

## Mothers' Struggle and Knowledge Towards Feeding a Child with a Cleft Lip and Palate

Amel Eltayeb<sup>1\*</sup>, Asim Satti<sup>2</sup> and Haithem Elhadi Babiker<sup>3</sup>

<sup>1</sup>Assistant Professor of Oral and Maxillofacial Surgery, Faculty of Dentistry, Nile University, Sudan

<sup>2</sup>Assistant Professor of Restorative Dentistry, University of Science and Technology, Sudan

<sup>3</sup>Associate Professor of Plastic and Reconstructive Surgery, University of Cincinnati, Cincinnati Children's Hospital Medical Center, USA

\*Corresponding Author: Amel Eltayeb, Assistant Professor of Oral and Maxillofacial Surgery, Faculty of Dentistry, Nile University, Sudan.

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### Abstract

**Background and Purpose:** The most common problems that cleft lip and/or palate (CLP) patients in Sudan present with are prolonged feeding times and an inadequate nutritional intake. This study was undertaken to investigate Sudanese mothers' knowledge and experiences of having a child born with CLP as well how mothers receive support from professionals.

**Methods:** A survey of 100 mothers who have a child with CLP was carried out between February and March 2017. These mothers attended a CLP campaign at the Khartoum Teaching Dental Hospital (KTDH) for surgical correction of their child's cleft deformity. A questionnaire was administered which sought out socio-demographic information, mothers' knowledge and attitude towards feeding the child, and availability of a specialized feeding bottle.

**Results:** A total of 100 mothers were included in this study. Half of the mothers (50%) had breastfeeding difficulties at the beginning of the child's life. A significant correlation was found between the child's defect and the feeding techniques used by the mothers. None of the cleft palate patients (0%) received breast feeding. Of all mothers, 51% had heard about the special feeding bottle for CLP patients and only 13% from that subset have used it. A significant correlation was also found between mothers' level of education and their awareness of the existence of a specialized bottle (p-value 0.001).

**Conclusion:** This study concluded that Sudanese mothers do not receive adequate information from health care providers regarding feeding techniques for their children with CLP. Specialized cleft feeding bottles are not readily available for cleft babies. Health educational campaigns would be beneficial in improving the general understanding of the feeding techniques regarding a patient with CLP.

**Keywords:** Cleft Lip; Palate; Mother

### Introduction

Cleft lip and/or palate (CLP) is the most common congenital malformation with an incidence of approximately 1 in 700 live births worldwide [1]. There are differences in incidence rates

across racial groups, with the lowest reported incidence among African-Americans and Caucasians; and higher incidence among Native Americans and Asians [2]. In 2005, a study by Suleiman, et al. demonstrated a prevalence of 0.9 per 1000 of CLP in Sudan [3].

The etiology of CLP is still largely unknown. The majority of clefts of the lip and palate are believed to have a multi-factorial etiology with several genetic and environmental factors [4].

Feeding children affected with CLP is known to be difficult. Feeding difficulties associated with CLP are related to reduced sucking efficiency, nasal regurgitation and excessive air intake [5,6]. According to Reid., *et al.* there was a significant decrease in failure-to-thrive rates for infants with cleft palate after an early intervention feeding program was implemented [7].

Giving birth to a child with CLP can be emotionally traumatic for parents; especially the mother. They need reassurance, support and time to assimilate the information and come to grip with reality [8]. Parents experience varying degrees of shock, anger, denial, distress and anxiety. Many parents express a feeling of loss of control. Despite their efforts for a healthy pregnancy they were unable to control the outcome. Mothers especially may experience intense guilt as they feel their bodies are the custodians and nurturers of their unborn child [9].

The most common problem seen in cleft babies is prolonged feeding times and an inadequate nutritional intake. In fact, most babies who present late with a diagnosis of cleft palate usually come from the pediatric ward where they were admitted with failure-to-thrive [10]. One of the main concerns of parents with a child born with cleft lip and palate is in regards to feeding their baby. Young noted that for 95% of parents, issues around feeding were the main concern [11].

Feeding times should be a pleasurable experience for both mother and baby. Prolonged feeding times lead to frustration of the mother and distress of the infant [12]. This study was performed to investigate mothers' knowledge and experiences of having a child born with a CLP and how they perceive support from professionals. Our aim was to provide a greater insight into the special needs of these mothers and help guide professionals provide the necessary mental and social support.

**Materials and Methods**

A questionnaire of mothers who have a child with cleft lip and/or palate was carried out between February and March 2017. These mothers were attending a surgical campaign at Khartoum Teaching Dental Hospital (KTDH) for surgical correction of their

child's deformity. Approval was obtained from the Ethics and Research Committee of KTDH. All the respondents gave written consent prior to participation. The questionnaire sought information on socio-demographics, knowledge and attitude towards feeding the cleft child and availability of specialized feeding bottles. The level of significance was set at  $p < 0.05$ . Data was analyzed with Statistical Package for Social Sciences (SPSS) software (version 20).

**Results**

A total of 100 mothers were included in this study. The mean age of the respondent mothers was  $30.54 \pm 7.9$  years. Half of the mothers (50%) were in the 25-34 years age group and 13% of the mothers were illiterate. table 1.

		Frequency	Percent
Mother's age			
	14-24	19	19%
	25-34	50	50%
	35-44	25	25%
	45-54	6	6%
Mother's education			
	Illiterate	13	13%
	Primary school	35	35%
	Secondary school	38	38%
	Graduate degree	14	14%
Residence			
	Rural	75	75%
	Urban	25	25%
Number of children in the family			
	less than 5	74	74%
	more than 5	26	26%
	Total	100	100%

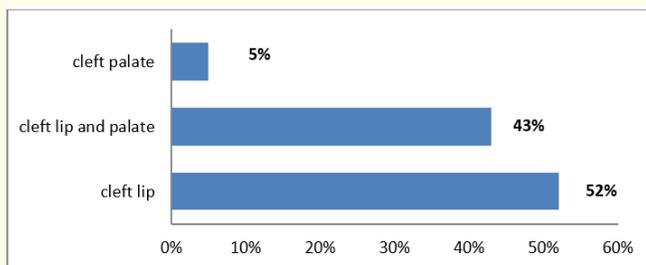
**Table 1:** Mothers' socio-demographic characteristics.

The mean age of CLP children was 15.81 months (range 1 to 72 months). Of all respondents, 45% of the children were less than 1 year old, 57% were male and 53% were born at home. The demographic information the CLP children are shown in table 2.

		Frequency	Percent
Child's age	Less than 1 year	45	45%
	1 - 2 years	25	25%
	2 years and more	30	30%
Child's gender	Male	57	57%
	Female	43	43%
Birth place	Home	53	53%
	Hospital	47	47%
Childhood Illness	Yes	5	5%
	No	95	95%
	Total	100	100%

**Table 2:** Demographics of CLP children.

The most common diagnosis of the participants' children was cleft lip (52%), meanwhile cleft lip and palate was seen in 43%, and isolated cleft palate in 5% only (Figure 1).

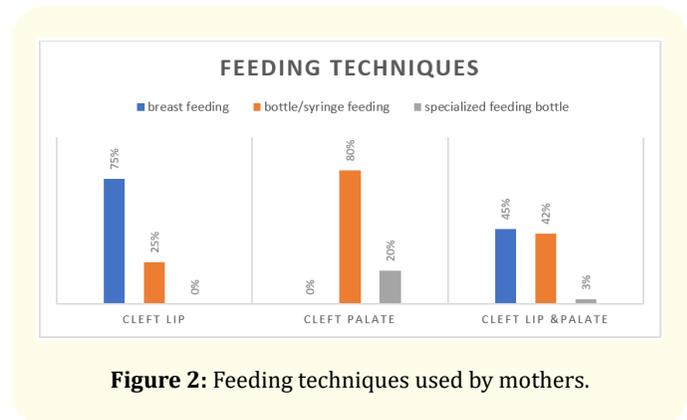


**Figure 1:** Cleft lip and palate distribution among children.

The majority of the cleft lip and palate defects (97%) were discovered at birth; meanwhile 3% were discovered later when these children were admitted to the pediatric ward for failure-to-thrive. Half of the mothers (50%) had breast feeding difficulties at the beginning, some mothers mentioned that the baby was unable to suck breast milk because of the cleft and others mentioned choking history when they tried to feed them and Only 45% continued to breast feed.

A significant correlation was found between the child's defect and the feeding techniques used by the mothers. A striking observation was that none of the cleft palate patients (0%) were breastfed. Most of these children (80%) were fed with a regular bottle/syringe and a small portion (20%) with a specialized feeding bot-

tle. Also 75% of Cleft lip children were breastfed and children with cleft lip and palate were mostly breastfed and bottle fed, 45% and 42% respectively (Figure 2).



**Figure 2:** Feeding techniques used by mothers.

Of all mothers, 51% have heard about the special feeding bottle for cleft lip and palate children and only 13% have used it. Of all mothers only 11% had received feeding advices mostly from doctors (48%) (Table 3).

		Frequency	Percent
Have you heard about specialized feeding bottle?	Yes	51	51%
	No	49	49%
What was the Source of information?	Hospital	100	100%
	Others	0	0%
Did you receive any Feeding advice?	Yes	11	11%
	No	89	89%
Source of Feeding Advice	Doctors/nurses	48	48%
	midwives	26	26%
	Mothers/grandmothers	26	26%
Type of feeding you are using now	Breast	45	45%
	Bottle/syringe	42	42%
	Specialized bottle	13	13%
Total		100	100%

**Table 3:** Special cleft bottle feeding awareness among mothers.

Age of the mothers was not found to be a significant factor when chi square test was done (P-value 0.729). The largest number of mothers who heard about the specialized cleft bottles was among the age group 25-34 years and the least number was among the oldest group 45-54 years. A statistically significant correlation was found between mothers' level of education and their awareness towards the specialized bottle existence (p-value 0.001). Only 15.4% of illiterate mothers had heard about it in comparison to 72.7% of mothers with a college degree. Birth place was found to be an insignificant factor for mother's knowledge since only 3.8% of mothers who had their labor at home had heard about the specialized feeding bottle in comparison to 4.3% of those who delivered at the hospital (p-value 0.902).

## Discussion

The most important post-natal concern is the feeding and nutrition of the newborn baby. For many years and in many nations it has been demonstrated that bottle-fed infants had more childhood illness than infants who are exclusively breast-fed for the first six months of life [13]. Human milk increases resistance to infections in early infancy since the major milk protein lactoferrin can destroy microbes and reduce inflammatory responses. It also prevents post-surgical infection [14]. It is also believed that breast milk enhances early development and protective effect on infant against middle ear, airway and digestive tract infections and neonatal sepsis [15-17].

Apart from breast feeding with modifications, other types of feeding method such as feeding plates, specialized bottles and nipples are also available. Spoon feeding and breast feeding were the most common feeding practice methods for cleft babies [2]. There are several bottles and teats designed for babies with cleft palate. Medela Special Needs (previously called Haberman) Feeder, Pigeon squeeze bottle, Dr Browns Bottle and teat and valve, The Softplax squeeze bottle, Cleft PALS squeeze bottle are few varieties available. A statistically significant difference in weight (kg) at 6 weeks post-surgery was shown in favor of breastfeeding when compared to spoon feeding [2].

Obturator is a simple acrylic feeding plate which covers or obturates the cleft area during feeding. It also helps prevent aspiration of food into the nasal cavity. Turner L., *et al.* concluded that the combined use of a palatal obturator and lactation education

reduced feeding time and increased volume intake and was associated with good growth. Obturators can be used with breast, bottle or any type of feeding [18].

Breastfeeding promotes optimal face and jaw development through the suckling effect. [19] cleft babies have an inherent poor suction, feeding as such is challenging. To achieve good breast feeding, the mothers should be trained to incorporate certain modifications like modified football hold and dancer hand position. In Denmark, Smedegaard., *et al.* found that only about 22% of children with orofacial clefts were breastfed exclusively [20]. In a 2017 Ugandan study, 50% of children with orofacial clefts aged less than 4 months were breastfed [21]. A Nigerian study by Adekunle., *et al.* revealed that initiation of breastfeeding was reported by the majority (83%) of the mothers, and only 18.5% of this proportion continued exclusive breastfeeding [22].

Most Sudanese women largely depend on breastfeeding their children, and hence CLP presents a major dilemma for them. In the current study, only 45% of the mothers breastfed their children and most of these children had isolated cleft lip. This is a much higher rate than that reported by Silva., *et al.* in Brazil where 21.4% of the mothers breastfed their babies [23]. None of the isolated cleft palate children in this study were breastfed. 80% of them used bottle or syringe techniques and 20% used the specialized cleft feeding bottle. By contrast, 22% of cleft palate children in Brazil were breastfed [23]. Babies with cleft lip only in our study, did not have the same problems with breastfeeding. The majority (75%) were breastfed and none of them used the specialized feeding bottle. A lower percentage were reported by Silva., *et al.* where 64.28% of the cleft lip babies had been breastfed [23].

A survey in 2005 from the United Kingdom, indicated that mothers may not have access to adequate practical advice and support from health care professionals to meet their needs [24]. Black., *et al.* reported on the United States recommendations regarding the establishment of a standard of care for high risk infants (such as children with CLP) which is reflected in hospital policies and mid-wifery policies and protocols [25].

The early care of cleft babies and feeding guidance of the families is indicated in the literature as fundamental for guaranteeing the needs of a child with a cleft [26]. Avedian and Ruberg (1980)

stated that the orientation should be provided by groups of professionals specialized in caring for children with CLP. In this study, 89% of the mothers reported that they received no counseling on overcoming challenges associated with feeding their babies with a cleft at the facility where they delivered. This is higher than a Nigerian study where 63% didn't receive any information or counseling [22].

Among the mothers who received feeding advices, Approximately half of the mothers (48%) received their feeding information from doctors and nurses, 26% were from midwives and 26% from their mothers/grandmothers. A recent survey of midwives, health visitors, pediatricians and voluntary-sector breastfeeding supporters in the United Kingdom identified that very few individuals were competent to support new mothers with breastfeeding, and many practitioners possessed outdated skills regarding breastfeeding [27]. Other countries like Hong Kong [28], Switzerland [29], and Denmark [30] have addressed these demands through arguing for establishment of standardized policies. When a mother is struggling to feed a hungry baby and cannot satisfy or pacify it, feeding times become a frustrating struggle for her and the infant becoming increasingly distressed [12]. One large scale quantitative study indicated that parents are concerned about the lack of knowledge of CLP among non-specialist staff (especially maternity services), and that more mothers wished to have the opportunity to breastfeed [31]. In order to solve such a problem Owens., *et al.* reported a great need for collaboration between specialist CLP nurses and maternity services concerning cleft lip and palate, its diagnosis and the associated feeding difficulties. They stressed the importance of offering the mother support and practical feeding advice that does not make a mother feel like a failure [36].

In this study, 47% of the mothers had their labor at a hospital where the birth attendants may not have delivered babies with CLP previously and therefore lack the experience in cleft care. Every effort should be made both by the care taker (mother) as well as attending healthcare professional to achieve good breast feeding and/or assisted feeding. The parents should be given instructions about avoiding emergencies like aspiration. According to Reid., *et al.* (2007), there was a significant decrease in failure-to-thrive rates for infants with cleft palate after an early intervention feeding program was implemented [32]. This program included domiciliary visits, breast-feeding support, feeding education, and monitoring of growth. Early intervention can come in many forms including

feeding equipment, feeding techniques, prostheses, and nutrition/lactation advice [6].

## Conclusion

This study shows that Sudanese mothers don't have enough information regarding feeding techniques used for cleft lip and/or palate children and only half of them had heard about the existence of specialized cleft feeding bottle. Specialized feeding bottles are not easily available to CLP children in Sudan. Moreover, health care providers don't offer enough information regarding the feeding techniques for these unfortunate children. Cleft lip and palate educational campaigns are necessary to improve the general population's understanding of the feeding techniques essential for cleft children.

Health care providers including doctors, nurses, dentists and midwives need to be interviewed in order to investigate their ability to provide such information in an appropriate manner and to improve the care provided for those children and their mothers.

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