

Original Research Article

A cross sectional study on mothers' insight of feeding babies with cleft lip and palate in Hyderabad city, Telangana

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ABSTRACT

Background: Feeding infants with cleft lip and palate is one of the most challenging and worrying events in a mother's life. When the baby fails to thrive, the mother becomes anxious as the effort goes futile which may inhibit maternal bonding with the child leading to other consequences. Hence, our aim was to assess the attitudes of mothers towards feeding their babies with cleft lip and palate.

Methods: A cross sectional study was conducted among mothers of children with cleft lip and palate at a cleft center in Hyderabad city. The mothers were interviewed using a self-administered questionnaire on a 3-point Likert scale. The collected data were subjected to statistical analysis using SPSS version 22.

Results: A total of 96 mothers participated in the study. Among them a majority of them bottle fed their baby (85%). Escape of milk through nostrils was reported to be the most common problem faced by the child (30%). The attitudes of mothers were categorized into good (29%), moderate (62.5%) and poor (28%). Also there was a significant difference between the educational qualification, household income and clinical diagnosis with the attitude of mothers.

Conclusions: In the present study, a majority of them had moderate attitude. Personal and professional care and support are the key factors influencing the mothers' attitude.

Keywords: Attitude, Cleft lip and palate, Feeding, Mother

INTRODUCTION

Pregnancy is a process that invites you to surrender to the unseen force behind all life. The process of becoming a mother starts in pregnancy and is one of the most momentous life events for a woman and her family. It exerts a physical, mental, emotional and social impact on her. As it is a major life-changing event, it affects the parents and their relationships in many ways.

For mothers, this change can be happy, frustrating and stressful and the obtainability of support can impact how she will cope with the new situation. This process is

influenced by elements related to both the mother and the baby, including the mothers' age, birth experience, self-concept, availability of support, and the baby's well-being and temperament. Having a child with a birth defect impacts the whole family as having a child with a birth defect is one of the most devastating events for parents. They find themselves challenged with imperative decisions on behalf of the child, decisions on the management of the child with a disability, and economic decisions that will affect the whole family. The event of a child born with a disability is always a misfortune for the family, but early intervention, care, and support may

perhaps help the family to adjust and become positively involved in the care and progress of the child.¹

Congenital malformations of the head and neck region are a wide and extremely heterogeneous group because this region contains all organ systems. Orofacial clefts are the most common congenital defects. Cleft lip and palate among humans is a major public health problem affecting 7-10 in every 10,000 births worldwide and in India, the estimated incidence is around 0.25 to 2.29 per 1000 births. In 2016, the calculated prevalence rate/100,000 was 33.27 for males, 31.01 for females.¹

Cleft lip and Cleft palate are defects that occur when the fetal mouth does not develop properly during pregnancy and may occur independently or together as cleft lip with cleft palate. CL/P is etiologically varied with both genetics and environmental contributions. Most of the epidemiologic studies support a role for environmental factors in the etiology of clefts. The most common risk factors stated were maternal exposure to tobacco products, alcohols, nutritional deficiencies, some viral infections, drugs, and teratogens in the place of work or at home in early pregnancy.²

Children with facial clefts have an increased risk to develop feeding difficulties where especially children with cleft palate only (CPO) are subject to feeding problem. There seems to be a spectrum of different problems with symptoms that we call feeding sequelae, such as choking, gagging, excessive air intake, and prolonged feeds. Garcez et al in a study conducted among 31 mothers reported that the most frequently mentioned difficulty was weak suction, especially in children with cleft involving the palate.³ Despite adequate sucking movements, they are unable to generate the negative pressure required. These findings were reported in a study done by Gopinath et al where only 40% of the mothers had successfully breastfed their babies. These children are vulnerable to nutritional problems since the healthiest and the harmless source of nourishment for infants is breast milk.⁴ Recurrent infections, repeated operations, and adverse psychosocial influences further aggravate the problem. In a study by Flynn et al, it showed that there was an increased prevalence of otitis media among children with cleft lip and palate compared to normal children. These infants are underfed and have compromised growth in the early months after birth.⁵ The growth problems of children with CLP have largely been attributed to poor Nutrition. Nutritional problems can affect weight gain during infancy and can have different effects based on the gender of the child. A study by Beaumont et al showed that there was a significant difference in weight gain among normal infants, those with isolated cleft lip and isolated cleft palate. This lead to increased levels of anxiety regarding mothers.⁶ As the studies pertaining to this area are very limited, the identification of these issues are neglected and thus a great concern.

Hence the objectives of this study are to investigate the practice of breastfeeding before and after surgical intervention and related difficulties in children born with CLP and to assess the attitudes of mothers regarding their feeding practices. The aim of this study is to describe the experiences and attitudes of mothers towards feeding their babies with CLP.

METHODS

A cross-sectional questionnaire-based study was conducted and data was collected for a period of three months, from June to August 2018, to assess the attitudes and experiences of feeding among mothers of children born with CLP. Ethical clearance was obtained from the Institutional Review Board of Sri Sai College of Dental Surgery. Permission was taken from the Director of GSR Institute of Craniofacial Surgery, Hyderabad where the study was conducted among mothers of CLP children. It is one among the Smile Train Centers where surgeries for CLP are carried out for underprivileged children. A pilot study was done to determine the feasibility of the study. A total of 96 mothers of children who were present on the day of data collection were invited to participate in the study after obtaining informed verbal consent. Children aged 6 months to 7 years were included and the exclusion criteria included children with any other clinical syndrome or systemic disease.

A convenience sampling technique was used to select the participants for the study. The mothers were interviewed using a pre-tested Cronbach's alpha ($\alpha=0.73$), structured questionnaire, which consisted of 10 items (attitude related). The responses were graded on a 3 point Likert scale, ranging from 1 (disagree) to 3 (agree). The score was calculated by summing up the item scores. They were graded as having good, moderate and poor attitudes based on the median scores. The collected data were subjected to statistical analysis using SPSS version 20 and descriptive statistics and chi-square test was used to assess the association with different variables ($p<0.05$).

RESULTS

A total of 96 mothers participated in the study. The questionnaire consisted of demographic details, type of feeding practices, questions related to the mother's attitude and problems relating to feeding the child. A majority of them (51%) had educational qualification below 10th standard. 82% of the children had cleft palate. 12.5% of the mothers' breastfed their baby, 85% of them bottle fed. Table 1 shows the distribution of study subjects based on the responses of the mother's attitude towards feeding the baby. The attitudes were divided into 3 tertiles (<31-poor, 32-36-average, >37-good) where about 28% (27) had a poor attitude, 62.5% (40) had a moderate attitude and 29% (24) had a good attitude towards feeding their baby. Figure 1 shows the distribution of study subjects based on problems faced by the baby during feeding. Weak suction and escape of milk

through nostrils were the most common problems reported. There was a statistically significant difference when Chi-square test was done to associate attitudes of mothers with educational qualification (0.003), household income (0.011), and clinical diagnosis (0.000).

Table 1: Distribution of study subjects based on the responses of mother's attitude towards feeding the baby.

Questions	Agree (%)	Neutral (%)	Disagree (%)
I was anxious after the baby was born	80.3	3.1	16.7
I was worried about feeding my baby properly	75.1	1	24
I was taught about feeding the baby with a special equipment	77.1	1	21.9
I was satisfied with feeding the baby with the special equipment.	70.8	15.6	13.5
I was concerned about feeding my baby after getting discharged home.	16.7	2.1	81.2
My partner supported me in the process of feeding.	78	4	18
The attitude of my doctor helped me in the process of feeding.	52.1	0	47.9
The attitude of the supporting staff helped me in the process of feeding.	58.3	0	47.9
Feeding ability of the baby has improved after the surgery.	20.8	45.8	33.4

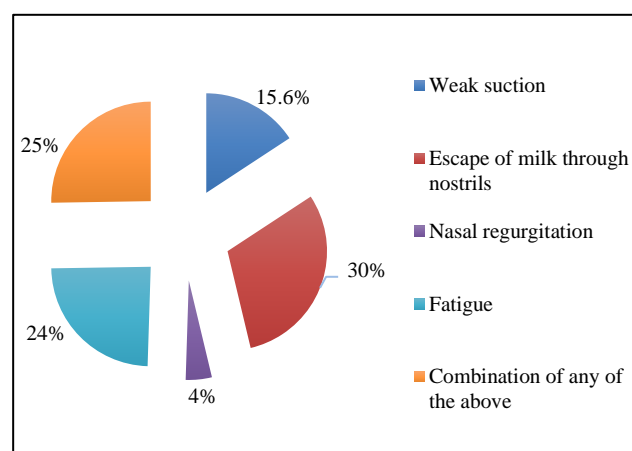


Figure 1: Distribution of study subjects based on problems faced by the baby during feeding.

DISCUSSION

Cleft lip and palate are the most common form of craniofacial defects which may occur isolated or in association with other anomalies and therefore have the potential to adversely affect feeding abilities, especially in the newborn. The family of a baby born with an oral-facial anomaly may find themselves not only dealing with the emotions surrounding the birth of a baby with a congenital defect but also struggling to feed their baby. These feeding difficulties may erode parental confidence and self-esteem, and further, inhibit the bonding process at a vulnerable time. The infant's growth is poor, adding to the family's stress around feeding. Inaccurate information, however well intended, can frustrate families with babies who have oral-facial anomalies and lead to the perception of lack of assistance or support by health providers.

The muscles activated during breastfeeding are stimulated, resulting in the proper development of oral sensory-motor system structures and functions such as speech and language, which are affected. Breastfeeding stimulates mother-child bonding. Such bonding can be threatened because of the child's defect, which commonly causes mothers- consciously or unconsciously to avoid face to face contact with the child.

The first 2 years of life is a critical age of rapid growth and brain development. During this period, nutrition and environmental factors play key roles in growth and cognitive development of a child. In the early months, when the baby is most at risk, exclusive breastfeeding helps to protect against diarrhea and other common infections.

Behavioral and feeding difficulties among the children clearly seemed to affect the mothers' anxiety level. The symptom level varied with background elements like the mothers' education, employment and age even after adjusting for the effect of strain and social support. In present study, only 1% had higher educational qualification and there is a significant difference with educational qualification and attitude of mothers which is in contrast to a study done by Bumin et al where similar results were obtained.⁷ The result was probably due to the predominance of the rural population in our study. Cleft lip and cleft palate, also known as orofacial cleft, is a group of conditions that includes cleft lip (CL), cleft palate (CP), and both together (CLP) which is a consequence of facial tissues not joining properly during development. Risk factors comprise smoking during pregnancy, diabetes, obesity, an older mother, and certain medications (such as some used to treat seizures). Cleft lip and cleft palate can often be diagnosed in the course of pregnancy with an ultrasound exam. In our study, 82% of the children had cleft palate which is in contrast to a study done by Fathy et al, where 48% of the children had cleft palate. This could be due to multiple follow up visits

requiring long term treatments for those with cleft palate when compared with cleft lip.⁸

Infants with a cleft lip only and an intact palate usually breastfeed or bottle feed without trouble once an adequate “seal” is made around the nipple while infants with a cleft lip and cleft palate or isolated cleft palate are usually not successful at breastfeeding. In present study, around 12.5% of the mothers could successfully breastfeed their infants which is in contrast to a study done by Gopinath et al 40% of mothers could successfully breastfeed.⁴

In the adult population, anxiety and depression are the most common emotional disorders. Parents often experience distress at the time of their child’s diagnosis, including feelings of shock, sadness, anger, grief, guilt, and anxiety. Parents may have limited social support and experience anxiety about their child’s treatment and fears. In cases when the infants are affected with orofacial cleft disorders there may be a significant influence on the psychology of their mothers. In our study, 80% of the mothers were anxious after the child was born with cleft lip and palate. The reason could be the lack of prenatal diagnosis and counselling of the parent. Mothers worry about the child’s future and social acceptance can also be the reasons for her anxiety.

Feeding a baby with cleft lip and palate is quite challenging and mothers of these children have concerns about feeding the baby thereby increasing the stress levels in them. In our study, 75% of the mothers reported that they were worried about feeding the baby properly which is in contrast to a study done by Martin et al, (26%) expressed their concern over difficulties feeding their baby.⁹ Cleft type, time of surgery, self-perception, socioeconomic status, accessibility to cleft centres and her educational qualification could be the reasons for their stress.

Infants with cleft palate ± lip are likely to require at least some modification of feeding strategies. Parents want guidelines and information that will help them to help their infant feed efficiently. In our study, 77% agreed that they were taught how to feed their baby, 71% responded that they were satisfied with feeding the baby, while only 17% were concerned about feeding the baby after getting discharged home. There is always a fear of facing feeding difficulties which may lead to disturbed bodily functions after being discharged home. As most of the population was from a rural area, limited access to health care facilities might also be the reason for the mother’s concern. Results of a similar study showed that about 63% of the mothers reported that feeding help in the hospital was satisfactory and about 84% of them were concerned about feeding their infants after they were discharged home.¹⁰ Although health care professionals offer timely support to breastfeeding women, the more constant presence and immediate support of the baby’s father, or mother’s partner offers opportunity to influence the maintenance and duration of breastfeeding.

In the current study, 78% of the mothers agreed that they had got enough support from their partners. In a similar study done by Mannion et al, 55% of women perceived that their partner was “encouraging,” 23% said their partners thought breastfeeding was best or healthiest for the baby. However, 22% indicated that their partner felt indifferent or negatively about breastfeeding. Fathers and partners have been identified as being influential in mothers’ feeding decisions and the continuation of breastfeeding.¹¹

In the current study, 48% and 42% of the mothers have strongly agreed that doctor’s attitude and the attitude of the health professional helped them in the process of feeding which is similar to a study done by Kronborg et al. The results showed that after the intervention health visitors on breastfeeding guidance in the intervention group reported significantly higher self-efficacy in guidance. The knowledge about lactation, guidelines on feeding practices helped mothers to face the challenges in the process of feeding and to overcome the feeding difficulties. This helps build confidence and self-esteem of the mother, thereby increasing the maternal bond with the child.¹² Suction occurs when the oral cavity forms a closed chamber. Hence an early closure of soft palate helps to generate adequate intraoral pressure thereby increasing the sucking ability of the baby. In the current study, only 21% of the mothers reported an improvement in feeding ability after the surgery. This depends on the type of cleft present, time of surgery or the presence of any other health issues. Early closure of soft palate helps to generate adequate intraoral pressure thereby increasing the sucking ability of the baby. In a similar study conducted by Vries de et al, 79% of all parents reported improvement in feeding after surgery.¹³ As this study was conducted at a single center, it is recommended that this study to be continued at multiple centers to identify the existing scenario, so that the required action plan can be initiated. Also, the age of the mother was not included in the study which is an important factor to be considered for addressing the attitudes. Since the studies pertaining to this area are few, further research needs to be carried out to get acquainted with the circumstances faced by the parents of children with cleft lip and palate.

CONCLUSION

In the present study, a majority of them had a moderate attitude. Support from their partners and healthcare professionals played a major role in shaping their attitudes. Therefore, it is clear that a psychological support from the surroundings will help them cope up with any situation. Hence early intervention in the form of counselling, knowledge of feeding skills and probable consequences will be a great benefit.

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