cleft palate can be anterior, i.e. only extending to incisor foramen or full i.e. extending beyond it. Isolated cleft palate can be median, unilateral or bilateral. We did not measure the cleft size by any tool, but noted the type of cleft as was described by the surgical team at Al-Mustafa Hospital. We collected data pertaining to basic demographics of the children and their mothers, as well as questions about the child's diagnosis, and continuous or exclusive breastfeeding practices before and after surgical repair. We went into detail about their intention to breastfeed prior to birth of the child, method of breastfeeding (if any), difficulties encountered by mothers and any support and/or guidance they might have received during their breastfeeding practice. We also went on to record whether they commenced breastfeeding post-operatively till one week. Exclusive breastfeeding was defined as the child being fed expressed mother's milk or directly at the breast without the ingestion of any other solids or liquids for the first six months of life or beyond, as recommended by the World Health Organization. Complementary feeding was defined as the child receiving mother's milk supplemented by other sources of nutrition and hydration, e.g. cow's milk or formula milk.

For the purpose of data collection, we constructed a questionnaire consisting of a series of questions. Verbal consent was taken from all mothers before conducting personal interviews with them. All interviews were conducted personally by doctors working on the cleft team, and conducted in Urdu, which is the national language of Pakistan. The questionnaire was similarly designed in Urdu.

We used IBM SPSS (Statistical Package for Social Sciences Version 23.0) for data management and statistical analysis. Descriptive statistics included mean (standard deviation) for continuous variables and proportions for categorical variables. The chi-squared test and the t-test were used to perform inferential statistics where appropriate, with the confidence interval set at 99% and a p-value $< 0.05$ considered as significant.

## Results

Mothers of 336 children were recruited with CLP during the 8-month study period, and the distribution included 65 (19.3%) children with unilateral cleft lip, 13 (3.9%) with bilateral cleft lip, 134 (39.9%) with unilateral cleft lip and palate, 60 (17.9%) with bilateral cleft lip and palate and 64 (19.0%) with isolated cleft palate. Mean age of the children in our study was 10.5 months (standard deviation ± 7.6), and their age at the time of surgery ranged from 3 month to 3 years. Demographic and socioeconomic characteristics of the study children and

their mothers are displayed in Table 1. Majority of mothers were aged 26-35 years (53%), had received education of primary level or below (53.6%), belonged to lower socioeconomic groups (93.4%) and were multiparous (74.1%) with only one child afflicted with cleft lip and/or palate (94.8%).

Table 2 highlights participant breast feeding practices by type of orofacial cleft. Our data shows that 327 (97.3%) mothers intended to feed breast milk before birth but only 255 (75.9%) could do so. Of these 255 infants, 168 (65.9%) stopped receiving breast milk before the age of 6 months, whereas the remaining 87(34.1%) continued to receive breast milk either exclusively (n=45) or complemented (n=42). There was a significant difference in prevalence of breastfeeding amongst different cleft types (p=0.03). It was most prevalent for children with isolated cleft lip (91%) and least amongst children with unilateral cleft lip and palate (67.2%). There was no statistically significant difference in prevalence of breastfeeding between children with combined cleft lip and palate when compared to infants with isolated cleft palate (p=0.28). However, a statistically significant difference was noted when comparing prevalence of breastfeeding in children with combined cleft lip and palate to infants with isolated cleft lip (p< 0.001).

The average length per breastfeeding session was 17.3 minutes (SD=14.4) and the average number of breast-

**Table 1:** *Socio-demographic characteristics of children born with cleft lip and/or palate and their mothers. (n=336)*

| Variables | N (%) |
|---|---|
| **Child's age (months)** | |
| Less than 6 | 108 (32.1) |
| 6 – 12 | 142 (42.3) |
| 13 – 24 | 75 (22.3) |
| 25 – 36 | 11 (3.3) |
| **Mother's age (years)** | |
| 15-25 | 138 (41.1) |
| 26-35 | 178 (52.9) |
| 36-45 | 16 (4.8) |
| 46-55 | 4 (1.2) |
| | |
| **Mother's education** | |
| None or primary schooling | 180 (53.6) |
| Post primary schooling to higher secondary school | 120 (35.7) |
| Undergraduate or postgraduate | 36 (10.7) |
| **Monthly income of household (USD $100 = Rs. 16000)** | |
| Rs. 25,000 or less | 314 (93.4) |
| Rs. 25001- 65,000 | 20 (6.0) |
| Greater than Rs. 65,000 | 2 (0.6) |
| **Parity** | |
| Primiparous | 87 (25.9) |
| Multiparous | 249 (74.1) |
| **Multiparous mothers with another child afflicted with cleft lip and/or palate** | |
| Yes | 13 (5.2) |
| No | 236 (94.8) |

**Table 2:** *Comparison of breastfeeding data amongst different cleft lip and/or palate groups*

| | | Type of orofacial cleft | | | |
|---|---|---|---|---|---|
| | **All (n=336) n (%)** | **Isolated cleft lip (n=78) n (%)** | **Unilateral lip and palate (n=134) n (%)** | **Bilateral lip and palate (n=60) n (%)** | **Isolated palate (n=64) n (%)** |
| Intention to breastfeed prior to child's birth | 327 (97.3) | 74 (94.9) | 130 (97.0) | 58 (96.7) | 64 (100) |
| Actual prevalence of breastfeeding | 255 (75.9) | 71 (91.0) | 90 (67.2) | 45 (75.0) | 49 (76.6) |
| **Methods attempted for breastfeeding** | | | | | |
| Directly from breast | 112 (33.3) | 55 (70.5) | 25 (18.7) | 9 (15.0) | 23 (35.9) |
| Expressed mother's milk via bottle | 105 (31.3) | 15 (19.2) | 46 (34.3) | 28 (46.7) | 16 (25.0) |
| Cup or Spoon | 60 (17.9) | 11 (14.1) | 27 (20.1) | 9 (15.0) | 13 (20.3) |
| Feeding Technique (Straddle position for feeding) | 50 (14.9) | 9 (11.5) | 14 (10.4) | 10 (16.7) | 17 (26.6) |
| Nasogastric Tube | 3 (0.9) | 0 | 3 (2.2) | 0 | 0 |
| Other | 3 (0.9) | 1 (1.3) | 2 (1.5) | 0 | 0 |
| **Infant's age at cessation of breastfeeding** | | | | | |
| Less than 1 month | 86 (25.6) | 10 (12.8) | 34 (25.4) | 23 (38.3) | 19 (29.7) |
| 1 month to less than 3 months | 56 (16.7) | 10 (12.8) | 26 (19.4) | 11 (18.3) | 9 (14.1) |
| 3 months to less than 6 months | 26 (7.7) | 3 (3.9) | 7 (5.2) | 7 (11.7) | 9 (14.1) |
| Exclusive breastfeeding past 6 months | 45 (13.4) | 33 (42.3) | 6 (4.5) | 0 | 5 (7.8) |
| Complementary breastfeeding past 6 months (breast milk + formula) | 42 (12.5) | 14 (17.9) | 17 (12.7) | 4 (6.7) | 7 (10.9) |
| **Commencement of breastfeeding after surgery** | 75 (22.3) | 45 (57.7) | 20 (14.9) | 6 (10.0) | 4 (6.2) |

feeding recorded per day was 7 (SD=3). The most common method for mother's milk feeding was directly at the breast (33.3%). Expressed milk given by bottle was the most common feeding method among children with unilateral and bilateral cleft lip and palate. Majority of the mothers (n=214, 63.7%) reported receiving feeding advice. The predominant source of advice was a healthcare professional (n=183, 85.5%), followed by friends and family (n=22, 10.3%), or a combination of the two (n=9, 4.2%). Of the 214 mothers that received any advice, a large majority (n=206, 96.3%) reported following the advice and 194 mothers (90.7%) felt that they received sufficient advice. Mothers that received feeding advice reported significantly higher rates of successful mother's milk feeding (175 out of 214, 81.8%) compared to mothers who did not receive any counselling (39 out of 122, 32%) (p=0.01).

Difficulties faced by participants by type of orofacial cleft are highlighted in Table 3. The most frequently reported difficulty was the inability of infants to form a seal around the nipple (43.2%), followed by the child choking or leaking milk through the nose (37.8%). Almost 15% of mothers (n=50) did not face any difficulty with breastfeeding their infants with orofacial clefts, and this finding was more pronounced in the group of children with unilateral cleft lip, with 35% of mothers reporting no difficulties with breastfeeding.

## Discussion

Breastfeeding has been medically proven to have multiple short- and long-term benefits for maternal and child health. Mothers are encouraged to breastfeed their infants as soon as possible after the delivery, however, in Pakistan only 18% of mothers initiate breastfeeding within one hour of birth.[10] Multiple factors can interfere with timely breastfeeding, and congenital anatomic abnormalities like cleft lip and palate are known to be a major factor. We found that among children with clefts, 255(75.9%) were breastfed at some point, but only 45 (13.4%) were exclusively breastfed until 6 months as per WHO recommendation. This is significantly lower than previously reported national data that found the incidence of breastfeeding in non-CLP children to be 94.3%, while exclusive breastfeeding rates were recorded at 37.7%.[11,12] The lower rates of breastfeeding in our cohort can be attributed to multiple factors, including the anatomical obstacle associated with the cleft deformity, maternal factors, or both[13,14].

We found that children with unilateral cleft lip had the highest rates of "at-breast" feeding via cradle position (Fig.1) 55(70.5%), likely because solitary cleft lip allows adequate oral pressure to be generated, leading to appropriate suction and compression required for breastfeeding. Alternately, children with combination lip/palate defects or isolated palate defects had higher incidence of being fed expressed mother's milk via bottle, cup or spoon, and their mothers reported more problems during breastfeeding, foremost being the inability to seal around the nipple. This was likely because the connection between their oral and nasal cavity did not allow adequate negative pressure to be created, thereby causing difficulty in sucking.[15]

Another commonly reported problem among our cohort was the child choking or having milk regurgitating from the nose while being fed breast milk. Therefore, the low exclusive breast milk feeding rates in children with cleft palate can potentially be attributed to problems faced by mothers during breastfeeding and lack of proper feeding during sessions, compelling them to supplement with either formula milk or expressed breast milk. Furthermore, the time consuming and tiresome task

**Table 3:** *Common difficulties encountered during breastfeeding infants with different orofacial clefts*

| Feeding difficulties encountered | All (n=336) n (%) | Type of orofacial cleft: Isolated cleft lip (n=78) n (%) | Unilateral lip and palate (n=134) n (%) | Bilateral lip and palate (n=60) n (%) | Isolated palate (n=64) n (%) |
|---|---|---|---|---|---|
| Child unable to seal around the nipple | 145 (43.2) | 25 (32.1) | 66 (49.3) | 29 (48.3) | 25 (39.1) |
| Child choking or milk regurgitating through the nose | 127 (37.8) | 13 (16.7) | 49 (36.6) | 28 (46.7) | 37 (57.8) |
| Maternal pain or discomfort | 53 (15.8) | 11 (14.1) | 20 (14.9) | 12 (20) | 10 (15.6) |
| Maternal malnourishment | 37 (11.0) | 11 (14.1) | 13 (9.7) | 4 (6.7) | 9 (14.1) |
| Insufficient knowledge | 18 (5.4) | 1 (1.3) | 10 (7.5) | 4 (6.7) | 3 (4.7) |
| Others | 33 (9.8) | 3 (3.9) | 17 (12.7) | 7 (11.7) | 6 (9.4) |
| None | 50 (14.9) | 24 (30.8) | 11 (8.2) | 10 (16.7) | 5 (7.8) |

of pumping breast milk could potentially overwhelm the mother and lead to her discontinuing breast milk feeding altogether and resorting to supplementation with formula, cow's milk or goat milk[16,17].

**Figure 1:** *Cradle position*

Our study reinforces the belief that the anatomy of the defect determines the degree of hindrance to feeding, and so influences the incidence of breast milk feeding as well, especially via "at-breast" feeding via the cradle method. Reid et al reported that there was no significant difference in the feeding skills of infants with cleft lip/palate or isolated cleft palate,[18] which is consistent with the incidence rates demonstrated in our cohort. However, when the incidence of breast milk feeding was compared between children with cleft lip/palate with those of children with cleft lip only, the difference was statistically significant ($p<0.001$).

That being said, mothers of children with isolated palates were the most likely to receive and follow feeding advice in our cohort. Consequently, they were most likely to use feeding techniques, like the horse-riding position to breastfeed. (Fig2.)

Although published surveys have reported parents of children with cleft lip and/or palate to be most dissatisfied with the level of information they receive regarding feeding in the hospital during the new born period of the child,[19] our data suggests otherwise. We found a significant association between mothers receiving feeding advice and the incidence of feeding the child breast milk successfully ($p=0.02$). However, it must be noted that the previously published surveys were conducted in developed countries with a patient population that had a higher education and socioeconomic level compared to ours. This could potentially result in higher expectation of support among the study participants, thereby leading to dissatisfaction with the breastfeeding advice subsequently provided. Also, the nature of breastfeeding advice given to mothers was not investigated extensively in our study.

**Figure 2:** *Horse riding position*

The rate of exclusive breast milk feeding in our sample of children with isolated cleft lip is 33(42.3%) being remarkably similar to the national rate of 38%, validating the notion that infants with cleft lip can be fed breast milk successfully.[19-20,21] The slightly higher rate may also show the impact of proper feeding advice received by the majority of the participants in our study, and the lack of even basic breastfeeding knowledge among the general population in Pakistan.[22,23,24] It is therefore imperative that medical personnel and midwives understand the importance of early initiation of breastfeeding, different methods of breastfeeding and common beliefs and misconceptions of mothers of CLP patients, so as to better counsel their patients.

Our study was conducted among patients presenting at a private welfare hospital, and majority of our study participants belonged to a lower socioeconomic and educational background. More than half of the mothers interviewed had very little or no formal education at all. Previous studies conducted in South Asian and African countries have reported a positive correlation between maternal education and breastfeeding incidence in the general population.[25,26,27,28] However, prior educational status of the mother did not correlate with the incidence of breastfeeding in our study ($p=0.29$). This may be attributed to cultural and religious inclinations towards breastfeeding[29] or preferential mother's milk feeding among lower income populations to spare the expense of formula milk.

## Conclusion

Prevalence of breast feeding was poor. One mother out of four was not able to feed their children due to various reasons. Challenges face by mothers were lack of financial support as well as lack of guidance and moral support from families in addition to physical

challenges posed by infant like unable to seal around the nipple, Child choking or milk regurgitating through the nose.

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