

# Feeding practices of children aged 0 to 24 months with clefts attending a specialized hospital in Uganda

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## Research article

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## **Abstract**

Background: Appropriate feeding practices are vital for child nutrition. Despite a low incidence of 0.73 in 1000, Ugandan children with oral clefts face feeding difficulties that affect their feeding practices, nutrition status and health.

Objective: To determine the feeding practices, techniques and maternal feeding knowledge among children with oral clefts attending Comprehensive Rehabilitative Services of Uganda (CoRSU) Hospital

Methods: This survey was part of a cross-sectional study on feeding practices, mothers' experiences and support. We consecutively sampled 32 mothers of children with oral clefts aged 0 to 24 months attending CoRSU hospital between April and May, 2018. A structured questionnaire collected data on feeding practices, techniques and maternal feeding knowledge. Descriptive statistics were analyzed using SPSS software.

Results: Most children (56%) had cleft lip and palate. Early initiation of breastfeeding was 44% and exclusive breastfeeding was 35%. None continued breastfeeding beyond 12 months. Timely introduction of complementary foods was 75%. 58% met the minimum dietary diversity score, 83% met the minimum meal frequency and 33% received a minimum acceptable diet. 75% of the mothers used bottles, cups and spoons in feeding their children. Majority preferred the specialized soft bottle (50%). 28% of the mothers were knowledgeable on the World Health Organization recommended feeding practices.

Conclusions: This cleft group had suboptimal feeding practices since none of the children breastfed beyond 12 months and only one third received an acceptable diet. Varied feeding techniques were employed to improve feeding; majority preferred the specialized soft bottle. Most mothers had inadequate knowledge on feeding. There is need to improve the feeding guidance given to mothers of children with oral clefts. Our findings can guide the design of appropriate feeding interventions for this group.

## **Background**

Oral clefts (Cleft lip and or Cleft palate) are congenital deformities that affect the lips, oral cavity and or nostril as a result of poor fusion of tissues during early pregnancy (1). Cleft severity can be classified as unilateral (one sided) or bilateral (two sided), complete or incomplete depending on the extent of failure of fusion of palatal shelves. Non-syndromic clefts occur in isolation while syndromic clefts are part of another congenital anomaly or medical condition (2).

Globally, clefts affect 0.9 newborns per 1,000 live births; the prevalence varies geographically from as high as 2 per 1,000 in Japan to as low as 0.2 per 1,000 in South Africa (3). Among African populations, Kenya reports 65 per 1,000 while Uganda reports 0.73 per 1,000 (4, 5).

Despite their low prevalence, the occurrence of clefts in children is associated with malnutrition due to feeding difficulties. Being malnourished compromises the child's growth, development and weight gain

needs which are critical for successful cleft repair surgery (6). Without cleft repair surgery, feeding difficulties in cleft infants include insufficient suction during breastfeeding, nasal regurgitation, and reduced food intake (6).

In addition, infant feeding can be affected by mothers' perceptions, inadequate knowledge, poor societal support and lack of guidance from health care professionals (7). Cleft specific feeding interventions include knowledge sharing, assisting mothers with positioning, expressing breast milk and specialized feeding guidance (6, 8).

In Infant and Young Child Feeding (IYCF), the World Health Organization (WHO) recommends that children receive breast milk within one hour of birth and be exclusively breastfed for the first six months of life. Thereafter, children should receive adequate and appropriate complementary foods and continue breastfeeding up to 24 months or beyond (9). Never the less low breastfeeding rates have been reported among cleft children. In Denmark, only 22% of children with oral clefts were exclusively breastfed for at least 4 months (10).

In a 2017 Ugandan study, 50% of children with clefts aged less than 4 months were breastfeeding in contrast to the national exclusive breastfeeding rate of 66% (11, 12). This poor feeding practice contributed to the high prevalence of wasting of 74%, which was higher than the 2016 national overall of 8% among children under 6 months of age (11, 12). Malnutrition affects cleft repair surgery to improve feeding in this group (13, 14).

Uganda has no published guidelines to address the special healthcare needs of children with clefts. The national IYCF policy by the Ministry of Health has gaps in feeding interventions for children with clefts (15). Access to nutrition and health services primarily relies on referral of cleft patients to the national referral hospital and two specialist hospitals. One of the two specialist hospitals providing cleft repair surgery and nutrition rehabilitation services in Uganda is CoRSU hospital (16).

Furthermore, published literature on breastfeeding, complementary feeding and techniques among cleft children in Uganda is limited (11, 12). This study therefore sought to describe the feeding practices, techniques and maternal knowledge among children with clefts, to recommend interventions that can improve their feeding and reduce their risk of malnutrition.

## Methods

### Study site

The study was conducted at CoRSU hospital in Uganda located in Wakiso District. The hospital was purposefully selected because of its provision of specialized services in nutrition rehabilitation and cleft repair surgery for cleft children referred from all over Uganda. Nutrition rehabilitation activities include screening for and treatment of malnutrition and provision of feeding guidance to the parents. In 2016, 163 children with cleft reported to CoRSU; 90% percent of them were below 12 months of age (16).

# **Study participants**

This study included mother-child pairs of children 0 to 24 months old, born with cleft in Uganda and presenting at CoRSU hospital between April and May 2018. Mother-child pairs where the mothers were unwilling or unable to participate in the study due to death, abandonment, psychological incapacitation or where the child was seriously ill were excluded.

## **Study design and participants**

A cross-sectional design was used to collect data on child's breastfeeding, complementary feeding practices, techniques and on maternal knowledge. We used the census method to select the survey respondents. This method lists all available elements in a population and it is applicable for rare groups like this (17). We used a consecutive sampling strategy, where each person who meets the inclusion criteria is selected until the sample size is achieved. Consequently, each consecutive mother-child pair with cleft who attended CoRSU hospital during the 2-month survey period was approached and consented for enrolment. The sample amounted to 32 ( $n = 32$ ). The researchers believed this consecutive sample was more representative of the target population than one from convenience sampling.

## **Study variables and tool**

We adapted and used a structured questionnaire from the WHO recommended measures of IYCF indicators that was previously used in Kampala (18, 19). The tool was translated into Luganda. All interviews were conducted in English or Luganda according to participant preference. We specifically collected data on the following indicators: Early initiation of breastfeeding; Exclusive breastfeeding for the first six (6) months; Timely introduction of complementary feeding; Minimum dietary diversity; Minimum meal frequency; Minimum acceptable diet; Continued breastfeeding for 24 months and beyond and Currently breastfeeding.

Feeding techniques referred to use of a spoon, cup, bottle with nipple, tube, specialized bottle and a specialized cup. Furthermore, maternal knowledge on four (04) recommended feeding practices was assessed. Knowledge on signs and symptoms of malnutrition and attendance of feeding guidance sessions were also assessed.

## **Data management and analysis**

All questionnaires were checked daily for errors and the information verified with the participants. Data was entered and cleaned in EpiData (version 3.1, EpiData Association, Odense, Denmark). Data was then analyzed into means, medians and percentages using SPSS (version 16.0: SPSS Inc., Chicago, IL).

## Results

# Demographic and socio-economic characteristics

The questionnaire was administered to 32 mothers of children with clefts. The most prevalent cleft type was Cleft Lip and Palate and classified as Complete Bilateral Cleft Lip and Palate. The detailed characteristics are presented in Table 1 and Figure 1.

**Table 1: Demographic characteristics of the mother-child pairs (n = 32)**

<b>Child's age</b>	<b>n (%)</b>	<b>Child's type of Cleft</b>	<b>n (%)</b>
0 to 5 months	20 (63)	Cleft Lip	11 (34)
6 to 11 months	8 (25)	Cleft Palate	3 (9)
12 to 24 months	4 (13)	Cleft Lip and Palate	18 (56)
<b>Child's sex</b>		<b>Child's congenital anomalies</b>	
Male	18 (56)	None	29 (91)
Female	14 (44)	Pierre Robin Sequence	2 (6)
<b>Birth weight</b>		Constricting ring syndrome	1 (3)
< 2.5Kg	3 (9)	<b>Maternal residence</b>	
≥ 2.5Kg	28 (88)	Eastern Region	9 (28)
Unknown	1 (3)	Western Region	5 (16)
<b>Term at birth</b>		Central Region	18 (56)
Before 37 weeks	3 (9)	<b>Maternal education</b>	
At or after 37 weeks	29 (91)	None	1 (3)
<b>Delivery location</b>		Primary	14 (44)
Health Facility	28 (88)	Secondary	9 (28)
Home	4 (13)	Tertiary	8 (25)

*Figure 1: Classification of cleft types and percentage of children affected*

# Breastfeeding practices

Majority of mothers (72%) had ever breastfed and 35% breastfed exclusively for the first 6 months. The proportions of children breastfeeding steadily declined with increasing age and once in the 12 to 23

months age category, none of the children were breastfeeding (Table 2). The duration of breastfeeding at the time of the study varied according to the child's cleft type (Figure 2).

*Figure 2: Mean breastfeeding duration according to child's cleft type*

Of the 18 mother-child pairs that were not breastfeeding at the time of the study, majority of the children (44%) failed to latch onto the breast. Other reasons were: Mother not knowing how to breastfeed (17%); Child's failure to suckle (17%); No breast milk (11%); Milk escaping through the child's nose (6%) and Mother fearing to breastfeed child (6%).

## Breast milk alternatives

Majority of the children (59%), were currently feeding on cow's milk. Other alternatives to breast milk were porridge (25%), water (16%) and other liquids (6%). Only one child (3%) was feeding on infant formula.

## Complementary feeding practices

The complementary feeding practices are shown in Table 2. Among the 8 children aged 6 to 8 months, 75% had been introduced to solid, semi-solid or soft foods. Twelve children were aged 6 to 24 months, 58% of whom received foods from 4 or more food groups and met the minimum dietary diversity. Among the 12 children aged 6 to 24 months, 3 (25%) were breastfed and received complementary foods the minimum number of times. Nine (75%) were non-breastfed and of these, 7 received complementary foods the minimum number of times. Therefore 10 (83%) of the children aged 6 to 24 months met the minimum meal frequency.

**Table 2: Breastfeeding and complementary feeding practices**

Breastfeeding Practice	n (%)	Complementary feeding practice	n (%)
<b>Early initiation of Breastfeeding</b>	<b>n = 32</b>	<b>Timely introduction of complementary foods</b>	<b>n= 8</b>
Within first hour	14(44)	Yes	6 (75)
Within first 24 hours	4 (13)	No	2 (25)
Within days	5 (16)	<b>Minimum Dietary Diversity</b>	<b>n = 12</b>
Never	9 (28)	Yes	7 (58)
<b>Ever Breastfed</b>	<b>n = 32</b>	No	5 (42)
Yes	23(72)	<b>Minimum Meal Frequency</b>	<b>n = 12</b>
No	9 (28)	Yes	10 (83)
<b>Currently Breastfeeding</b>	<b>n = 32</b>	No	2 (17)
Yes	14 (44)	<b>Minimum Acceptable Diet</b>	<b>n = 12</b>
No	18 (56)	Yes	4 (33)
<b>Exclusive Breastfeeding</b>	<b>n = 20</b>	No	8 (67)
Yes	7 (35)		
No	13 (65)		

## Feeding technique usage

Majority of the mothers (75%) reported using at least 1 technique in feeding their children. The most popular choice of feeding technique was the specialized squeezable bottle (50%), followed by the spoon (25%), cup (17%), while 4% used either the bottle with nipple or the Nasal Gastric (NG) tube. None used the specialized cup. Half of the mothers cited ease of feeding as their main reason for choice of feeding technique as shown in Figure 3.

*Figure 3: Mothers' reasons for choice of feeding technique (n = 24)*

## Maternal knowledge of IYCF feeding practices and child malnutrition

Of the 32 mothers, 22% of the mothers could not name any of the 4 recommended infant and young child feeding practices and were classified as having no knowledge on feeding. Half of the mothers (n = 16) could name at least 2 and were classified as having basic knowledge while 28% were knowledgeable on

all the feeding practices. In addition, majority (59%) could not name any signs or symptoms of malnutrition in children and were classified as having no knowledge. 38% knew at least 2 signs or symptoms of malnutrition and were classified as having basic knowledge and 3% knew more than 4 signs or symptoms of malnutrition and was classified as knowledgeable (Table 3). Half of the mothers (n = 16) had attended a session guiding them on how to feed children (Table 3).

**Table 3: Maternal feeding knowledge and attendance of feeding guidance sessions (n=32)**

Knowledge on feeding practices	n (%)	Attendance of feeding guidance sessions	n (%)
Knowledgeable	9 (28)	Yes	16 (50)
Basic knowledge	16 (50)	No	16 (50)
No Knowledge	7 (22)		
<b>Knowledge on malnutrition</b>		<b>Timing of feeding guidance</b>	
Knowledgeable	1 (3)	During Cleft care	13 (41)
Basic knowledge	12 (38)	When child was sick	2 (6)
No knowledge	19 (59)	During Postnatal care	1 (3)

## Discussion

### Breastfeeding

Most children (72%) in this survey had ever breastfed. It is not uncommon for mothers to children with cleft to attempt to breastfeed. Similar ever breastfed rates have been reported: 72% in Brazil and 92% in Norway (20, 21). Breastfeeding plays a preventive role in reducing morbidity and mortality from childhood infectious diseases (22). In children with clefts, breastfeeding further reduces the risk of infections like otitis media and promotes proper development of oral sensory motor system structures (23, 24).

Early initiation of breastfeeding among this cleft group was fair at 44%; comparable to Uganda's early initiation rate of 52.5% (25). These rates imply that while some mothers are willing to, and follow the recommendation of initiating breastfeeding as soon as possible after delivery, others may be giving pre-lacteals and pre-disposing their children to malnutrition early in life. In a 2012 Ugandan study where 32% of children were fed on pre-lacteals like home-made sugar water, 33% of them were stunted and 13% were under weight (26).

Less than half of this cleft group was currently breastfeeding. Studies on children with clefts in Uganda, Brazil and Norway reported similar breastfeeding rates of less than half (11, 20, 21). Not breastfeeding is a disadvantage because breast milk is the only nutrition option for children if their mothers cannot afford appropriate breast milk substitutes. In our study, we found that cow's milk was the main breast milk

substitute; this is probably because it is cheaper and more available than formula. WHO's guidelines for feeding the non-breastfed child stipulate that, "commercial infant formula is an option when it is available, affordable, can be safely used, and provides a nutritional advantage over animal milk" (27).

Exclusive breastfeeding was 35% in this cleft group compared to 66% in the general Ugandan population (12). In contrast, EBF was 0% among the Brazilian cleft population (24). Denmark however reported EBF of 77% which could be attributed to the early provision of breast pumps to mothers of children with cleft (10).

Children with Cleft Lip (CL) had the longest average breastfeeding duration of 13 weeks, children with Cleft Lip and Palate (CLP) had 4 weeks while children with Cleft Palate (CP) did not breast feed. Cleft type and severity are determinants of breastfeeding outcomes and children with a CP and more so with a complete CLP face additional disadvantages in creating a seal around the oral cavity (8). The three (03) children with CP in this study also had associated congenital anomalies (Pierre Robin Sequence and Constricting ring syndrome) which could have further disadvantaged their feeding. Breastfeeding durations may vary among cleft populations; Norway reported 12 weeks in a child with CLP while in stark contrast, Brazil reported durations of 30 weeks among CL, 8 weeks among CP and 2 weeks among CLP (21, 24).

None of the children in our cleft group breastfed beyond 12 months. Breastfeeding practices are better in the general Ugandan population; the 2006 national demographic and health survey reported an average of 14 months (28). In the 2016 survey, 82% (ages 12–17 months) and 50% (ages 18–23 months) of children were breast fed (12). However, these national health surveys exclude children with cleft and the methodology used complicates direct comparison with this study's cleft group.

Mothers in our study struggled to attach their children onto the breast and the children failed to suckle. They also did not know how to breastfeed a child with cleft. These challenges could explain the poor breastfeeding practices. In cleft, difficulty creating negative intraoral pressure which in turn affects attaching to the breast causes the child to fail at maintaining a stable feeding position. These ultimately affect the mother's let-down reflex and finally milk extraction by the child (8, 29).

## Complementary feeding

Most children started complementary feeding (CF) at the right time, however the feeding was not varied (minimum dietary diversity was 58%) and not of good quality (minimum acceptable diet was 33%). The poor CF could be explained by: the mothers' limited knowledge on feeding practices (22% had no knowledge); and mothers' limited financial resources (75% ran small businesses or were unemployed). At 75%, timely introduction of CF in this cleft group is comparable to the general population's of 79% (12). However, Ugandan children generally have poor CF practices with only 14% receiving a minimum acceptable diet (12, 30). This could further explain the poor feeding even among cleft children even though the small sample size in our study could have over-estimated these indicators all together.

# **Knowledge as a barrier to feeding**

Mothers in this study reported a lack of knowledge on how to feed and fear of breastfeeding their cleft children. In Lindberg and Berglund's study, mothers had limited knowledge about oral clefts, experienced shock and were concerned about how to feed their children (21). Oliver & Jones also reported that mothers experience stress and anxiety as a result of either the cleft, the feeding difficulties or both (31).

In addition, only 28% of the mothers had adequate knowledge of the recommended feeding practices while most mothers had no knowledge of malnutrition. This is contrary to the fact that half of the mothers had attended a feeding guidance session and had received some feeding guidance either during antenatal or during cleft care. In Uganda, the poor child feeding practices are partly attributed to inadequate knowledge and low literacy among mothers (30, 32). This study's findings suggest that either the feeding guidance provided was inadequate or the mothers having had just a primary level education did not understand it.

## **Feeding technique usage**

To ease their child's feeding, most mothers (75%) used spoons, cups, ordinary bottles, specialized soft bottles, nasal gastric tubes and syringes. Most (50%) preferred the specialized (squeezable) soft bottle given to them by CoRSU because they could regulate the flow of milk into the child's mouth and this improved their child's feeding. Similarly, mothers in Brazil also used multiple feeding techniques including tubes, bottle nipples, cups, spoons, droppers and syringes although most mothers preferred the ordinary bottle with a nipple (6, 20). Likewise, in a recent systematic review comparing feeding methods for children with cleft, the squeezable bottle improved feeding (33).

## **Strengths and limitations**

The rich description of feeding practices using WHO IYCF indicators addresses a knowledge gap in feeding children with clefts in Uganda. However, the study had a small sample size ( $n = 32$ ) because of the low prevalence of clefts, the children's age group (0 to 24 months) and the short study period (April to May). To mitigate this, the researcher used the consecutive sampling method such that all mother-child cleft pairs that visited the hospital during the study period were approached for enrollment. Previous cleft studies in Uganda had similar sample sizes; Kesande et al., (2014) had  $n = 20$  while Tungotyo et al., (2017) had  $n = 44$ . Our findings should not be generalized to all mothers and their children with cleft in Uganda. Further cleft research on impact of the current feeding guidance on nutrition status will generate evidence for appropriate feeding interventions applicable in our context.

## **Conclusions And Recommendations**

The breastfeeding and complementary feeding practices of children with clefts in this study were suboptimal and did not meet the WHO and national IYCF recommendations. The biggest inhibitor to breastfeeding was difficulty attaching and creating suction. Mothers lacked knowledge on feeding and malnutrition and this combined with the feeding difficulties could explain the poor feeding practices. Majority of mothers used feeding techniques to cope with the feeding difficulties of which the specialized soft bottles were preferred to spoons, cups, bottles with nipples and nasal gastric tubes because they improved feeding.

We recommend that Uganda's Ministry of Health should review the national feeding guidelines to include breastfeeding assistance and feeding techniques for mothers and their children with cleft. Feeding guidance at hospitals should emphasize the recommended feeding practices and prevention and management of malnutrition in the context of cleft. Feeding guidance should be simplified with pictures, simple local language, models and take-home brochures to cater for the mothers with low literacy levels.

## **Abbreviations Used**

EBF: Exclusive Breastfeeding; CL: Cleft Lip; CP: Cleft Palate; CLP: Cleft Lip and Palate; CF: Complementary Feeding; CoRSU: Comprehensive Rehabilitative Services of Uganda Hospital IYCF: Infant and Young Child Feeding; WHO: World Health Organization

## **Declarations**

### **Ethics**

The study was approved by the Makerere University School of Public Health Higher Degrees Research and Ethics Committee and the CoRSU Hospital Research committee. All mothers gave informed consent after understanding the study rationale and procedures. All interviews were private and mother-child pairs were assigned unique identifiers in data collection and analysis for confidentiality.

### **Consent for publication**

Not Applicable

### **Availability of data and material**

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

### **Competing interests**

The authors declare that they have no competing interests.

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## Authors' contributions

MN participated in the design, data collection and analysis, and wrote the first draft of the manuscript. DL and GKS participated in design, supervision and manuscript preparation. FT participated in manuscript preparation.

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## Figures

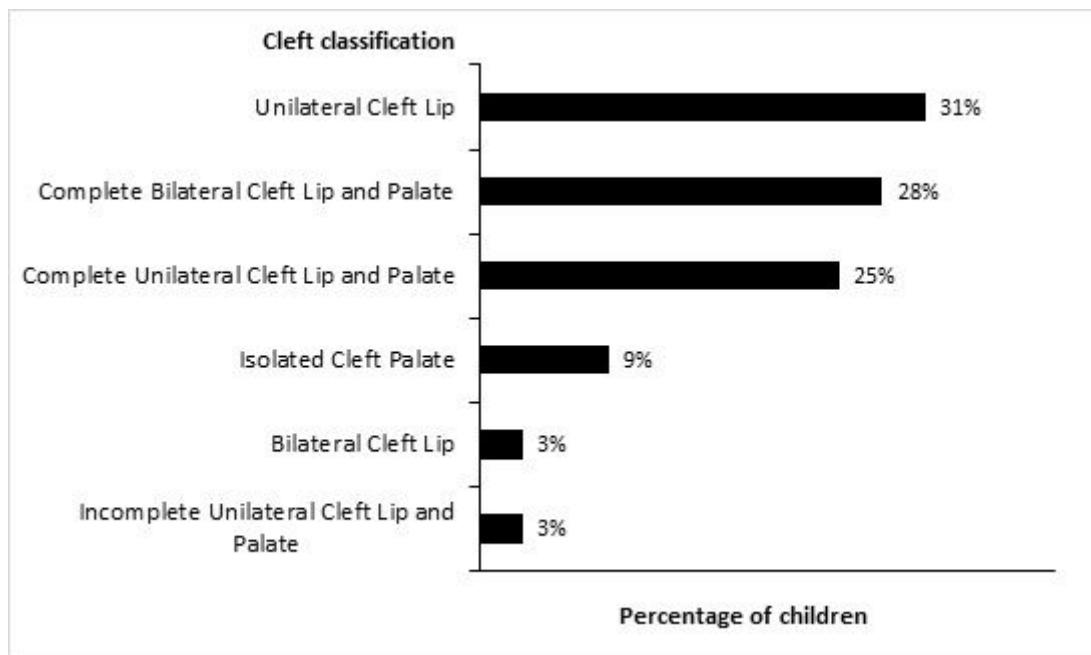


Figure 1

Classification of cleft types and percentage of children affected

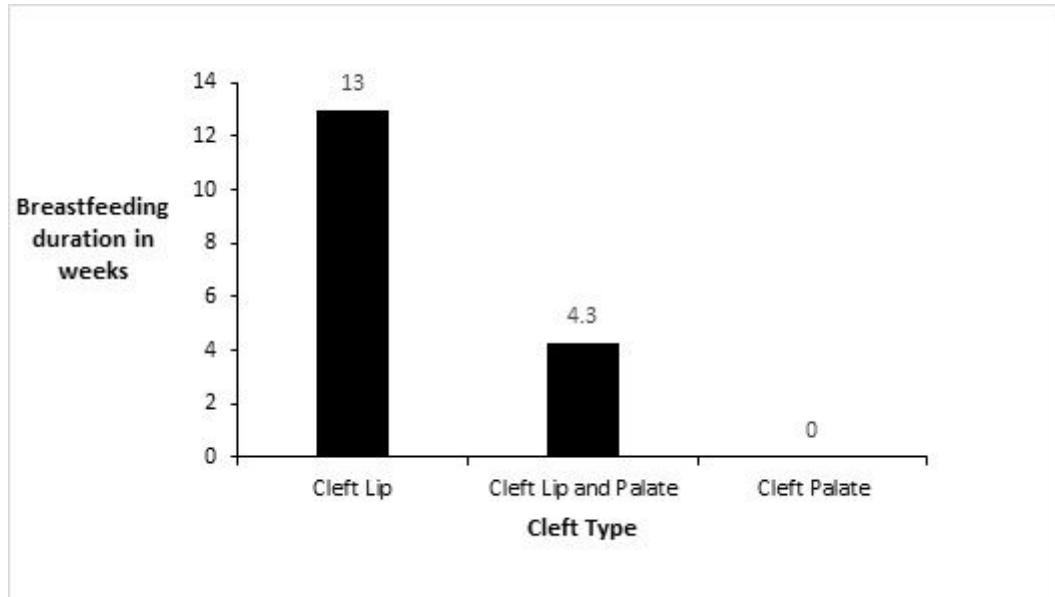
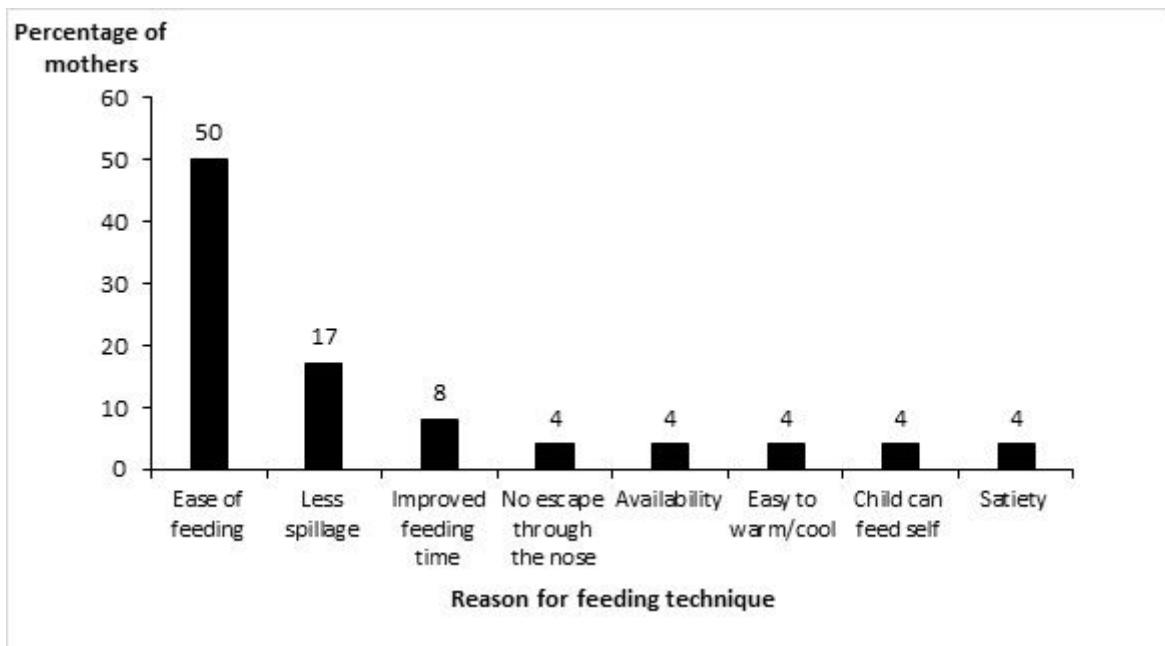


Figure 2

Mean breastfeeding duration according to child's cleft type



**Figure 3**

Mothers' reasons for choice of feeding technique (n = 24)