FEEDING PRACTICES, CHALLENGES AND NUTRITION STATUS OF INFANTS WITH OROFACIAL CLEFTS ATTENDING AFRICAN INLAND CHURCH KIJABE AND CURE HOSPITALS, KIAMBU COUNTY, KENYA

MAINA ANNASTACIA WAITHERA (BSc, FND)
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DECLARATION

"This thesis is my original work and has not been submitted for a degree in any other University or for any other award"

Signature: _____ Date: 9/08/2024

Maina Annastacia Waithera
Department of Food, Nutrition and Dietetics

SUPERVISORS

We confirm that the work reported in this thesis was carried out by the candidate under our supervision.

1. Signature: _____ Date: 9/08/2024
   Dr. Peter M. Chege (Ph.D.)
   Department of Food, Nutrition and Dietetics

2. Signature: _____ Date: 9/08/2024
   Prof. Elizabeth Kuria (Ph.D.)
   Department of Food, Nutrition and Dietetics

DEDICATION

To my loving husband Dr. Kingori for his unwavering support and my children Aziel, Amayah and Amitai who give me a reason to work harder.

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ABBREVIATIONS AND ACRONYMS

AIC: Africa Inland Church

BCL: Bilateral Cleft Lip

BCLP: Bilateral Cleft Lip and Palate

CFP: Complementary Feeding Practices

CHWs: Community Health Workers

CL/P: Cleft Lip and/or cleft palate

CL: Cleft Lip

CLP: Cleft Lip with cleft palate

CP: Cleft Palate alone

EBF: Exclusive Breastfeeding

ENA: Emergency Nutrition Assessment

FTT: Failure to Thrive

FFQ: Food Frequency Questionnaire

GBD: Global Burden of Diseases

HFA: Height for Age Z score

ICL: Isolated Cleft Lip

KDHS: Kenya Demographic Health Survey

LFA: Length for Age Z score

LMIC: Low and middle-income countries

MUAC: Mid Upper Arm Circumference

MAD: Minimum Acceptable Diet

MDD: Minimum Dietary Diversity

MMF: Minimum Meal Frequency

OFC: Orofacial Clefts

SPSS: Statistical Package for Social Sciences

UCL: Unilateral Cleft Lip

UCLP: Unilateral Cleft Lip and Palate

WFA: Weight for Age Z score

WHO: World Health Organization

WFL: Weight for Length Z score

OPERATIONAL DEFINITION OF TERMS

Breastfeeding: This referred to the direct placement of a child with orofacial cleft to the breast.

Breastmilk feeding: Breastmilk delivery to a child with orofacial cleft via spoon, cup, bottle, or any other way except direct on the breast.

Exclusive breastfeeding: This referred to the feeding of an infant with orofacial clefts under six months with only breast milk, whether directly or through expression, without any additions of solids or liquids apart from syrups or drops containing mineral, vitamins, or medicine, and no other thing within 24 hours.

Feeding practices: These referred to early initiation of breastfeeding, exclusive breastfeeding under 6 months, giving alternative breastmilk substitute, continued breastfeeding at 1 year, and introduction of solids, semi-solids or soft foods.

Morbidity: This is the state of being symptomatic or unhealthy for a disease or condition.

Nutrition Status: This included the anthropometric measures for infants, length for age, weight for age and weight for length indices.

Non-Syndromic Clefts: Non-syndromic CL/P was a term used to refer to multifactorial illness derived by the interaction of the environmental and genetic factors. These had no other physical or developmental anomalies. It indicated that CL/P occurred in isolation of other birth defects.

Orofacial Clefts: This referred to common congenital malformations of the palate, lip, or both. It included cleft lip, cleft palate, or both cleft lip and palate.

Stunting: Referred to the association between the measured length and the expected length as per length for age standards (LFA).

Syndromic Clefts: These were mostly due to monogenic diseases or chromosomal aberrations. They appeared as a part of congenital anomalies that is when one or more additional features not related with the cleft itself were involved.

Underweight: Referred to the association between measured weight and the weight that is expected as per age (WFA).

Wasting: This was the association between one's body mass and the stature of the child (WFL).

Z-scores: This was the degree of measure of the dispersion of the LFA, WFA, and WFL concerning the median scores of the series.

ABSTRACT

Orofacial clefts are among the most common congenital disorders across the globe. Recent research indicates that in every three minutes a baby is born with a cleft. Inadequate nutrition in the critical months can lead to impaired nutritional status and growth failure in the cleft population resulting in delayed surgery which can have an impact on overall health and development. At the time of the study, the infant and young child nutrition guidelines in our country were lacking detailed information addressing the feeding challenges in the cleft population. This study therefore sort to ascertain the feeding practices, associated feeding challenges and the nutrition status of infants with orofacial clefts attending AIC Cure and Kijabe Hospitals. The main objective was to determine the feeding practices, associated feeding challenges, nutrition status and to establish the relationship between the variables. A cross-sectional analytical design was adopted on a sample size of 107 infants together with their caregivers. A researcher administered questionnaire was used to collect data. Data was analyzed using SPSS version 25. Logistic regression was used to show the direction and the magnitude of the associations between the factors associated with infant's nutrition status at 95% confidence interval. A p value of < 0.05 was considered as statistically significant. Nutrition status was analyzed using Ena software for Smart. Descriptive statistics such as means, standard deviations, frequencies and percentages were used to describe the study population. The Chi-square test was used to establish the association between the independent variables and the outcome variable (nutrition status). Results showed unemployed caregivers were 40.2% with 49.5% having an average household income of less than KSh 10000. Infants less than 6 months were the majority at 54.2%. Early initiation of breastfeeding within 1 hour was at 29.0 % those who were exclusive breastfed at 28.0%. Infants who were bottle fed were at 47.6%. The minimum acceptable diet was 16.3%. Global malnutrition was at 17.8% (95% CI: 11.7-26.1). Global underweight at 31.8% (95% CI: 23.7-41.4) while global stunting was at 33.6% (95% CI: 25.4-43.0). Morbidity status for this study was at 35.5%. The study established a significant association between the caregivers' occupation and infant nutrition status (P value = 0.09 df = 1, OR= 13.231). In addition, there was a significant association established between the caregivers' average household income and children nutrition status (P value = 0.047 df= 2, $\chi_2 = 5.717$). Caregiver's occupation (AOR= 12.1; 95% CI, 1.60-25.81; p value = 0.019), child's age (AOR = 2.6; 95% C.I, 0.93-7.00, p value 0.05), caregivers average household income (AOR= 5.0; 95% CI, 1.13-21.80, p value = 0.034) and meal frequency (AOR = 5.0, C.I, 1.032-24.064, p value = 0.046) were the predictors of the children nutrition status. Equipping health care providers adequately in knowledge to early identify and address the feeding difficulties that infants born with orofacial clefts present with and prioritizing prevention of malnutrition in all its forms by consistent follow up and intervening appropriately at each encounter were some of the recommendations made.

CHAPTER ONE: INTRODUCTION

1.1 Background of the Study

Orofacial clefts (OFCs) collectively refer to a Cleft lip alone or with a palate and cleft palate alone. Research shows that orofacial clefts are one the commonest congenital disorders worldwide (Kadir et al., 2017). Their prevalence varies depending on different factors such as genetic disposition, geographical regions and ethnic variations the estimation that's most accepted is 1 out of 700 live births (Panamonta et al., 2015) making clefts the second most common congenital defect after clubfoot. This rate is at its peak among Asians (1/500), moderate among Caucasians (1/1,000), and lowermost among Africans (1/2,500) (Conway et al., 2015). More recent research reported that 1 in every 1,400 babies in Africa was born with a cleft (Kassebaum & Delage, 2022). In the extant literature, the orofacial clefts occurrence at birth in middle- and low -income nations is notably less, and it is ascribed to the dearth of information on the subject in the LMICs, especially in Sub-Saharan Africa.

Wanjeri and Wachira (2009) support the premise that there is a dearth of information on Cleft Lip and Palate (CLP) literature from Sub-Saharan Africa, and the little that is published does not have sufficient statistical data (Wanjeri & Wachira, 2009). In addition, the variation may have been due to lack of birth defect surveillance system put in place that count every baby born with a congenital anomaly and record the type of anomaly (Kassebaum & Delage, 2022).The multidisciplinary cleft clinic records in AIC Kijabe hospital indicated a total of 235 children with clefts that were attended to from the year 2020 to September 2021.

Children born with orofacial clefts are bound to experience nutritional challenges arising from feeding challenges in their early months. Feeding challenges surface at birth, owing to the swallowing mechanism and suction impairment due to changes in the anatomical structures (Duarte et al., 2016).

Infants with cleft palate face major feeding problems particularly in the first six months and failure to address the feeding challenges can lead to a drop in weight gain in a short span of time (Pandya & Boorman, 2001). In comparison to children without clefts, infants with orofacial clefts face significant nutritional challenges that can lead to the impairment of growth and other nutritionally related problems. Early interventions of regular feeding and sufficient intake are key in children to help in normal development and growth. The goals, nonetheless, are usually harder to attain in the cleft group (Kaye et al., 2017a). Studies have demonstrated on the difficulties that come with feeding among infants who have cleft palate and/or lip (Ravi et al., 2015). The level of difficulty in feeding depends on the cleft lesion severity. Infants who have cleft palate show difficulties emanating from the lack of producing a negative pressure to facilitate sucking. Most of the difficulties associated with feeding are due to reduced efficiency in sucking (Goyal et al., 2012).

Corrective surgery for the lip ideally should be done from three months old and nine to twelve months in the case of the palate. Adequate nutrition is crucial for children to undergo cleft repair surgery that is a stable weight gain with no health alterations and the capability to safely receive anesthetics (Duarte et al., 2016). Malnutrition can delay surgery or result in undesirable outcomes. Surgical healing is affected when malnutrition is present (Escher et al., 2021). Orofacial clefts have been linked with high mortality rates among infants as well as heightened morbidity in several developing countries where hindrances to ensure

multidisciplinary treatment are present. OFCs may impact the nutritional status of children if there are no precautions taken (Babalola et al., 2016). Malnutrition appears to be an extra burden on the children who have feeding issues (Ravi et al., 2015). Therefore, this research aimed at looking at the feeding practices, associated feeding challenges and nutritional status of infants who had orofacial clefts. This was a hospital-based study that took place at the ear, nose and throat (ENT) unit of AIC Kijabe Hospital and AIC Cure Hospital.

1.2 Problem statement

Nutrition and feeding problems are usually the first challenges that children who have orofacial clefts experience (Kaye et al., 2017a). The prevalence of malnutrition is high in children who have orofacial clefts (Sampagar et al., 2018). Infants with CP are sometimes unidentified until after they are born and are at times discharged without diagnosis only to come back with challenges in feeding and poor weight gain (Lewis et al., 2017). The available specific information of the initiation rates or the period human milk is used in children with orofacial clefts is limited (Kaye et al., 2019). A research study conducted in Nigeria indicated a higher initiation rate of breastfeeding but lower rates of continued breastfeeding due to problems encountered with breastfeeding (Tungotyo et al., 2017).

Mothers of infants with orofacial clefts need assistance for successfully feeding them. A study conducted in the United Kingdom reported a decline in growth failure in infants with CL/P after the early feeding program implementation including growth monitoring, feeding education, breast feeding support, and domiciliary visits (Reid, 2004). Mothers who deliver children with CL/P need support, equipment, and information to establish and sustain their milk supply. Family education is key for different health professions to address the feeding challenges encountered and thus reduce the risk of malnutrition.

According to (Burca et al., 2016) few healthcare professionals are trained adequately to provide lactation support for the cleft population especially those with cleft palate.

Inconsistencies and discoordination in healthcare providers may negatively influence mothers making it challenging for them to address the feeding difficulties their children face and sustaining their milk supply. Without a deliberate effort to ensure children born with orofacial clefts receive sufficient assistance and education on appropriate feeding practices to address their specific difficulties with feeding, these population is more prone to suffer from under-nutrition from inappropriate feeding practices. Under-nutrition makes children much more vulnerable to disease and death. One of the objectives and target aligned with the SDGs is to end all malnutrition forms and address the children's nutritional needs by 2030. This study aspired to assess current feeding practices, associated feeding challenges, and the nutrition status (wasting, stunting, and underweight) of infants with orofacial clefts attending AIC Kijabe Hospital and AIC Cure Hospital for the first time before any intervention was given and assessment done.

1.3 Study Purpose

To assess the current feeding practices, associated feeding challenges, and nutrition status of infants with orofacial clefts who attended AIC Kijabe Hospital and AIC Cure Hospital for the first time before any assessment and assistance by the multidisciplinary cleft team.

1.4 Study Objectives

1. To determine the demographics and socio-economic characteristics of parents and their infants with orofacial clefts who attended AIC Cure and AIC Kijabe Hospitals

2. To establish the feeding practices and associated feeding challenges encountered by infants with orofacial clefts who attended AIC Cure and AIC Kijabe Hospitals

3. To establish the morbidity status of infants with orofacial clefts who attended AIC Cure and AIC Kijabe Hospitals

4. To determine the nutrition status of infants with orofacial clefts who attended AIC Cure and AIC Kijabe Hospitals

5. To establish the relationship between feeding practices, morbidity status and nutrition status of infants with orofacial clefts who attended AIC Cure and AIC Kijabe Hospitals

1.5 Research hypothesis

H_{01} - There was no significant association between the caregiver socioeconomic/ demographic characteristic and the nutrition status of infants with orofacial clefts who attended AIC Cure and AIC Kijabe Hospitals

H_{02} - There was no significant association between feeding practices and nutrition status of infants with orofacial clefts who attended AIC Cure and AIC Kijabe Hospitals

H_{03} – There was no significant association between morbidity and the nutrition status of infants with orofacial clefts who attended AIC Cure and AIC Kijabe Hospitals

1.6 Study delimitation

The study only covered infants with orofacial clefts who attended AIC Cure International scheduled cleft clinic and AIC Kijabe Hospital first-time visit in the multidisciplinary clinic that happened twice in a month.

1.7 Study limitations

The study was hospital-based research, and the outcomes were inferred to children with the same characteristics that is infants with orofacial clefts in a hospital set up.

1.8 Conceptual framework

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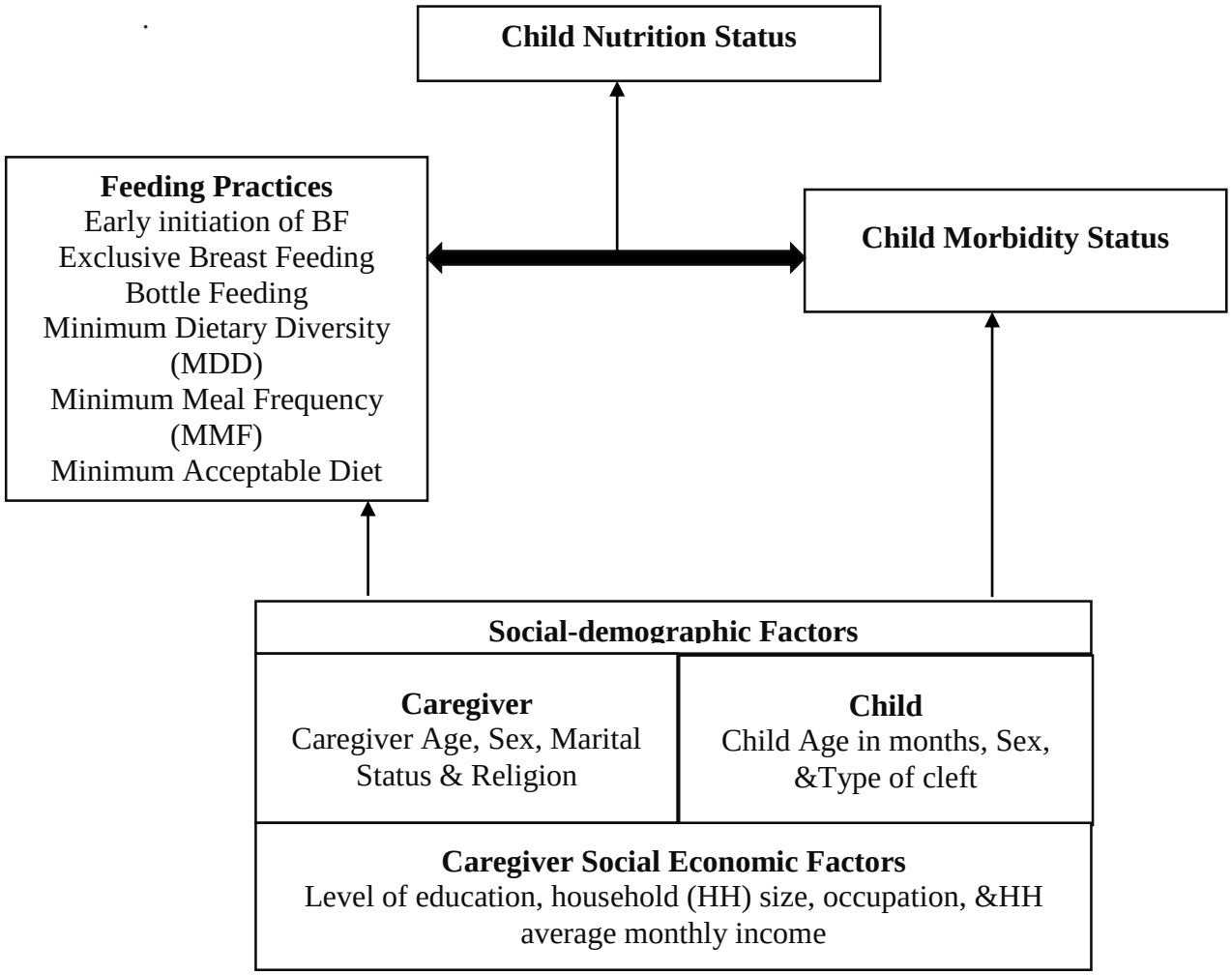

Figure 1:1 Conceptual framework on how feeding practices, morbidity status and nutrition status of infants with orofacial clefts may relate.

1.9 Study significance

The research findings would provide introductory data of mothers' reported feeding practices with regarding breastfeeding or offering expressed human milk and introduction of complementary foods to their infants with orofacial clefts. This research aimed at identifying the predictors of mothers' decision on current feeding practices. Opportunities to improve care delivery related to support and education regarding early feeding of infants born with orofacial clefts would be identified thus be resourceful in empowering community health workers (CHWs) and maternity staff who come into first contact with these mothers. The findings would also ensure the developing and improving of any available written protocols on feeding practices of the cleft population that would be shared with the policy implementers in the relevant institutions and in the sub- county and county thus inform policymakers and Ministry of Health.

CHAPTER TWO: LITERATURE REVIEW

2.1 Overview of Orofacial Clefts

Orofacial clefts, particularly cleft palate and/or lip (CL/P) are some of the commonest anomalies at birth. The World Health Organization notes that 1 out of every 500-700 individuals are born with this congenital defect. The defect usually occurs during development, between the fourth and twelfth weeks after conception (Burca et al., 2016). CL/P differ in terms of severity as well as their location and include three main categories: cleft lip alone (CL), cleft palate alone (CP), and cleft lip with palate (CLP) (Lewis et al., 2017). A cleft lip is described as an opening between the nose and the mouth, and it varies from a wide extension that spans to the nose to a small notch on the upper side lip.

According to (Burca et al., 2016), a cleft palate is an opening that exists at the mouth's roof between the oral and nasal cavities, and it varies in degree from an opening of the soft palate and can extend into the hard palate. A soft palate refers to the back muscular part of the mouth roof while a hard palate is the bony part of the roof. Cleft Palate emanates because of failure of the palatal shelves to fuse properly between the eighth and twelfth weeks during the development process of an embryo (Tabari et al., 2015). Cleft types can be divided further into bilateral cleft lip and palate (BCLP) and unilateral cleft lip and palate (UCLP) and as per the involved side by the cleft to fuse (right or left) (Lithovius et al., 2013).

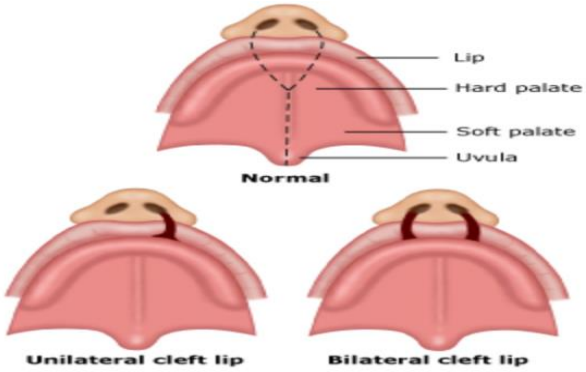

Figure 2:1. Classification of cleft lip (Source: Haug et al., 2020 www.uptodate.com)

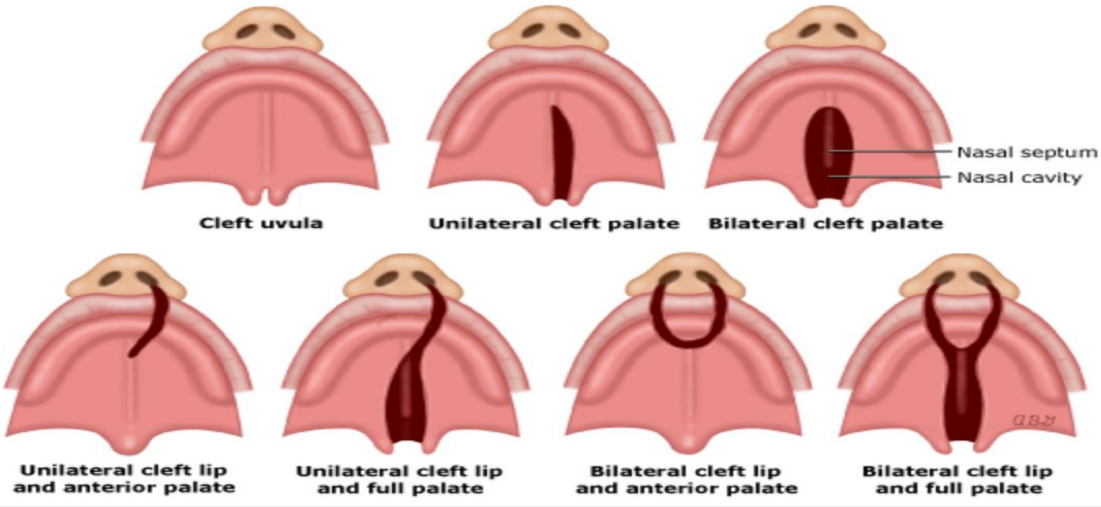

Figure 2:2 Classification of cleft lip and palate (Source: Haug et al., 2020 www.uptodate.com)

Although reports differ on this issue, it is projected that of all the infants with CL/P, around 30% only have isolated CP while 50% have both cleft palate and lip, and a further 20% have isolated CL with cleft lip that subsumes the alveolus having a prevalence of 5% in the cases. Clefts can either be unilateral with around 10% of the cases being bilateral (Reilly et al., 2013). Clefts most notably happen as isolated birth defects but they can also be

related to certain inherited genetic syndromes or conditions. Around 30% of cases of clefts are considered syndromic. Syndromic cases experience a range of malfunctions including central nervous system, cardiovascular, and musculoskeletal disorders (Conway et al., 2015). The available records in AIC Kijabe multidisciplinary clinic indicated a total of 205 children with clefts seen in the period between January 2019 and September 2021.

2.2 Demographic and socio-economic characteristics of Caregivers of children with Orofacial Clefts

Clefts bear a great influence on the health, life quality and development of children even in settings with early and specialized care access (Kadir et al., 2017). CL/P rates vary depending on various factors including geographic origin, gender, ethnicity, race, and socioeconomic status (Burca et al., 2016). Compared to girls, boys have a higher probability of being affected with a 2:1 reported ratio with CL and/or CLP, whereas the CP risk only is greater slightly in females (Id et al., 2019). With cleft anomalies of all races brought together, 15% to 20% is cleft palate only, 30% to 35% are lip only, and 50% are CLP (Wanjeri & Wachira, 2009). The available cleft data from the Multidisciplinary clinic in AIC Kijabe Hospital indicates 114 boys and 91 girls of all the orofacial clefts cases seen between January 2019 and September 2021. Children with CL/P usually go through multiple reconstructive surgeries throughout their childhood.

The period that surrounds surgeries can be both frightening as well as stressful for both children as well as their families thus requiring planning and support (Lewis et al., 2017). According to research, patient-related factors affecting cleft care subsume patients' awareness, difficulties with transportation due to living in remote locations where transport is poor, and the capacity for caregivers to work and earn the money necessary for care is

severely limited (A. Oluwasen, F. Rachel, 2012). Success is possible in the treatment of both functional and cosmetic orofacial cleft anomalies aspects, but it can be a lengthy process which can be challenging for the caregivers, costly, and relies on the experience and skills of specialists' surgeons (Agbenorku, 2013). Comprehensive cleft care is expensive especially in resource limited settings and can be a daunting task for any family in every aspect especially if there is no financial aid available to assist with needed surgery and other additional costs.

2.3 Feeding challenges of Infants with Orofacial Clefts

Feeding difficulty is one of the immediate challenges that newborn infants with orofacial clefts present with (Goyal et al., 2012). The level of intricacy in feeding depends on the cleft lesion's severity. If there is only a split on the infant's palate or a small notch on the infant's lip, feeding may not be an issue (Mizuno et al., 2002). Children who have isolated cleft lip (ICL) experience fewer feeding problems as compared to ones with CP without or with CL. This issue is more severe among younger infants with cleft palate, majorly in the first growing year (Miranda et al., 2016). The main challenges experienced by infants with cleft palate include a weak suck, non-rhythmic suck, swallowing too much air and problems with maintaining a good seal. These children also experience choking, gagging, and leaking milk. Feeding practices need to be modified for each infant depending on the unique challenges each infant experiences. An example is difficulties with latching and creating enough negative pressure at the nipple which might lead to wasted energy expenditure and prolonged feeding times. Other consequences include exhaustion during the breastfeeding process, that is, tiring too fast before they reach the hind milk that has higher fat content. Nasal regurgitation, vomiting, impaired growth and nutrition,

insufficient milk transfer, and reflux are additional challenges that these infants experience (Boyce et al., 2019).

Infants with orofacial clefts might require a special feeding device since they are unable to provide adequate negative intraoral pressure to effectively suck milk especially those with a cleft palate (Lewis et al., 2017) . The nutritional recommendations may vary in these patients. Priority for these children may include replacing an almost normal feeding approach the strategy being to increase the oral movement for motor capability development (Tabari et al., 2015). Special feeding bottles are given to infants with CLP or CP. The special bottles are easily available in resource-rich countries compared to resource limited settings and they help infants especially those with cleft palates to feed in an efficient way (Kaye et al., 2019). This should not bar the infants born with CP or CLP from receiving expressed human milk from a bottle or partial feedings sessions directly from the breast as it promotes bonding between the mother and infant. In our settings, these feeding devices are, however, expensive and not always easily accessible and the practice is the use of cup and spoon or the regular feeding bottle. Often, infants may be born in a hospital set up where cleft awareness is limited even among healthcare givers. This may result in the mothers or caregivers feeling overwhelmed as they try to address the feeding challenges their infants present with. Mothers whose infants have clefts often experience stress and without reaffirming, reassurance and guided assistance may struggle to commence the expression of milk earlier for promotion of a supply that is adequate and sustainable (Kaye et al., 2019). The figure below shows different brands of special bottles in the market that are available for use by children with orofacial clefts who have difficulty nursing.

Figure 2.3 Cleft feeders (Source: Lewis et al., 2017)

2.4. Breastfeeding Infants born with Orofacial Clefts

The World Health Organization states that all infants should be exclusive breastfeed for 6 months. This is because breastmilk provides numerous benefits for all infants, including the ones who have CL/P. However, only 44% of infants between 0-6 months worldwide

were exclusively breastfed as per studies done between 2015-2020 (WHO, 2020). A study carried out in a tertiary heath institution of 65 mothers with OFC in Nigeria reported the initiation of breastfeeding at (83% n= 54) with only (18.5% n= 10) continuing with exclusively breastfeeding (Adekunle et al., 2020a). Mothers normally use either compression or suction in breastfeeding their children. The capacity of generating suction is critical and essential for maintaining a stable feeding position, attachment to the breast and, milk extraction when combined with the let-down reflex, (Boyce et al., 2019).

Compression happens when the child presses the breast in between the jaw and the tongue. Breastfeeding requires a good latch and efficient suction. Compression and suction assist in transferring the milk during the process of breastfeeding (Reilly et al., 2013). There is an association between the size of cleft, the cleft type, the infant's maturity level, and oral pressure amount produced when feeding. Children who only have the cleft lip may have difficulties in forming a seal around the nipple but can be breastfed generally before as well as after lip surgery. However, the cleft palate being there makes it harder to cause negative pressure required to feed (Chigurupati et al., 2017). Infants who have CP or CLP find it daunting to create suction as well as the consequent negative pressure since during the process of feeding, the oral cavity is unable to separate sufficiently from the nasal cavity (Boyce et al., 2019).

These children therefore have trouble closing the nasopharynx and building the required negative pressure in the mouth with a hole in the palate that lets air circulate between the nose and the mouth. The negative pressure created intraorally is required for both sucking and swallowing to be efficient (Madhoun et al., 2019).Children normally present with non-coordination of sucking with swallowing, nasal obstruction, choking, and breathing

(Miranda et al., 2016). The flow of milk is dependent on the sucking and expression pressure. In clefts, the expression pressure is either one-third or half of the sucking pressure. Children with CLP often experience challenges with breastfeeding adequately that can support weight gain that is sufficient for surgery repair (Lewis et al., 2017).

Pumping and expressing milk provides human milk's benefits which include protection against ear infections, which is a greater risk for infants with CLP (Lewis et al., 2017). Infants with CL or CL ± A and no CP can form a sufficient seal to produce enough intraoral negative pressure to enable them effectively to transfer or suck milk. To attain this, mothers with infants born with OFC require help with both proper positioning as well as the latch to optimize breastfeeding (Lewis et al., 2017). Breastfeeding children with clefts should therefore be promoted and prioritized as it provides numerous benefits which include; strengthening the muscles around the face and mouth, playing a role to promote better speech in the future and provides more control over positioning and milk flow. In addition, a breast is more comfortable compared to a bottle nipple and since breastmilk is a natural substance it is not as irritating when regurgitated through the nose and it offers interaction and comfort which infants born with clefts need.

For all infants, human milk is regarded as the optimal nutrition and has been indicated to provide various protective and preventive effects for at risk and healthy infants. A lot of scientific support for human milk use and recommendations on the breast feeding period and maternal initiation has been generated by nutritional research for all newborns. Issues related with expression of milk for infants who are unable to directly breastfeed like the ones with orofacial anomalies are highlighted in several studies. The available specific

information of the initiation rates or the period human milk is used in children with orofacial clefts is limited (Kaye et al., 2019).

2.5 Nutritional status of children with cleft lip and /or palate

Nutritional and growth problems are seen more among children who have either both a cleft lip and or palate only and differ depending on the cleft status and type (Tabari et al., 2015). Feeding difficulties experienced by children with cleft palate if not addressed early enough may have a negative impact on their nutritional status (Boyce et al., 2019). Due to the feeding difficulties these children experience, more calories might be consumed during the feeding process creating a (nonproductive cycle promoted) resulting to little or no weight gain thus creating a net negative calorie balance (Kaye et al., 2017b). Additionally, parents of children with CLP may experience feelings of inadequacies when feeding their infants which may lead to reduced ingested milk volume thus leading to failure to thrive. (Miranda et al., 2016).

The malnutrition prevalence in children with CLP vary between 30 and 50% (Tungotyo et al., 2017). Recent research reports that children who are under five years with clefts are two times likely to be malnourished compared to children of the same age without clefts (Kassebaum & Delage, 2022b). Good nutrition is crucial for children with CL, CLP as it quickens post-operative wound healing (Tungotyo et al., 2017). Studies show that if an early intervention is done there is a notable decline in failure to thrive rates. This early intervention may include growth monitoring, feeding education, breast feeding support, and domiciliary visits. It may also be in other ways which include nutrition / lactation advice, prostheses, feeding techniques, and feeding equipment (Shetty, 2016).

2.6 Morbidity status and Orofacial Clefts

Patients who have orofacial clefts especially cleft palates have higher risks of malnutrition and anemia if timely and appropriate feeding interventions are not given to address the feeding difficulties they present with (Nagalo, Ouédraogo, Laberge, Caouette-laberge, et al., 2017). Because children with CL/P are more likely to chock on food, they are more prone to frequent infections of the respiratory system. Where there is no sufficient protection from bad weather conditions, infants with OFCs stand more exposed and vulnerable to poor weather conditions and thus prone to coughs, colds, pneumonia, and colds (Nagalo, Ouédraogo, Laberge, Caouette-Laberge, et al., 2017a) .

2.7 Summary of literature review

Children born with any kind of cleft have nutritional requirements like other children who do not have clefts provided there are no other systematic issues. Adequate feeding and nutrition are among the earliest and highly profitable strategies of managing CLP in newborns early. Different studies have shown that parents of infants with CLP mostly report that their biggest worry and problems are around feeding issues. These difficulties in feeding among children with CLP are common and surface during delivery owing to the sucking impairment as well as swallowing functions. FTT is notably connected to cleft palate and lip patients. Adequate nutrition is critical for these children to enable them to go through cleft repair surgery, that is the ability to receive anesthetics safely and weight gain that is stable with no health issues. Addressing the nutritional issues from birth that children with CLP undergo is crucial in improving these infants' health, nutrition, growth and development to enable them to undergo surgery at the required time which is the initial treatment.

CHAPTER THREE: METHODOLOGY

3.1 Research design

A cross-sectional analytical design was employed. It was effective in obtaining quantitative and qualitative data and also provided the necessary population characteristics during the study period (Mugenda & Mugenda, 2003).

3.2 Research variables

3.2.1 Dependent variables

This was the nutritional status of subjects aged 0-11 months with orofacial clefts as per the inclusion criteria who attended AIC Cure Hospital and AIC Kijabe Hospital. It was assessed using weight-for- length z score < -2 to check for wasting, length-for- age z score < - 2 used to check for stunting and weight- for-age z score < -2 to check for underweight as per the WHO growth standards. Presenting bilateral pitting edema was also checked. This was any swelling of both feet and/or both legs, both hands, and face. Mid-Upper-Arm Circumference (MUAC) was also used as a screening tool for acute malnutrition for infants who were 6 months and above.

3.2.2. Independent variables

For this study, the independent variables were the infants' feeding practices that is (early breastfeeding initiation within 1hour, exclusive breastfeeding for infants under 6 months, timely complementary foods introduction and achievement of MDD, MMF, MAD. Dietary assessment tools that were used were 24-hour recall and 7-day food frequency. Parents/caregivers demographic factors included household size, religion, marital status, age, sex and number of children. Child's demographic factors of interest included age, sex and cleft type.

The socio-economic factors of parents or the primary caregivers were subsumed into the level of education, occupation, and monthly household income. The morbidity status rate of the infants at the time of study that was not associated with any syndromes were an additional independent variable. For this study, the morbidity status rate mainly focused on any illness the infant suffered from or had suffered from the last 2 weeks prior to the study.

3.3 Study location

The study area was AIC-Cure International Hospital and AIC Kijabe Hospital. They are located in Kiambu County, Lari sub- county 5 kms from Gichiengo along the Nakuru – Nairobi highway. AIC Kijabe hospital is classified as a level 6B tertiary teaching referral hospital. Both Cure and Kijabe hospitals are faith based sponsored by Africa Inland Church (AIC) and serve patients from diverse cultural, religious and socio- economic backgrounds countrywide and neighboring countries. AIC Cure hospital purely is an orthopedic hospital for children with disabilities. Both hospitals have a partnership with Smile Train, an NGO and charity funding corrective surgery for CLP children. AIC Kijabe Hospital runs a multidisciplinary cleft lip and palate clinic every first and third Wednesday of the month which is under the ENT department. AIC Cure admits children with orofacial clefts on scheduled days within a month.

3.4 Target population

It entailed infants with orofacial clefts who attended AIC-Cure International Hospital and AIC Kijabe Hospitals. All Infants who attended the two hospitals, met the inclusion criteria and consented to be part of the exercise were included.

According to AIC Kijabe hospital annual google form records, the average number of patients seen in a month in 2021 was 15. AIC Cure International Hospital schedules cleft

patients who are then called for surgery as per the bookings either monthly or depending on the numbers available.

3.4.1 Inclusion criteria

All infants with orofacial clefts who attended AIC Cure International Hospital and AIC Kijabe hospitals at first visit and were at least 2 weeks old to capture current feeding practices and whose caregivers were living with them for more than a week at the study time and consented were part of the study.

3.4.2 Exclusion criteria

Infants with other confirmed congenital anomalies like cerebral palsy and any other that had an impact on their nutritional status were excluded in the research.

3.5 Sample size

Yamane's (1967) formula was deployed in determining this. For a 95% confidence level

$$n = \frac{N}{1 + N(e^2)}$$

Where n = the sample size

N is the population size

e = level of precision =0.05

N= using 2021 statistics the total number of patients seen in the MDT cleft clinic from January to September was 125 the average being 15 each month. AIC Cure International model of attending to cleft patients changed during the study period thus we worked with an estimate of 50 patients for a period of 6 months. The total population for a period of six months was therefore

(15*6) = 90 + 50 =140

Thus n= $\frac{140}{1+140(0.05^2)}$

=103.7 ~ 104 an addition of 10% will be included to cater for defaulters. Thus, totaling to 104 + {(10/100) *104} = 104 + 10.4= 114.4 ~ 114 infants.

3.6 Sampling technique

The technique employed to select AIC-Cure International Hospital and AIC Kijabe Hospital was purposive sampling. All patients with unrepaired orofacial clefts attending the multidisciplinary CLP clinic in AIC Kijabe Hospital and AIC-Cure International Hospital who also met the inclusion criteria were chosen.

3.7 Research tools

The principal data gathering tool was a structured questionnaire (see Appendix B). Data included was on demographics, socio-economic factors and feeding practices including challenges, anthropometric measurements with Z- scores computed and morbidity status rate. The dietary assessment method employed was a 7-day food frequency and a 24-hour recall questionnaire.

Anthropometric tools included a length board and a digital scale /salter scale for taking weights. Infants' length and weight were the anthropometric measurements of interest and to determine the participants' nutritional status, WHO standard growth charts were used. MUAC measurements were also taken for all infants that were six months and above.

3.8 Research tools pre-testing

Pre-testing of the questionnaire was done before the study commenced. This was done to check accuracy, clarity and determine how much time it would take to administer and thereafter any necessary adjustments were made to improve the tools' validity and reliability. Pre-testing of questionnaires was done in 10 mothers of infants with an orofacial cleft attending both hospitals but were not included as study participants.

3.8.1 Reliability

Test re-reset technique was utilized to ensure consistent results were obtained. The questionnaire was administered twice to 10% of the sample. This was done over a period of two weeks. The results were then compared to measure the correlation between scores from the two administrations of the questionnaire from the same respondent. Cronbach's alpha (correlation co-efficient) was calculated.

3.8.2 Validity

The study was reviewed by nutrition experts to ascertain the questionnaire's appropriateness and accuracy as per the study purpose and the objectives.

3.9 Research assistants training

The researcher recruited two assistants to help with collecting data. Their required qualifications were a minimum of a Diploma in nutrition. They got training on the study topic, objectives, purpose, contents of the questionnaire and responses expected from each question, interviewing skills, data collection techniques, and taking of weights and length using appropriate equipment and techniques.

3.10 Data collection technique

3.10.1 Researcher administered questionnaire.

Data collected included infants and caregivers' demographics and caregiver's socio-economic characteristics. The infant's age and immunization information were verified by the child's health card. A recall method was used to estimate date of birth for caregivers/mothers who did not have the child's clinic book, the mother/caregiver was asked to determine the date as closely as possible, and an example is concerning a local event or holiday. Anthropometric data for all the children was obtained using standard procedures. A Contrex MS20E digital baby scale and Seca salter scale were used to take the weights. Before commencement of weighing the scales were tested with a weight of known load. Weights were then taken in kilograms with the difference not exceeding 0.1Kgs. All infants were weighed twice with minimal clothing and the mean computed and recorded. A length board which was placed on a flat, stable surface helped take the length with the infant lying down in a recumbent position. The length was then taken after ensuring the infants buttocks, and heels, back of the head, shoulders, touched the board. Length measurements were in centimeters to the nearest 0.1centimeter accuracy. The length readings were taken two times mean computed and then recorded.

3.10.2 24-Hour dietary intake recall

This tool was deployed in recording a detailed description of all drinks and foods taken on the previous day, methods of cooking, and brand names recorded if available. The mother or caretaker was asked to state what they had fed their child that is, foods, fluids and any condiment added in the last 24 hours before the study. The portion sizes were determined using standard household equipment such as cups, plates, and spoons. The time when food

was consumed was captured with a reference of 24 hours to minimize recall bias and enhance accuracy that is from waking time to bedtime. The five-step approach recall method was used. A quick list was first shared and the respondents listed all the food items taken the prior 24 hour period (Steinfeldt et al., 2013). The second step included probing questions for foods consumed and forgotten during the first step. Thirdly was to find out the time every food had been taken and the name of the eating occasion. Step four was to ask questions that review each eating occasion and intervals between the occasions while step five was to act as the final probe that gave the respondent one more opportunity to recall any other food that was not recorded in the interview session.

3.10.3 7-Day food frequency questionnaire

In assessing the infant's regular consumption, a 7-day FFQ was recorded using the 8 food groups for children.

The 8 food categories included breastmilk, vegetables and fruits rich in vitamin A, eggs, flesh foods, dairy products, legumes and nuts, tubers/roots/grains and other vegetables and fruits. Study subjects were requested to state the number of times the infant had eaten from each food group for the past 7 days.

3.11 Data management

A structured questionnaire was used to obtain all data. The filled questionnaires were then entered in a google version template within two days of collection. Data was verified and cleaned before any analyses were done. All questionnaires were identified by a unique number and participants' names were not included in the individual data. Signed forms and questionnaires were kept in a lockable file cabinet whose key was only accessed by the researcher.

3.12 Data analysis

ENA software for Smart was utilized in analyzing anthropometric data including MUAC. The Z- scores of interests were weight-for-length (WFL) a measure of wasting, weight-for-age (WFA) a measure of underweight and length-for-age (LFA) that will measure stunting. Entering and analyzing of dietary intake data was done by use of Nutri-survey software and later exported to SPSS version 25 for cross analysis. Univariate analysis described socio demographic and economic attributes. Standard deviation and means presented Continuous variables. Percentages or frequency distributions were used to present categorical and ordinal data. Bivariate analysis that is binary logistic regression was used for nutritional status. Odds ratio and chi-square tests were performed.

The dependent variable (nutritional status) and independent variables feeding practices and associated challenges, morbidity, demographic and socio-economic factors association was assessed using Multivariable logistic regression. Level of significance assumed a probability (p) value of < 0.05. The T-test tested the significance of the difference between mean values.

3.12 Ethical considerations

Authorization letter was given by "Kenyatta University graduate school". Consent was solicited from AIC Kijabe Hospital Institutional ethics review committee, and Cure Hospital Institutional ethics review committee. The researcher further sought authorization from NACOSTI. Consent to take part was gotten from the children's parents or primary caretakers that met the inclusion criteria (See Appendix A).

CHAPTER FOUR: RESULTS

This chapter presents the study findings. The study had a response rate of over 100% of the minimum expected sample size (104) which was 93.9% of the calculated sample size (114) thus resulting in 107 reported caregiver child pairs.

4.0 Demographics and socio-economic characteristics of the caregivers with infants with orofacial clefts

The caregivers' demographic information of interest were age, sex, marital status, religion, and household size while the socio-economic characteristics were level of education, occupation, and average monthly household income. The caregivers' mean age was 29 (±5.5) years, 12 % were over 35 years old. Majority of the caregivers who were interviewed were female which was 95.3% mostly mothers while 4.7% were male all being the fathers of the infants. The percentage of married caregivers was 81.3% while 18.7 % were in single parenthood category. The protestant category religion was the highest with 73.8% Catholics being 23.4% and Muslims being the least at 2.8%. Unemployed caregivers were the majority at 40.2% while those who were on a salary amounted to 15.9%. Those who engaged in business were 22.4% while casual laborer's and farmers were 9.3% and 12.1 % respectively. Those who had no basic education were 11.2%, while primary level 31.8%. Almost half (49.5%) of the caregivers had an average household income of below KSh 10,000. The next category of more than KSh 10001-20000 were 29%, between KSh 20001-40000 were 9.3% while those that earned more than KSh 40000 were 12.1 %. The mean income level was KSh 17070.09 ±18572.963. The mean household size was 5.07 (± 2.0) while the majority had 2 children or less at 57%. Those who had 3-4 children were 30.8%

while 12.1% had 5 or more children. Table 4.0.1 and 4.0.2 provides a detailed summary of the demographics and socio- economic characteristics of the caregivers.

Table 4.1 Demographics characteristics of the caregivers

	Category	**N= 107**	
		Frequency	%
Mean age (SD)years	29 (±5.5)		
Age	≤ 25 years	26	24.3
	26-35 years	68	63.6
	≥ 36 years	13	12.1
Sex	Female	102	95.3
	Male	5	4.7
Marital Status	Single	20	18.7
	Married	87	81.3
Religion	Protestant	79	73.8
	Muslim	3	2.8
	Catholic	25	23.4
Relationship with child	Father	5	4.7
	Mother	102	95.3

Table 4.2 Socio-Economic characteristics of the caregivers

Variable	Category	N= 107	
		Frequency	%
Level of Education	No basic education	12	11.2
	Primary level	34	31.8
	Secondary level	32	29.9
	Tertiary level	29	27.1
Occupation	Unemployed	43	40.2
	Business	24	22.4
	Casual labor	10	9.3
	Farming	13	12.1
	Employed (salaried)	17	15.9
Average HH Income	≤ KSh 10000	53	49.5
	KSh 10001-20000	31	29
	KSh 20001-40000	10	9.3
	≥ KSh 40001	13	12.1
Mother's Parity Category	≤ 2 children	61	57
	3-4 Children	33	30.8
	≥ 5 Children	13	12.1

4.1 Characteristics of Infants with Orofacial Clefts

The male infants studied were more than half (55.1 %) while the female was at 44.9%. In terms of age the majority were less than 6 months at 54.2%. Those who were 6-8 months were 22.4% while 23.4 % were in the 9-11 months category. The most frequent cleft type was unilateral CLP at n = 32, (29.9%) followed by bilateral cleft lip and palate at n= 31, (29%). Infants who had unilateral cleft lip only were n = 30 at (28%), bilateral cleft lip were n= 9 at 8.4% and the least percent was cleft palate alone at n=5 at 4.7%. The table below summarizes the characteristics of infants with orofacial clefts.

Table 4.3 Demographics characteristics of Infants with Orofacial clefts

Variable	Category	N= 107	
		Frequency	**Percent**
Birth weight	Mean birth weight in kgs (±SD)	3.0 (±0.6)	
	Mean Age in months (±SD)	5.6(±3.2)	
Age	Less than 6 months	58	54.2
	6-8 months	24	22.4
	9-11 months	25	23.4
Sex	Female	48	44.9
	Male	59	55.1

		Sex of child	
		Female	Male
Type of cleft	Unilateral cleft lip	8	22
	Bilateral cleft lip	5	4
	Unilateral cleft lip with palate	15	17
	Bilateral cleft lip with palate	18	13
	Cleft palate alone	2	3
Total		**48**	**59**

Type of cleft		**Frequency**	**Percent**
Valid	Unilateral cleft lip	30	28.0
	Bilateral cleft lip	9	8.4
	Unilateral cleft lip with palate	32	29.9
	Bilateral cleft lip with palate	31	29.0
	Cleft palate alone	5	4.7
	Total	**107**	**100.0**

4.2 Feeding Practices of infants with Orofacial Clefts

4.2.1 Breastfeeding practices of Infants with Orofacial Clefts

The objective on feeding practices focused mainly on measuring the breastfeeding practices and complementary feeding practices (CFP) of infants with orofacial clefts. The breastfeeding practices of focus were early initiation of breastmilk within an hour as per WHO guidelines, exclusively breastfeeding for children under 6 months.

The percentage of infants who breastfed within 1 hour as WHO recommendation was 29%. Infants who were exclusively breastfed were slightly more than a quarter of the sample size at 28%. The most common reason reported for not putting children on the breast directly was the inability to latch properly due to orofacial cleft, which was more than half of all infants who reported not being breastfed directly on breast. Infants who were receiving breastmilk at the time of interview either directly or as expressed breastmilk were at 66.4% while those who had never breastfed or received breastmilk were 3.7%. Commercial Infant Formula was the breast milk substitute used by majority of the infants at 29% followed by whole cow's milk at 15.9%. Fifty five percent (n= 55.1 %) had not given any breast milk alternative. Bottle feeding was the mode of feeding used by almost half the population with 24.3% using the normal bottle and 23.4% using the special bottle. The above information is summarized in table 4.2.1 below.

Table 4.4 Breastfeeding Practices of Infants with Orofacial Clefts

	Frequency	**N=107 Percentage%**
Early Initiation of Breastfeeding (Within 1 hour)	31	29
Exclusive BF (<6m)	30	28
Given Anything other than Breastmilk ≤ 3 days	42	39.3
Bottle Feeding	51	47.6
Those who were Receiving Breastmilk at the time of study directly or expressed breast milk	71	66.4
Never Breastfed	4	3.7
Feeding Assistance		
Total who Received Assistance	61	57
Assistance within 1 hour	29	27.1
Assistance on BM Expression	66	61.7

4.2.2 Feeding Challenges

Eighty percent (n= 86) of the mothers reported to have experienced difficulties breastfeeding their infants. The most reported difficulty was burping and intake of excessive air while breastfeeding. The figure below

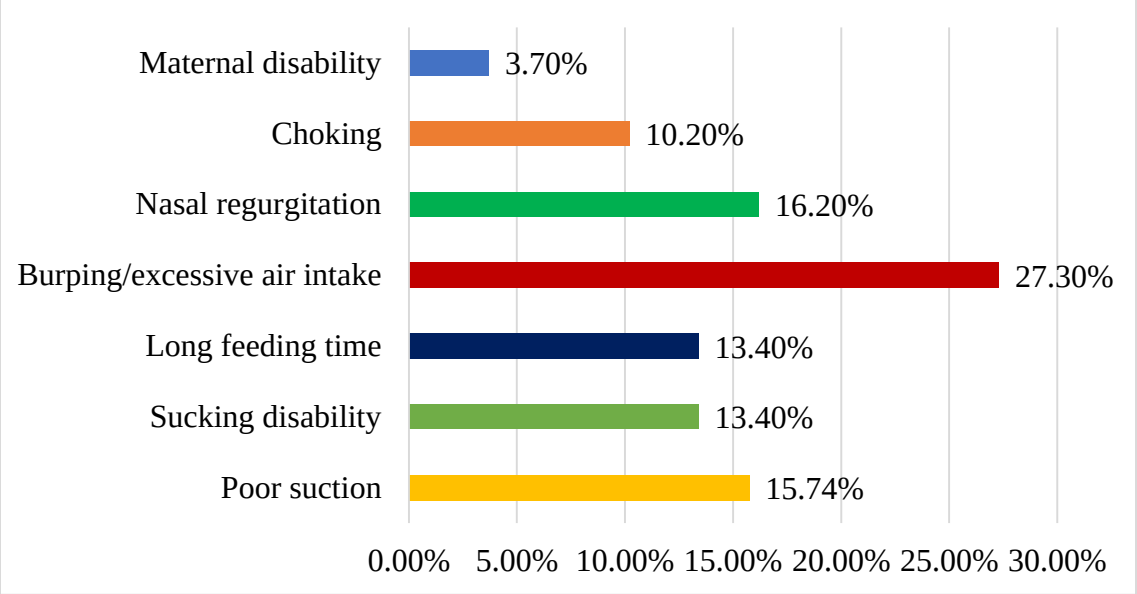

Figure 4:1 Summary of the challenges of breastfeeding as reported by mothers.

The study results show that 64.5 percent of the mothers expressed breastmilk. They adopted different feeding methods as shown in the figure below.

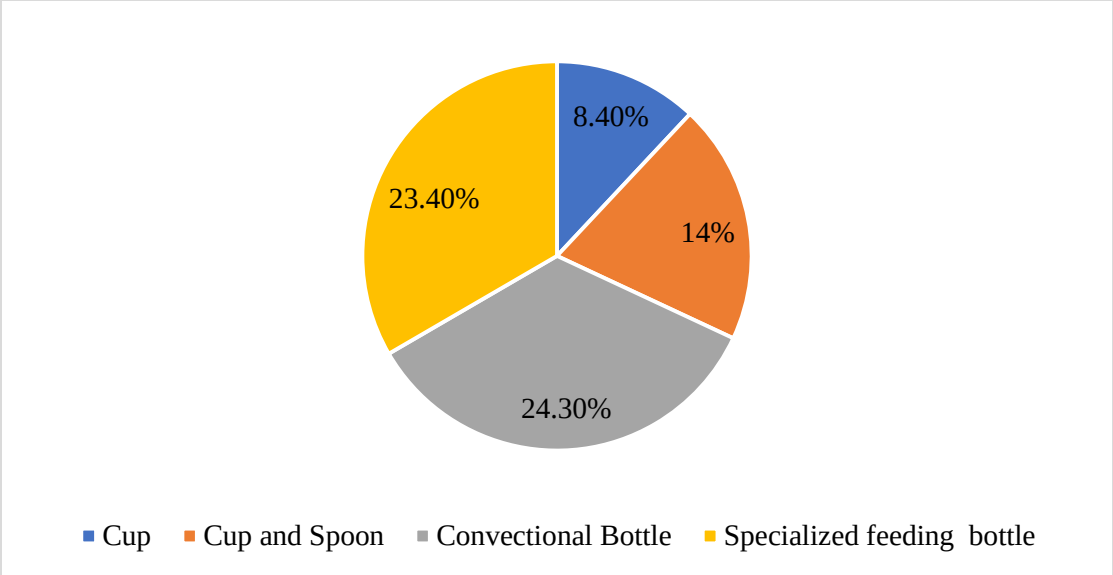

Figure 4.2: Feeding methods adopted by mothers with infants with Orafacial clefts

4.2.3 Complementary feeding practices

Complementary feeding indicators were introduction of soft, semi-solid or solid foods, minimum dietary diversity, minimum meal frequency and minimum acceptable diet.

4.2.3.1 Introduction of soft, semi-solid or solid foods

This indicator was assessed depending on the caregivers' 24-hour recall whereby the infant's proportion who were 6-8 months of age and fed on soft, semi-solid or solid foods the previous day was calculated and was at 48.9%.

4.2.3.2 Dietary Diversity

This was determined by a dietary diversity questionnaire, 7 day- food frequency and 24-hour recall questionnaire. To calculate this indicator the groups of foods used were eight as follows; breastmilk, flesh foods, dairy products, eggs, legumes, grains tubers and roots and nut, vegetables rich in vitamin A and other fruits and vegetables (WHO., 2010). Any food quantity from every food category consumed was enough to count. Consumption of

at least five food groups from the eight food groups increased the likelihood of consuming at least one fruit or vegetable and at least food from an animal source in addition to the food groups that are staple. Out of the forty-nine infants who were on complementary foods only 46.9% were breastfeeding. The dairy food group was the most consumed at 75.5% followed by grains, roots and tubers at 71.4 %. Vitamin A rich fruits and vegetables and other fruits and vegetables groups were both at 63.3%. The least consumed food groups were flesh meats at 26.5% and eggs at 38.8% at a mean of 2.15 days and 2.16 days respectively. The figure below gives a summary of dietary diversity as per the 8 food groups.

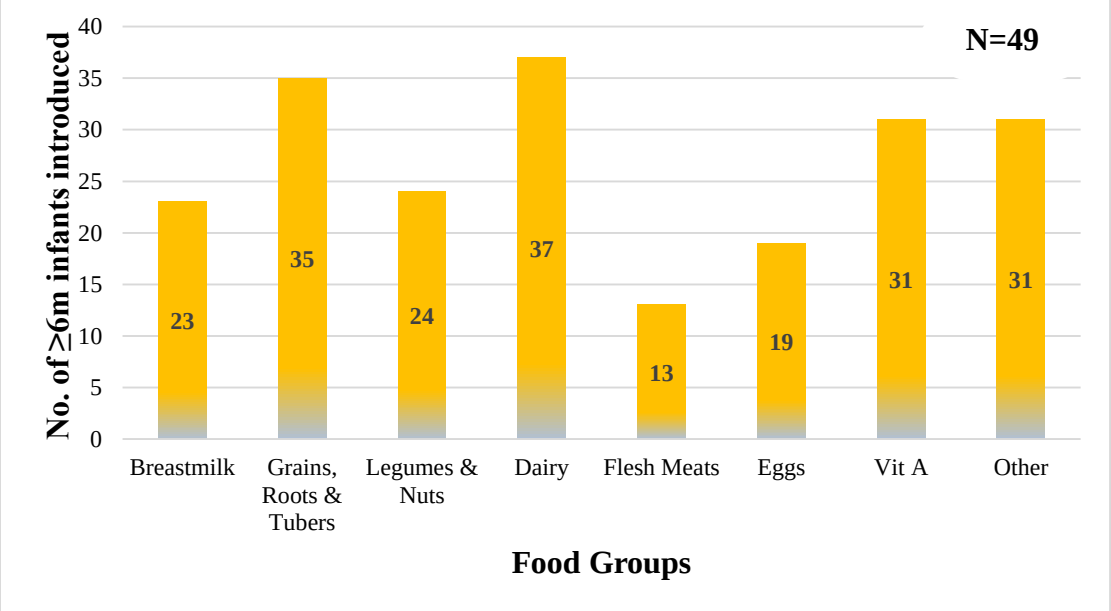

Figure 4:3 Summary of the dietary diversity questionnaire representing 8 food groups and the mean days they were consumed.

4.2.3.3 Minimum Meal Frequency

This included the proportion of infants both breastfed and non- breastfed who had soft, semi-solid or solid foods (even milk feeds for the non-breastfed infants) the minimum times or more. 2-3 meals per day are needed for breastfed infants 6-8 months old, while 3-4 meals per day with 1-2 additional snacks is needed for 9-23 months. (WHO. 2010). 44 % of children above 6 months met the minimum meal frequency.

4.2.3.4 Minimum Dietary Diversity

These were the infants 6-11 months old proportion as per my population who got foods from 5 or more food groups as indicated in the figure below. The infants who met the MDD were at 61.2%.

4.2.3.5 Minimum Acceptable Diet

The calculation of this composite indicator included all infants with at least the minimum dietary diversity and meal frequency during the previous day from the 24- hour recall. Only 16.3% (8) of all infants 6 months and above had met the minimum acceptable diet as indicated in the figure below.

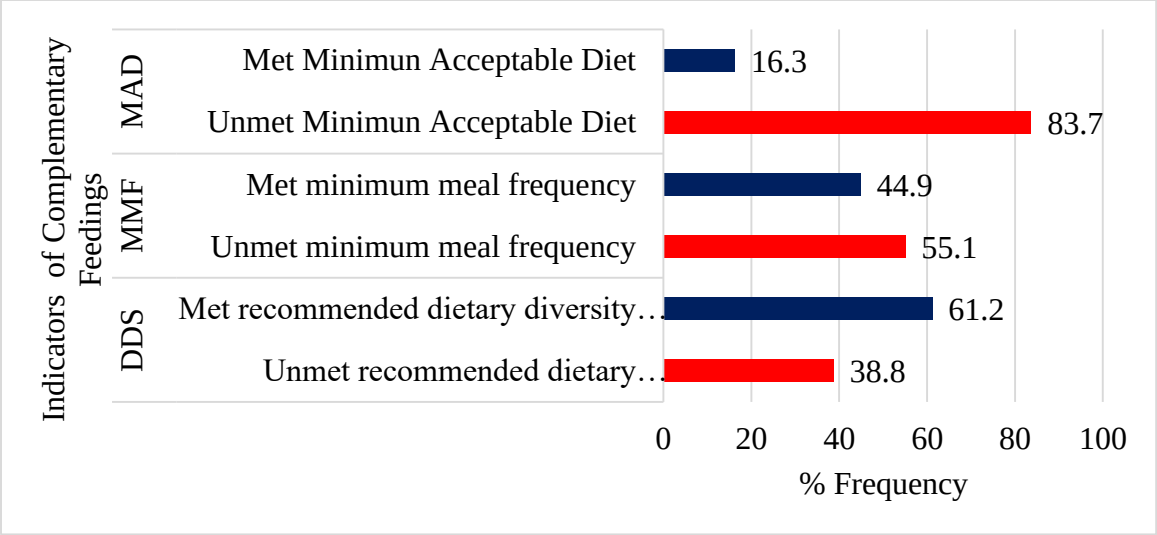

Figure 4:4 Summary of Minimum acceptable diet.

4.3. Morbidity Status of Infants with Orofacial clefts

This was the proportion of infants who were ill within two weeks preceding this research based on what the caregivers recall. The percentage of infants who had been sick was 35.5%. The main symptoms reported were fever and cough at 12.1 % and 15.9% respectively. Other symptoms that were reported included vomiting, diarrhea, and difficulty breathing. More than three quarters of the caregivers sought treatment, the majority being at a public health facility. The mean days of illness was 4.84. The table below summarizes this information.

Table 4.5 Morbidity Status and Health Seeking Behavior of Infant's with Orofacial clefts

		N=107	
		n=38	**%**
Sick Child in past 2 Weeks		38	35.5
Main Symptoms Reported	Fever	13	12.1
	Cough	17	15.9
	Vomiting	3	2.8
	Diarrhea	1	0.9
	Difficulty breathing	4	3.7
Duration before seeking treatment.	Within 24 hours	12	35.3
	After 24 hours	22	64.7
Caregiver HSB	Sought treatment	34	31.8
	Did not Seek Treatment	4	3.7
Where Treatment was sought	Public hospital	20	18.7
	Private hospital	9	8.4
	Pharmacy/shop	5	4.7
Illness Duration Mean 4.84			

4.4 Nutrition Status of Infants with Orofacial Clefts

To assess the nutrition status of infants with orofacial clefts three indices were used weight -for-age to measure underweight, weight-for- length to measure wasting, and length-for-age to measure stunting plus middle upper arm circumference. The presence of bilateral pitting edema was also checked. WHO growth standards interpreted the infants' nutritional status and ENA for smart software for determining the nutritional status. Malnutrition was categorized as normal (>- 2 to <+ 2 z- score, no odema), malnourished moderately (< - 2 z-score and >= - 3 z-score, no odema) or a mid- upper arm circumference (MUAC) of (<125mm and >=115mm, no odema). Severe acute malnutrition was defined as (< - 3 z-scores and/or oedema) or a mid- upper arm circumference of (< 115 mm and/or odema). Global malnutrition was (<- 2 z-score and/or oedema) or mid-upper arm circumference

MUAC of (<125mm and/or oedema) that is all moderately and severely malnourished cases. The sample sizes within the age categories were relatively small which resulted in wide confidence intervals.

4.4.1 Nutrition Status based on weight- for- length Z-Scores (wasting)

Global malnutrition for infants with orofacial clefts was 17.8% (95% CI: 11.7-26.1). Infants who had severe acute malnutrition (SAM) were 9.3% (95% CI: 5.2-16.4) while moderate acute malnutrition (MAM) was at 8.4% (95% CI: 4.5-15.2). There were no infants presenting with bilateral pitting oedema. The table below provides a summary.

Table 4.6 Prevalence of Wasting

	Prevalence		
Infants 0-11 months (N=107)	**Freq**	**Rate (%)**	**95% CI**
Moderate Acute Malnutrition (MAM)	09	8.4	4.5-15.2
Severe Acute Malnutrition (SAM)	10	9.3	5.2-16.4
SAM based on WHZ and MUAC	15	14	19.5-44.5
Global Malnutrition	19	17.8	11.7-26.1
Overweight >2 WHZ z-Scores	7	6.5	
Severe Overweight WHZ >3 z-Scores	04	3.7	
Normal (weight- for -length) and /or oedema	88	82.2	
Prevalence of Acute Malnutrition by Age Group			
0-5 (n=58)	11	18.9	
6-8 (n=24)	03	12.5	
9-11 (n=25)	05	20	
Prevalence of Acute Malnutrition by Sex			
Boys (n=59)	12	20.3	12-32.3
Girls (n=48)	07	14.6	7.2-27.2
Global malnutrition based on WHZ and MUAC	31	29	49.3-75.3

4.5.2 Prevalence of Underweight

Global underweight was at 31.8% (95 % CI: 23.7-41.4). The proportion of infants who were moderate underweight and severe underweight was 13.1% at (95% CI: 8.0 -20.8) and 18.7% at (95% CI: 12.4 -27.1) respectively as shown in the table below.

Table 4.7 Prevalence of Underweight

Infants 0-11 months (N=107)	**Prevalence**		
	Freq	**Rate (%)**	**95% CI**
Moderate Underweight	14	13.1	8.0-20.8
Severe Underweight	20	18.7	12.4-27.1
Global Underweight	34	31.8	23.7-41.4
Global Underweight by Age Group			
0-5 (n=58)	23	39.7	
6-8 (n=24)	5	20.8	
9-11 (n=25)	6	24	
Normal weight-for- age z-scores	73	68.2	
Global Underweight by Sex			
Boys (n=59)	17	28.8	18.8-41.4
Girls (n=48)	17	35.4	23.4-49.6

4.5.3 Prevalence of stunting

The total percent of global stunting was at 33.6% (95% CI: 25.4-43) with moderate stunting being 13.1% (95% CI: 8.0 -20.8) and severe stunting at 20.6% (95% CI: 14.0- 29.2) respectively as indicated in the table below.

Table 4.8 Prevalence of Stunting

Infants 0-11 months (N=107)	Prevalence		
	Freq	**Rate (%)**	**95% CI**
Moderate Stunting	14	13.1	8.0-20.8
Severe Stunting	22	20.6	14.0-29.2
Global Stunting	36	33.6	25.4-43.0
Global Stunting by age Group			
0-5 (n=58)	28	36.2	
6-8 (n=24)	8	33.3	
9-11 (n=25)	7	28	
Normal length – for- age z-score	71	66.4	
Global stunting by Sex			
Boys (n=59)	21	35.6	24.6-48.3
Girls (n=48)	15	31.3	19.9-45.3

4.5 Relationship between socioeconomic characteristics and child nutrition status (underweight).

Logistic regression established relationships between the variables. Chi-square was applied to establish associations of socioeconomic characteristics and nutrition status (underweight). There was no significant connection between the caregivers' age, sex, marital status, religion and the education level and their respective children nutrition status. The association between the occupation of the caregivers and their children's nutrition status was found to be significant. Casual laborers were 13 times more likely to have children with sub-optimal nutrition status compared to caregivers who were employed (OR = 13; CI, 1.921-87.990). Caregivers' average household income and their respective children nutrition status was also found to have a significant association. An average household income of between KSh10000 and KSh 20000 contributed to 3.4 times more likely to have children with sub-optimal nutrition status as compared to caregivers who had

an average of more than KSh 20000 (OR = 3.4; CI, 1.001-11.383). This information is summarized in the table below.

Table 4.9 Summary of the association Between Socioeconomic Characteristics and Child Nutrition Status (Underweight).

		Nutrition Status N=107		
Variable	**Category**	**Sub-optimal n=34**	**Optimal n=73**	**p-Value**
Caregiver Age	18-30	21	51	0.507
	31-50	13	22	
Caregiver Sex	Female	33	69	0.547
	Male	1	4	
Caregiver Marital Status	Single	6	14	0.849
	Married	28	59	
Caregiver Religion	Protestant	25	54	0.998
	Muslim	1	2	
	Catholic	8	17	
Caregiver Level of Education	No. Basic Education	4	8	0.484
	Primary	12	22	
	Secondary	12	20	
	Tertiary	6	23	
Caregiver Occupation	Unemployed	9	34	**0.01**
	Business	8	16	
	Casual Labor	8	2	
	Farming	5	8	
	Salaried Employee	4	13	
Average HH Income	≤10,000	14	30	**0.04**
	10,001-20,000	15	16	
	>20,000	5	18	
Parity	One	10	24	0.62
	Two and above	24	48	

4.5 Relationship between Morbidity and Nutrition Status

The number of infants who had any illness during the past two weeks at the time of the study was 38 (35.5 %). A cross tabulation of nutrition status and morbidity below shows that more than half (26) of those who had any illness during the past two weeks had optimal

nutrition status. Logistic regression was used to model the probability and chi - square tests used to determine any relationship. There was no significant association established between child morbidity status and their respective nutrition status **P value = 0.974 df= 1, χ_2 = 0.001**

The table below provides the summary:

Table 4.10: Relationship between Morbidity and Nutrition Status

	Morbidity Status		
Nutrition Status	No	Yes	
Sub-optimal status	22	12	34
Optimal nutrition status	47	26	73
	69	**38**	**107**

P value = 0.974 df= 1, χ_2 = 0.001: Not statistically significant

4.6 Association between Feeding Practices and Nutrition Status of Infants with Orofacial Clefts

The total number of infants receiving complementary foods was forty-nine. Using the (MUAC Category). There were 18 infants (36.7%) who had sub optimal nutrition status and a third of whom had unmet recommended dietary diversity score. Infants who had optimal nutrition status were 63.3 % (31) more than a half having met the recommended dietary diversity score. There was no notable association established between the child dietary diversity and their respective nutrition status in the MUAC Category. There was also no significant association between dietary practices (minimum acceptable diet) and children's nutrition status. An association that was significant was established between the

child meal frequency and their respective nutrition status in the MUAC category was reported at P value = 0.015 df= 1, $\chi 2 = 5.913$.

4.7 Predictors of Nutrition Status

A multivariate logistic regression analysis to further determine the association with nutrition status showed that casual laborers were 12 times more likely to have infants with sub optimal nutrition status (underweight) compared with caregivers who were employed. Infants who were less than 6 months were three times more likely to be underweight compared to those who were 6 to 12 months. Caregivers who had an average household monthly income of between KSh10000 and KSh 20000 were 5 times more likely to have infants with sub-optimal nutrition status compared to those who earned more than KSh 20000. In addition, those children who did not meet the minimum meal frequency were 5 times to have suboptimal nutrition status (MUAC) as compared to those who met.

The table below provides a summary of all the predictors of nutrition status.

Table 4.11: Predictors of Nutrition Status

Predictor	AOR (95% CI)	p-value
	Underweight	
Occupation	12.1[CI 1.52-25.89]	0.019
Child	2.6[CI 0.99-6.99]	0.042
Average HH Income	5.0 [CI 1.13-21.80]	0.034
	MUAC	
Meal Frequency	5.0 [C.I 1.03-24.06]	0.042

p-Value <0.05=Statistically Significant

CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

The overall purpose of this study was to establish the feeding practices of infants born with orofacial clefts in relationship to their nutrition status. The study aimed specifically at establishing their breastfeeding practices in comparison to WHO recommendations and the initiation of complementary feeds in terms of timely introduction of the minimum acceptable diet, dietary diversity, meal frequency, and complementary foods. The feeding challenges experienced by infants with orofacial clefts were also identified in this study. Morbidity status that that was any illness the infants suffered from during the past two weeks before the study was also established.

5.1 Socio-demographics and socio-economic characteristics of caregivers of infants with orofacial clefts

In this study, most caregivers were below the age of 35 years, married and almost a third in each category had attained primary and secondary level of education respectively. Majority of the infants in this study were males at (55.1%) infants less than six months had the highest percent at 54.2 %. The distribution of the clefts was as follows; the commonest condition was unilateral CLP at (29.9%) followed by bilateral cleft lip and palate at (29%) isolated cleft lips were at (36.4%) while isolated cleft palate was the rarest at 4.7%. This distribution agrees with a study conducted in India and agrees with other studies highlighted in the study by (Sampagar et al., 2018).

5.2 Feeding practices of infants with orofacial clefts

5.2.1 Breastfeeding practices of infants with orofacial clefts

Breastfeeding benefits are well documented as supportive of children's growth and development. Initiation of Breastfeeding should be done within the first hour of birth. This recommendation promotes the consumption of colostrum, the first milk produced after birth that is highly nutritious and contains antibodies and is protective from infections, a benefit to the cleft population as they are at risk of ear infections. Early initiation also promotes bonding between mother and their newborn. This closeness and interaction are important and is needed by many infants born with orofacial clefts. The percentage of infants with orofacial clefts who were breastfed within the first hour in this study was 29%. This is lower compared to a study conducted in Uganda which was at 44% (Nabatanzi, 2019) and lower compared to the national level reported at 66% (Ariana, 2022). A higher breastfeeding initiation rate of 83% was reported in a study conducted in Nigeria however only 18.5% continued exclusive breastfeeding (Adekunle et al., 2020a). Brazil reported an initiation rate of 100% (Garcez & Giugliani, 2005).

Brazilian report indicated initiation of exclusive breastfeeding at 67.7% and maintenance for 15 days. In this study infants born with orofacial clefts who had been exclusively breastfed were 28% which is lower compared to the general Kenyan population which was at 66 % (Ariana, 2022). A study conducted in Uganda reported a higher rate at 35% (Nabatanzi, 2019). At the time the study was being conducted infants who were still receiving breast milk or breastfeeding directly were at n= 68 (63.6%) majority of whom were below six months of age. Most studies have reported that having an isolated cleft lip is compatible with successful breastfeeding modified breastfeeding positions may need to

be employed depending on the type of CP and the size. Infants with CLP or an isolated cleft palate may not be able to suck directly and feeding of expressed human milk and being fed by alternative feeding methods comes in handy (Garcez & Giugliani, 2005).

5.2.2 Feeding Challenges of Infants with Orofacial clefts

Feeding is one of the initial difficulties that infants born with orofacial clefts especially a cleft of the palate experience. This was also reported by majority of parents in a study conducted in West Virginia University Cleft Palate Clinic who also indicated that they needed to seek assistance and information from different sources (Snyder & Ruscello, 2019). The total number of caregivers who reported experiencing feeding difficulties initially or ongoing was 80.4%. The feeding challenges mentioned most frequently was infants burping and taking in of excessive air at 27.3% followed by nasal regurgitation at 16.2 % and a weak suck at 15.7% the last two being reported mostly by infants who had cleft lip and palate (Snyder & Ruscello, 2019).

These difficulties agreed with a study conducted in Brazil where weak suction was mentioned most especially with cleft involving a palate (Garcez & Giugliani, 2005). Other difficulties that were reported included difficulty attaching to the breast, milk escaping from the nostrils, child choking, and in-sufficient weight gain. This study agrees with other studies concerning challenges related to breastfeeding as they were significantly co-related with the type of cleft (Adekunle et al., 2020b).Mothers with infants with isolated cleft lip only reported fewer difficulties. At the time of the study 64.5% were expressing breast milk and the equipment used to administer feeds were normal bottle at 24.3%, special bottle at 23.4% and cup and spoon at 14%.

These feeding techniques have been reported by other studies in Uganda 75% of the mothers' used syringes, spoons and cups, nasogastric tubes, ordinary bottles and specialized squeezable bottles that could regulate milk flow which was similar to what mothers in Brazil reported the use of multiple techniques (Nabatanzi, 2019); (Garcez & Giugliani, 2005)

The use of regular feeding bottle was the most used equipment in research done in Nigeria (Adekunle et al., 2020a).The use of adaptive equipment supports feeding children with orofacial clefts. Mothers who used the special bottle in this study reported better outcomes. The specialized equipment helps decrease the generation of suction by the infant while feeding by increasing the milk flow for regulation of infant's sucking capability and swallow. Infants should be monitored while using this equipment to check tolerance and ensure the milk consumed is not overwhelming in terms of volume (Burca et al., 2016).The most used breastmilk substitute in this study was infant formula at 29% followed by whole cow's milk at 15.9%. Nabatanzi reported whole cow milk as being the main breast milk substitute used in a study conducted in Uganda because it was cheaper and readily available (Nabatanzi, 2019).

5.2.3 Complementary Feeding Practices of Infants with Orofacial Clefts

Introduction to solids for the cleft population should begin at 6 months just as for the children without clefts. When caregivers are guided on the appropriate texture that matches the developmental milestones of the infant, spoon feeding is usually successful for infants with orofacial clefts preoperatively and postoperatively (Shetty, 2016)**.** Most of the infants were given complementary foods at 6 months in this study.

However, there were gaps identified in meals fed as they did not all meet the appropriate variety and frequency to meet their nutrient and energy needs. Minimum dietary diversity is proxy indicator for adequate micronutrient density of foods. A child has a higher likelihood of consuming foods from at least one animal source, at least one fruit or vegetable in addition to grains, roots or tubers if they consume at least 5 food categories out of the 8 food groups recommended. The food groups include breastmilk flesh foods, dairy products, legumes grains, tubers and roots and nuts, vegetables vitamin. The least consumed groups were flesh meats followed by eggs respectively. This may be attributed to caregiver's knowledge gap on proper infant feeding practices for this age group, in addition mothers probable fear of protein allergies and the high cost of these foods compared to other food groups. Minimum meal frequency is proxy for meeting energy requirements. To meet the MMF infants aged 6-8 should be receiving solids, semi-solid, or soft foods at least twice a day while those aged 9-23 should be receiving at least three times a day (WHO, 2010). For the non- breastfed children, the minimum meal frequency was considered if they receive solids, semisolids, or soft foods or milk feeds at least four times a day and if at least one of the feeds was a solid, semisolid or soft food. The infants who had met the minimum dietary diversity were at 61.2 %, minimum meal frequency was at 44.9%. The MDD of a study conducted in Uganda was at 58% slightly lower than this study and resulting to a MAD of 33% which was higher compared to this study.

5.3 Morbidity status of infants with orofacial clefts

Infants who had been sick during the two weeks before the study were 35.5%. The main symptom that was reported was cough at 44.3% followed by fever at 34.4%. KDHS, 2022 reported 2% of children below 5 had ARI symptoms while 17% had fever and 14% reported diarrhea 2 weeks before the survey (Ariana, 2022). A study conducted in Burkina-Faso where the sample size was 185 children with CL and /or CLP reported frequencies of associated medical conditions as follows; anemia was at 39.4%, infections at 9.2% while malnutrition at 7.5% (Nagalo, Ouédraogo, Laberge, Caouette-Laberge, et al., 2017b).

Without adequate protection, having an orofacial cleft exposes children making them more vulnerable to bad weather conditions thus many cold, pneumonia, bronchitis and cough cases (Nagalo, Ouédraogo, Laberge, Caouette-Laberge, et al., 2017b). Children with cleft palates are also at higher risks of middle ear infections risk because the eustachian tube cannot drain the ear and in children without a CP (Lewis et al., 2017)(Gani et al., 2012) . Infants born with orofacial clefts are at risk of otitis media. In the year 2008, World Health Organization included CPL in their Global Burden of Disease (GBD) initiative as they recognized that non-communicable diseases including birth defects can cause notable childhood morbidity and infant mortality (Mossey & Little, 2009).

5.4. Nutrition status of infants with orofacial clefts

The results showed that 33.6 % of the infants with orofacial clefts were stunted, 31.8 % were underweight while 17.8% were too thin for their length (wasted). A study conducted in India posted a high prevalence of wasting at 47.8 % of children under-five born with cleft lip and /or palate (Sampagar et al., 2018). The prevalence of malnutrition of the cleft population was also higher in a study conducted in Uganda where weight for length was at

68% (Tungotyo et al., 2017). Malnutrition levels of children with non-syndromic in the Uganda study clefts were at 26 % (underweight) 18% (wasting) and 14% (stunting). The levels of wasting are comparable to this study.

The infants' nutritional status results with cleft in this study are higher compared to the recent published results of the national level of children under-five which reported that 18% children were stunted, five percent were wasted while 10 % were underweight (Ariana, 2022). There were no Kenyan published studies on the feeding practices of cleft population that could compare with this study but similar studies of the noncleft population reported stunting levels to be at 26%, underweight at 25.3% among children aged 6- 23 months (Mutuku et al., 2020).The overall prevalence of underweight of records retrieved from Smile Train database of children under five of age with orofacial clefts was at 28.6% at the time of surgery (Delage et al., 2022).

A report published on World Smile Day highlighted malnutrition in children with OFCs to be worse compared to the general population all scenarios factored in. The report's findings at the global level of children under five years with a cleft were 2.15 times more likely to be underweight compared to the general population of under-fives. As per from the year 2000 to 2020 the report indicated about 200000 children under five with cleft being underweight with more than 46000 deaths related to malnutrition in this population. The complete picture of the long-term implications of the burden of malnutrition in the cleft population is likely higher (Kassebaum & Delage, 2022b).

5.5. Relationship between feeding practices, morbidity status and nutrition status of infants with orofacial clefts

From this study, there was no notable relationship identified between feeding practices underweight, wasting and stunting among the study subjects. There was no established notable connection between child morbidity status and their respective nutrition status.

An association of child's meal frequency (AOR = 5.0, C.I, 1.032-24.064, p value = 0.046) and nutrition status was established to be significant whereby children who did not meet the minimum meal frequency had a 5 times chance of having suboptimal nutrition status as compared to those who met.

5.6 Relationship between Socio-Economic and Socio-Demographics and nutrition status of infants with orofacial clefts

The study established a notable linkage between the caregivers' occupation and their respective children's nutrition status (P value = 0.09 df= 1, OR= 13.231). Those who engaged in casual labour were 13 times more likely to have children with sub-optimal nutrition status as compared to those who were employed (OR = 13; CI, 1.921-17.990).

There was also a significant association between the caregivers' average household income and their respective children nutrition status (**P value = 0.047 df= 2, $\chi 2 = 5.717$).** Those caregivers who had an average household income of between KSh.10000 and 20000 were 3.4 times more likely to have children with sub-optimal nutrition status as compared to those who had an average of more than KSh. 20000 (OR = 3.4; CI, 1.001-11.383).

5.7 Hypotheses conclusions

$H0_1$: The null hypothesis that stated that there is no statistically significant association between the caregiver socioeconomic/demographic characteristic and the child nutrition status was thereby rejected.

$H0_2$: The null hypothesis that stated that there is no statistically significant association between the caregiver child feeding practices and their children nutrition status was thereby rejected.

$H0_3$: The null hypothesis that stated that there is no statistically significant association between the child morbidity status and their respective nutrition status was thereby not rejected.

5.8 Summary of Findings

5.8.1 Socio-demographic and socio-economic characteristics

Majority of the caregivers who responded were female who were married and below the age of 35years. More than a third of the caregivers were employed, the majority having attained secondary level education and above. Majority of the infants in this study were males at (55.1%) with infants less than six months being the highest at 54.2 %. The most frequent condition was unilateral cleft lip and palate at (29.9%) followed by bilateral cleft lip and palate at (29%). A significant association was established between the caregivers' occupation, average household income and infants' nutrition status.

5.8.2 Feeding practices of Infants with Orofacial Clefts

WHO recommends exclusive breastfeeding for 6 months as the optimal method for feeding infants. Early initiation of breastfeeding was at (29%) while exclusively breastfeeding was at (28%). The percentage of Infants who were bottle feeding was at 47.6%. Timely introduction of solids, semi-solid and soft foods was at 48.9% more than half (61.2%) attained the MDD while those who met the MMF were at (44.9%) resulting to a low achievement of MAD of (16.3%). Burping and intake of excessive air was the most feeding challenge reported followed closely by nasal regurgitation. There was a significant association established between the child meal frequency and their respective nutrition status in the Muac category.

5.8.3 Nutrition Status of Infants with Orofacial Clefts

Malnutrition is a problem that is well documented and associated with cleft lip and palate. Levels of underweight, stunting and wasting of the cleft population was higher than other comparable studies done in Nigeria, Uganda and above the national prevalence rate.

5.8.4 Morbidity Status

There was no significant association established between morbidity status and nutrition status in this study.

5.8.5 Predictors of Nutrition Status

Occupation (AOR = 12.1, C.I, 1.518-25.805, p value = 0.019), Child‘s age (AOR = 2.6, C.I, 0.993-6.997, p value = 0.05) and caregivers average household income (AOR = 5.0, C.I, 1.132-21.800, p value = 0.034) were the predictors of the infant’s nutrition status

(weight for age- bivariate < 0.2). Furthermore, meal frequency (AOR = 5.0, C.I, 1.032-24.064, p value = 0.046) was the predictors of the children nutrition status (MUAC-bivariate < 0.2).). Those children who did not meet the minimum meal frequency were five times to have suboptimal nutrition status (MUAC) as compared to those who met.

5.9 Conclusion

This study made the following conclusions from its findings. The breastfeeding practices of infants with orofacial clefts were sub-optimal as the initiation rate and exclusive breastfeeding was lower than most studies conducted in the cleft population and the general Kenyan population. A significant association was established between the caregivers' occupation, caregivers' average household income and their respective children's nutrition status. Child's meal frequency and their respective children nutrition status also had a significant association with their nutrition status.

5.10 Recommendations

To improve the feeding practices and nutrition status of infants born with orofacial clefts, this study recommends the following for practice, research and policy:

5.11 Recommendations on practice

i. Training of healthcare providers using standardized feeding recommendations for the cleft population. Education resources should be made available for health care providers with inadequate cleft training which include written protocols, posters with illustrations and live feeding demonstrations to enable them offer correct guidance and counseling regarding feeding and support mothers to establish milk supply.

ii. Promote, prioritize and support giving these infants human milk.

iii. Consistent home visit follow-ups to identify and address any feeding challenge and growth faltering encountered by caregivers.

iv. Provide prenatal support and offer early complex feeding advice where possible if a diagnosis was made early through diagnostic imaging.

v. Partner with organizations that can assist with funding assistive feeding devices.

vi. Health care providers with feeding and nutritional management expertise should always be part of the management team to perform continuous assessment on feeding for children born with orofacial clefts.

5.12 Recommendations for research

i. Longitudinal study to be conducted on feeding practices that includes home visits to gain better understanding of the family's experience at a home set up pre-surgery and post-surgery until fully recovery

ii. Study on the effectiveness of the different adaptive feeding interventions in relationship to attaining the expected growth using WHO growth standard charts

iii. Research on the role of support groups

5.13 Recommendations for policy

i. Review of the Kenyan Infant and Young Child Feeding Guidelines to include breastfeeding practical guidelines for children born with orofacial clefts with inclusion of use of special bottles for ease of feeding for this population.

ii. Subsidizing the price of special bottles making them affordable to infants born with orofacial clefts due to feeding difficulties.

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APPENDICES

APPENDIX I: LETTER OF INTRODUCTION

KENYATTA UNIVERSITY

DEPARTMENT OF FOOD, NUTRITION AND DIETETICS

Dear Participants,
My name is Maina Annastacia Waithera, currently undertaking a master's degree in the department of foods, nutrition, and dietetics at Kenyatta University. I am doing a research on Feeding Practices, associated feeding challenges and the nutrition Status of infants with orofacial clefts attending AIC Kijabe Mission Hospital and AIC Cure Hospital. The outcomes of this research will provide meaningful input to the Ministry of Health and others in the nutrition field in developing of policies and guidelines to improve feeding of children with cleft congenital defects in Kenya.

Procedure

Taking part in this exercise will call for the answering of all the questions, some which concern your child's personal information. I will also examine your child and his/her nutrition status by measuring weight, length and mid-upper arm circumference (MUAC). I will record all the information from you in a questionnaire. The exercise will take about 30 minutes of your time. You will only be allowed to fill the questionnaire if you have read, agreed, and signed the consent of the study. Signing the consent form will mean that you understand what is expected of you and your child in the study.

Voluntarism

Participation is purely through personal volition and thus you are permitted to decline or withdraw from taking part in the study. You are also free to answer any question in the questionnaire, in full or partly, at any stage of the study. Refusal to participate or respond to any question will not have any consequence on the care you or your child will receive from the clinic today or at any other time.

Confidentiality

All information collected in this study and personal data associated with the collection of data will be kept confidential throughout and after the study period.

Discomfort and Risks

Participating in this study does not bear any risks or does not pause any harm to you and your child as the participants. During the process of collecting anthropometrics, your child may need to be involved in an exercise that may involve removal of shoes, heavy clothing, hats in order to collect correct measurements. The interview may also increase the normal time spent in the facility during the involvement in the study. Other than that, there will be no other inconveniences caused by the study. There are no invasive tests that will be involved.

Benefits

Notably, participating will not attract any remuneration or direct benefits in terms of monetary rewards. However, there will be benefits of finding out anthropometric

measurements of your child, feeding counselling, education the eventual benefits from the results of the study.

Contact Information

In case of any questions during the process of the study, do not hesitate to contact

Dr. Peter Chege on 0722642356 email: chege.peter@ku.ac.ke or Professor Elizabeth Kuria on 0721433619 email: kuria.elizabeth@ku.ac.ke or the Kenyatta University Ethical Review Committee Secretariat on chairman.kuerc@ku.ac.ke or secretary.kuerc@ku.ac.ke

Consent

The information that has been presented to me regarding my participation and my child in the research is clear and I give consent in my participation and my child. I have read everything concerning this study and understood every statement. I understand that if I agree to take part in this research, it means that I am willingly going to answer the questions about me and my child presented to me through the study tools and I will do so truthfully and to the best of my knowledge.I understand that it purely voluntary to participate in this study; that my child and I can choose withdraw at any point in time if we feel that there are some aspects of the study that do not make us comfortable.

I understand that any data collected by this research will not maintain data that can be able to identify me or my child such as names or specific information and that any other personal data will be kept in confidence until the research period is over.
I understand that there are no direct benefits or remuneration for taking part in this study and that the only benefits are the outcomes of the study which are aimed at benefiting the wider population sampled by the study and that if I have any questions regarding my rights, my child's rights or the study, as a study respondent I can get in touch with:
Annastacia Waithera Maina Tel 0723916055 /0751409966Email: annastaciaking@gmail.com
Participants Signature:……..
Date:……
Interviewers name:…….
Signature:……Date:……

Interviewer's statement

I, the undersigned, have explained the procedures to be followed in the study and the benefits and risks involved to the volunteer in a language s/he understands.

Name of Interviewer: ……
Interviewer Signature: …… Date.....

BARUA YA UTANGULIZI

KENYATTA UNIVERSITY

DEPARTMENT OF FOOD, NUTRITION AND DIETETICS

Washiriki Wapendwa,

Jina langu ni Maina Annastacia Waithera, mwanafunzi katika Chuo Kikuu cha Kenyatta. Nasomea shahada ya uzamili katika Idara ya Chakula na Lishe. Nafanya utafiti kuhusu Mazoea ya Kulisha na Hali ya Lishe ya watoto walio na kasoro mdomoni (*orofacial clefts*) kwa watoto wenye umri wa miezi 0-12 Hospitali ya AIC Kijabe na AIC Cure. Matokeo ya utafiti huu yatakuwa na faida kwa Wizara ya Afya na wadau wengine katika sera na miongozo kuhusu kulisha idadi ya watoto walio na kosoro ya mdomo katika taifa la Kenya.

Utaratibu wa kufuatwa

Kushiriki katika zoezi hili kutahitaji kujibu maswali kadhaa kuhusu wewe na mtoto wako na kuchukua vipimo vya mtoto. Utapewa dodoso la kujaza na hii itachukua takriban dakika 30. Uzito na urefu wa mtoto utachukuliwa pamoja na kipimo cha MUAC. Hi itasaidia kujua jinsi mtoto anavyokua. Ni wale tu ambao wanakubali kutia sahihi fomu hii ya idhini ndio watapewa dodoso. Hautahitajika kuandika jina lako au habari nyingine yoyote ambayo inaweza kukutambulisha wewe au mtoto wako. Kwa kusaini fomu ya idhini utakuwa unaonyesha kuwa unaelewa kabisa kile kinachotarajiwa kwako na kwamba uko tayari kushiriki katika utafiti huu.

Kujitolea

Ni hiari kwa hivyo ni haki yako na ya mtoto wako kukataa kushiriki katika masomo au kuondoa idhini yenu wakati wowote. Uko huru kukataa kujibu maswali yoyote kuhusu mtoto wako na wewe, iwe kwa sehemu au kamili, katika hatua yoyote ya mahojiano.Kutoshiriki kwako na mtoto hakutabadilisha huduma ambayo wewe na mtoto mnafaa kupokea kwenye kliniki kwa njia yoyote sasa na wakati wowote. Hata hivyo ningekuhimiza ushiriki pamoja na mtoto kwani matokeo yatakuwa muhimu.

Usiri

Ushiriki wenu na data iliyotolewa itakuwa ya siri kabisa na majina yenu hayatatumika katika ripoti yoyote ya utafiti.

Usumbufu na Hatari

Hakuna hatari yoyote au hatari ambazo utamwonyesha mtoto wako kwa kushiriki kwenye utafiti huu. Mtoto wako anaweza kutatizwa kwa kulazimika kuondoa viatu, kofia na mavazi yoyote mazito wakati wa kupima urefu na uzito. Mahojiano yanaweza kuongeza takriban dakika 30 kwa wakati unaotumia hospitalini kutokana na mahojiano na msaidizi wa utafiti. Utafiti huu hauhusiani na majaribio yoyote ya matibabu yanayoweza kuvamia na kwa hivyo kwa kushiriki katika utafiti huu mtoto wako hatakabiliwa na madhara au hatari yoyote ya mwili au ya kisaikolojia.

Faida

Hakuna faida za kifedha au faida zozote ambazo utapata kwa mtoto wako kushiriki kwenye utafiti huu, hata hivyo utakuwa na uwezo wa kujua hali ya lishe ya mtoto wako na ikiwa atapatikana duni utaelekezwa kwa mtaalam wa lishe. Pia utaweza kuelimishwa na kupewa mawaidha ya kumlisha mtoto wako. Kwa kuongeza, unaweza kufikiria ni faida kwamba utakuwa unasaidia jamii kwa ujumla kupata maarifa ambayo yatasaidia katika kulisha watoto waliozaliwa na kasoro mdomoni.

Habari ya Mawasiliano

Ikiwa una maswali yoyote, unaweza kuwasiliana na Daktari Peter Chege kwa namba 0722642356 au Profesa Elizabeth Kuria kwa namba 0721433619 au Sekretarieti ya Maadili ya Chuo Kikuu cha Kenyatta kwa barua pepe chairman.kuerc@ku.ac.ke au secretary.kuerc@ku.ac.ke

Idhini

Kuhusu habari hapo juu, ushiriki wangu na mtoto ni wazi kwangu na ninakubali kushiriki katika utafiti uliyotajwa. Nimesoma na kuelewa taarifa ya ufafanuzi na nimepata nafasi ya kuzingatia habari hiyo, kuuliza maswali na nimefanya haya kujibiwa kwa kuridhisha. Ninaelewa kuwa kukubali kuchukua sehemu inamaanisha kuwa niko tayari kujibu maswali yote kunihusu na mtoto na kwenye dodoso kwa ukweli iwezekanavyo na kwa ufahamu wangu bora.

Ninaelewa kuwa ushiriki wangu na mtoto ni wa hiari, na kwamba tuweza kuchagua kutoshiriki katika sehemu au masomo yote, na kwamba naweza kujiondoa na mtoto katika hatua yoyote bila kupatwa na adhabu au shida kwa njia yoyote.

Ninaelewa kuwa data yoyote ambayo msaidizi wa utafiti kutoka kwa dodoso la matumizi katika ripoti, chini ya hali yoyote, haitakuwa na majina au chochote cha kututambulisha mimi na mtoto, habari yoyote ambayo ninatoa ni ya siri.

Ninaelewa kuwa hatutapokea faida yoyote moja kwa moja kwa suala la malipo ya fedha kwa ushiriki. Ninaelewa kuwa matokeo ya utafiti huu nitapewa ikiwa nitawauliza na ikiwa nina maswali yoyote juu ya kusoma au juu ya haki zangu na mtoto kama washiriki wa masomo naweza kuwasiliana na:

Annastacia Waithera Maina kupitia nambari ya simu 0723916055/0751409966

Sahihi ya mshiriki: …… Tarehe: ……

Jina la mhoji: …….

Sahihi: …… Tarehe: ……

Taarifa ya Mhoji

Mimi, nimeelezea mshiriki kwa lugha anaelewa, taratibu zinazopaswa kufuatwa katika utafiti na hatari na faida zinazohusika.

Saini ya mhoji: …… Tarehe …….

APPENDIX II: DATA COLLECTING INSTRUMENT: STRUCTURED QUESTIONNAIRE

DATA COLLECTING INSTRUMENT: STRUCTURED QUESTIONNAIRE

QUESTIONNAIRE NUMBER_____ DATE _____
COUNTY _____SUB – COUNTY_____ TOWN/VILLAGE_____
CLIENT'S CODE_____INTERVIEWER_____

Consent, Interview Language	**Response**	**Code**
Consent has been read and obtained	**1= Yes** **2= No**	☐
Interview Language	**1= English** **2=Kiswahili** **3= Other**	☐

Caregiver's Personal Information and Demographic characteristics

Caregivers Age (Record age in completed years)	Sex	Marital Status	Religion	What is your relationship with the (Child's Name)?	(How many children do you have?)
	1= Male 2=Female	1= Single 2= Married 3= Separated 4= Divorced 5= Widowed	1= Catholic 2= Protestant 3= Muslim 4= Other	1=Mother 2=Father 3=Grandparent 4=Elder sibling 5=Other (Specify)……	
Enter Code	Enter Code	Enter Code	Enter Code	Enter Code	

Caregiver's Socio-Economic Characteristics

Highest Education Level	Occupation	Average Monthly Household Income Level	Household size: How many household members eat from the same pot with you?

1= Never went to school 2= Less than primary school 3= Completed Primary school 4= Completed Secondary school 5=Completed College/University 6= Vocational training 7= Postgraduate degree 8= Refusal to say	1= Casual Labor 2= Farmer 3= Business 4= Unemployed 5= Salaried employed 6= Others (specify)……..		
Enter Code	Enter Code	Enter Code	

Child's Personal Information

Childs Code_____ Child's First Name_____

Date of Birth- |_ _|_ _|20_ _| Date Verified by: MCH booklet/card [1]
Birth certificate [2]
Baptism certificate [3]
Verbal recall [4]
Other [5]

How old is (name of baby)? ***Age in weeks*** _____***Age in completed months*** _____

Child's birth order : _____

Where did you deliver your child?
1. At home
2.Private clinic/hospital
4.Health centre
5.Sub- district hospital
6.Nursing home
7 .Sub-county hospital
8.Mission hospital
8.County hospital
9.National hospital

ENTER CODE:

Nutrition Assessment (Anthropometric Data)

Sex	Birth weight (Check MCH Card)	Weight (to the nearest 0.1kg)	Length (to the nearest 0.1cm)	MUAC (to the nearest 0.1cm)	Presence of bilateral pitting odema	Cleft Type
1= Male 2= Female Enter Code		1st Reading |__.__|kg 2nd Reading |__.__|kg Average |__.__|kg	1st Reading |__ __.__|cm 2nd Reading |__.__.__|cm Average |__ __.__|cm	1st Reading |__ __.__|cm 2nd Reading |__.__.__|cm Average |__ __.__|cm	Yes []01 No []02	1.Unilateral Cleft Lip 2.Incomplete unilateral cleft lip 3.Complete unilateral cleft lip 4.Incomplete bilateral cleft lip 5.Complete bilateral cleft lip 6.Incomplete cleft palate 7.Complete cleft palate 8. Unilateral cleft lip and palate 9.Bilateral cleft lip with full palate Enter code [ ]

Infant's Feeding Practices

Child's Code_____ Age (weeks)_____ Age (months) _____

Do you breastfeed (name)? 1=Yes, 2= No, 3= Not sure	If no , explain See codes	If yes how early after delivery did you breastfeed?	In the first three days after baby's delivery, did you give the baby breast milk 1=Yes, 2= No, 3= Not sure	Did you give the baby anything other than breastmilk in the first three days after delivery? 1=Yes, 2= No, 3= Not sure	Are you still breastfeeding or expressing breastmilk (Name) 1=Yes, 2= No, 3= Not sure	
	1=No milk 2=Traditional belief 3= Difficult to return to work 4= Mother who has a chronic disease 5= Separation of infant from mother 6= Child was unable to latch due to orofacial cleft 7=Didn't breastfeed but	1= within 1hr 2=< 24 hours 3= < 3 days 4= > 3 days 5= does not know		1=plain water 2= sugar water or glucose water 3= fresh milk or powdered milk 4= gripe water 5= nothing given 6= infant formula 7 = others specify		

	offered expressed breastmilk					
Enter code	**Enter code**	**Enter code**	**Enter code**	**Enter code**	**Enter code**	**Enter code**

Associated Feeding Challenges

a) Do you or did you ever put your baby on the breast directly? Tick appropriately YES [ ] NO [ ] If No kindly give a reason

b) If your answer is no to the above question did you ever give your child breastmilk?

c) Did you receive any assistance or education with regards to breastfeeding (positioning and latching)?

Yes [ ] No [ ]

if yes: How long after birth was this help offered?

i. Within the first hour of your baby's birth

ii. More than 1 hour following your baby's birth

d) If yes what assistance was offered Tick appropriately

i. Positioning and latching baby on breast

ii. Expression of breastmilk

iii. Issued with a special feeding bottle

iv. Counselling of breastfeeding children born with cleft

v. I was given a brochure on breastfeeding and how to feed my baby

e) Did you receive any education on your child's condition?

1= Yes [ ] 2= No [ ]

If Yes, what information was shared?

i. Causes of the condition?

ii. Challenges expected?

iii. How to feed my baby?

iv. When my baby will be repaired?

v. Any other information?

f) Did the hospital staff show you or give relevant information to help in the expressing of milk by hand or any other method? 1= Yes [ ] 2= No [ ]

g) Did you or have you tried expressing your milk yourself? 1 Yes [ ] 2 No [ ]

h) If yes, were you able to express your milk manually or using a pump? 1= Yes [ ] 2= No [ ]

i) How long did you or have you breastfed directly from breast or given expressed breastmilk exclusively before introducing other liquids including milks or foods?

i. Less than 1 month (how many days /weeks) =

ii. 1 month

iii. 2 months

iv. 3 months

v. 4 months

vi. 5 months

vii. 6 months

j) If you are giving your child expressed breast milk what equipment do you or did you use to feed the baby?

i. Cup

ii. Cup and spoon

iii. Sippy cup

iv. Normal bottle

v. Normal bottle with widened nipple

vi. Special bottle (name brand if you can remember)

k) What milk alternative did you or do you give your child stating the duration before introducing other foods or liquids?

i. Commercial Infant formula

ii. Home- modified cow's milk plus vitamins and minerals

iii. Home-made cow milk formula

iv. Whole cow's milk

v. Other home- made milk formulas (specify)

vi. Other whole milks (specify animal)

l) Please tick or indicate any feeding difficulties that's not part of the list that you have encountered while feeding your child?

a. Poor suction

b. Sucking disability

c. Nasal regurgitation

d. Excessive air intake

e. Frequent burping

f. Long feeding times

g. Choking

h. Maternal disability for breastfeeding

i. Lack of maternal desire for breastfeeding

j. Other problems

24-Hour Dietary Recall

YESTERDAY, during the night and day did (Name) get any of the below fluids?

Child's code_____ Age in (weeks) _____ Age in completed months _____

Breastmilk	Infant Formula	Other milks	Sweetened Juice	Tea/Coffee	Porridge	Plain water	ORS
1= Yes 2= No	1= Yes 2= No	1= Yes 2= No	1= Yes 2=No	1=Yes 2=No	1= Yes 2= No	1= Yes 2= No	1=Yes 2= No
Enter code	**Enter code**	**Enter code**	**Enter code**	**Enter code**	**Enter code**	**Enter code**	**Enter code**

Now, I will ask you about what solid/ semi solid foods [Name] ate YESTERDAY during the day and the night. YESTERDAY during the day and night, what food items did [Name] receive? Start with the first food taken in the morning until the last thing taken prior waking up the next morning. (Ask the mother /caregiver to mention all foods given to the child and record as mentioned in the appropriate category)

Grains an grain products and all other starch staples –Tubers (Ugali, Irish Potatoes, Bread, Rice, Pasta, Sweet potatoes, Yams, Porridge, Chapatti, green bananas) 1= Yes 2= No 3= Not sure	Pulses, Legumes and Nuts (ground nuts, lentils, green grams, pigeon-peas, Cow-peas, Beans) 1= Yes 2= No 3= Not sure	Dairy products (Ghee, cheese, Milk, Yoghurt, Mala) 1=Yes 2=No 3=Not sure	Flesh Meats (Fish, Mutton, Goat, Liver, Kidney, Beef, Chicken) 1=Yes 2=No 3=Not sure	Eggs 1= Yes 2=No 3=Yes	Vitamin A rich fruits and vegetables {green leafy vegetables (erg Sukuma wiki, cow pea leaves, spinach), Sweet red pepper, Pawpaw, Carrots, Pumpkin, Mangoes, water melon} 1=Yes 2=No 3=Not sure	Other vegetables and fruits (tomatoes3=, orange, avocado, bananas, onions,) 1=Yes 2=No 3=Not sure

Transfer the foods mentioned to the table below

Childs Code …….. Age in weeks ……. Age in completed months …….

I will inquire concerning semi-solid/ solid foods the infant consumed yesterday during the day and night.

								Official use
Time/ Meal	Food name	Ingredients	Measure	Amount in Grams	Volume cooked	Volume served	Volume taken (Difference of what was served and left over)	Amount taken gm
Breakfast								
Snack 1								
Lunch								

Snack 2								
Supper								
Snack 3								

7 Day- FFQ

Kindly check how number of times in a week that you feed your child the below listed foods.

	Food Groups	Code	How many times in a week (7days)did you feed your child from each food group
1	Grains an grain products and all other starch staples –Tubers (Ugali, Irish Potatoes, Bread, Rice, Pasta, Sweet potatoes, Yams, Porridge, Chapatti, green bananas)	1= Yes 2= No	
2	Pulses, Legumes and Nuts (ground nuts, lentils, green grams, pigeon- peas, Cow-peas, Beans)	1= Yes 2= No	
3	Dairy products (Ghee, cheese, Milk, Yoghurt, Mala)	1= Yes 2= No	
4	Flesh Meats (Fish, Mutton, Goat, Liver, Kidney, Beef, Chicken)	1= Yes 2= No	
5	Eggs	1= Yes 2= No	
6	Vitamin A rich fruits and vegetables {green leafy vegetables (erg Sukuma wiki, cow pea leaves, spinach), Sweet red pepper, Pawpaw, Carrots, Pumpkin, Mangoes, water melon}	1= Yes 2= No	
7	Other vegetables and fruits (tomatoes, orange, avocado, bananas, onions,)	1= Yes 2= No	

Morbidity status

Child's Code ....… Age in Weeks ……. Age in completed months……

During the past 2 weeks, has your child suffered from any illness or injury?	1= Yes 2= No
How many days was your child sick from the injury or illness in the last 2 weeks?(1-14 days)	
What symptoms did the child present with in the last 2 weeks?	1= Fever 2= Cough 3= Watery Diarrhea (An episode of 3 or more loose /watery stools in 24 hours) 4= Bloody Diarrhea (An Episode of 3 or more watery stool with blood in 24 hours) 5= Difficult breathing 6= Vomiting 7= Convulsions Others specify……..
What was the main symptom?	
Did you seek medical attention for the injury or illness in the last 2 weeks?	1= Yes 2= No
Where did you first consult in the last 2 weeks?	1= Friend/Relative 2= Sent for medicine (where _____) 3= Private clinic 4= Public clinic

	5= Traditional Healer 6= Herbalist 7= Pharmacy/Chemist 8= others (specify

APPENDIX III: CLEARANCE FROM KUERC

KENYATTA UNIVERSITY
CENTRE FOR RESEARCH ETHICS AND SAFETY

Fax: 8711242/8711575 **P. O. Box 43844,**
Email: chairman.kuerc@ku.ac.ke
Nairobi, 00100

Tel: 8710901/12

Website: www.ku.ac.ke
Our Ref: **KU/ERC/APPROVAL/VOL.1** Date: 3rd /11/2021

Annastacia Waithera Maina.
P.O Box 43844, 00100
Nairobi.

Dear Ms. Maina,

APPLICATION NUMBER: PKU/2357/11494 – FEEDING PRACTICES CHALLENGES AND NUTRITIONSTATUS OF INFANTS WITH OROFACIAL CLEFTS ATTENDING AFRICA INLAND CHURCH CURE AND KIJABE HOSPITALS , KIAMBU COUNTY, KENYA.

This is to inform you that ***KENYATTA UNIVERSITY ETHICS REVIEW COMMITTEE*** has reviewed and approved your above research proposal. Your application approval number is **PKU/2714/I1838.** The approval period is **3rd** ***/11/2021 to 3rd /11/2022***

This approval is subject to compliance with the following requirements;

i. Only approved documents including (informed consents, study instruments, MTA) will be used
ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by ***KENYATTA UNIVERSITY ETHICS REVIEW COMMITTEE***
iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to ***KENYATTA UNIVERSITY ETHICS REVIEW COMMITTEE*** within 72 hours of notification
iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be

reported to ***KENYATTA UNIVERSITY ETHICS REVIEW COMMITTEE*** within 72 hours

v. Clearance for export of biological specimens must be obtained from relevant institutions.
vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
vii. Submission of an executive summary report within 90 days upon completion of the study to ***KENYATTA UNIVERSITY ETHICS REVIEW COMMITTEE***

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) https://research-portal.nacosti.go.ke and also obtain other clearances needed.

To serve you better, researchers are kindly requested to access and complete a customer feedback form and sent it back online as you continue with research and upon completion of data collection found on the following website link; ;(https://docs.google.com/forms/d/1ytWefDwvyz5h1oz_VIn0xbxg3uGdlDzMXFWNDsMrRPQ/edit?usp=sharing

Yours sincerely

KENYATTA UNIVERSITY
OFFICE OF THE CHAIRMAN
23 NOV 2021
ETHICS REVIEW COMMITTEE
P.O. BOX 43844 - 00100 NAIROBI

Prof. Judith Kimiywe

Director: Centre for Research Ethics and Safety

APPENDIX IV: ETHICAL APPROVAL FROM CURE

AIC CURE International Hospital
P.O.Box 52 - 00220 kijabe, Kenya
Tel: 020 3246620, 0733 770 653
Email: info@curekenya.org

ACIH Institutional Research and Ethics Board (IRB) Ethics Approval Letter

28th October 2021

To: Annastacia Waithera Maina

RE: ETHICAL APPROVAL FOR YOUR STUDY

The Ethics and Research Board of AIC Cure International Hospital has gone through your submitted proposal to undertake a non-invasive study titled: **"Feeding practices, challenges and nutrition status of infants with orofacial cleft attending Africa inland church-Kijabe Hospitals, Kiambu County Kenya."**

And grants the approval for the study to be carried from November to December 2021.

Any variations to the protocol or dates of the study must have prior permission of the IRB. Any severe adverse effects on patients or bad outcomes must be reported within 24 hours to the IRB using the Incidence Reporting Forms.

We expect at the end of collecting results you will alert IRB and that you will share the final study outcomes copy with us to facilitate transfer of knowledge and future decision – making.

Should you abandon your study mid – way, kindly alert us in writing giving the reasons for such a decision.

We wish you well in your study. Feel free to seek further guidance from the IRB during your study.

Signed:

Dr. Philemon Nyambati

Consultant Orthopedic Surgeon

IRB Chairperson, AIC Cure International Hospital.

Kijabe-Kenya.

AIC CURE INTERNATIONAL HOSPITAL
P. O. BOX 52 - 00200
KIJABE

Healing changes everything

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AIC CURE International Hospital
P.O.Box 52 - 00220 kijabe, Kenya
Tel: 020 3246620, 0733 770 653
Email: info@curekenya.org

ACIH Institutional Research and Ethics Board (IRB) Ethics Approval Letter

17th January 2022

To: Annastacia Waithera Maina

RE: DATA COLLECTION APPROVAL FOR YOUR STUDY .

The Ethics and Research Board of AIC Cure International Hospital has gone through the extension request and has granted permission for data collection for a period of four to six month on non-invasive study titled: **"Feeding practices, challenges and nutrition status of infants with orofacial cleft attending Africa inland church-Kijabe Hospitals, Kiambu County Kenya."**

We expect at the end of collecting results you will alert IRB and that you will share the final study outcomes copy with us to facilitate transfer of knowledge and future decision – making.

Should you abandon your study mid – way, kindly alert us in writing giving the reasons for such a decision.

We wish you well in your study. Feel free to seek further guidance from the IRB during your study.

Signed:

Dr. Philemon Nyambati

Consultant Orthopedic Surgeon

IRB Chairperson, AIC Cure International Hospital.

Kijabe-Kenya.

A.I.C. CURE INTERNATIONAL HOSPITAL
P. O. BOX 52 - 00200
KIJABE

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APPENDIX V : ETHICAL APPROVAL AIC KIJABE

AIC Kijabe Hospital
Health Care to God's Glory

KIJABE HOSPITAL INSTITUTIONAL ETHICS AND RESEARCH REVIEW COMMITTEE
PO Box 20 Kijabe 00220, Kenya
Tel: 0709728200/637
E-mail:researchcoord@kijabehospital.org
Website: www.kijabehospital.org

Reference : KH/IERC/0006/2022
Formal Approval Number: KH/ IERC/02718/0118/2022
Date: 11/02/2022

Dear Annastacia Waithera,

RE: FEEDING PRACTICES, CHALLENGES AND NUTRITION STATUS OF INFANTS WITH OROFACIAL CLEFTS ATTENDING AFRICA INLAND CHURCH-CURE AND KIJABE HOSPITALS,KIAMBU COUNTY,KENYA.

The Institutional Ethics and Research review Committee having carefully reviewed your above title proposal grants you approval to conduct this study as of 11TH February 2022.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc.) will be used.
b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KH IERC before implementation.
c. Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KH IERC immediately.
d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KH IERC immediately.
e. For studies lasting more than one year an annual report must be submitted for ongoing approval to be valid.

AIC Kijabe Hospital
Health Care to God's Glory

f. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period (attach a comprehensive progress report to support the renewal).
g. Clearance for export of biological specimen or any form of data must be obtained from KH IERC, NACOSTI and Ministry of Health for each batch of shipment /export.
h. Submission of an executive summary report within 90 days upon completion of the study. This information will form part of the database that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.
Please do not hesitate to contact the AIC Kijabe Hospital IERC Coordinator (researchcoord@kijabehospital.org) for any clarification or query.
We wish you all the best in the study.
Thank you.

Yours Sincerely,

Peter Halestrap
BMBCh, MRCGP, DCH, DRCOG,MA (OXON)

Chair, AIC Kijabe Hospital IERC

APPENDIX VI: NACOSTI RESEARCH LICENSE

REPUBLIC OF KENYA

NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Ref No: **821519**

Date of Issue: **14/February/2022**

RESEARCH LICENSE

This is to Certify that Ms.. Annastacia Waithera Maina of Kenyatta University, has been licensed to conduct research in Kiambu on the topic: FEEDING PRACTICES, CHALLENGES AND NUTRITION STATUS OF INFANTS WITH OROFACIAL CLEFTS ATTENDING AFRICA INLAND CHURCH- CURE for the period ending : 14/February/2023.

License No: **NACOSTI/P/22/15772**

821519

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Verification QR Code

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