COLLEGE OF EDUCATION AND BEHAVIORAL STUDIES

DEPARTMENT OF SPECIAL NEEDS AND INCLUSIVE EDUCATION

THE QUALITY OF CLEFT CARE SERVIES AT A TERTIARY CLEFT CARE CENTER IN ADDIS ABABA, ETHIOPIA

By: Tsion Girma Awata

October, 2024

Addis Ababa, Ethiopia

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DECLARATION

I, the undersigned, affirm that the thesis titled "*The quality of cleft care services at a tertiary cleft care center in Addis Ababa, Ethiopia*" is my original work. All the sources of information used in its preparation have been duly acknowledged.

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Table of Contents

List of tables

Abstract

Background: Comprehensive cleft care is needed for a child born with orofacial cleft. Reconstructive surgery addresses problems associated with feeding and aesthetic concerns; however, without a comprehensive treatment, functional problems such as speech challenges, dental concerns, hearing, and psychosocial problems may persist for life.

Objective: Yekatit 12 Hospital Medical College is currently the only government hospital in Ethiopia offering comprehensive cleft care through a multidisciplinary team. The present study aimed to explore the quality of care provided at the hospital's cleft care center.

Method: A qualitative study approach was used with a case study design to explore the perspectives of plastic surgeons and speech and language therapists who are working in the hospital's multidisciplinary team. Insights from parents receiving treatment for their child at the hospital were also included in the study.

Result: The findings of this research indicate that Yekatit 12 Hospital Medical College provides comprehensive cleft care services, adhering to the recommended timeframe for initial assessment, and surgical, and speech therapy interventions. However, parents reported delays in primary lip surgery due to weight eligibility criteria not being met. Major challenges identified at the hospital were limited resources and hospital capacity, shortage of professionals mainly speech therapists and nutritionists, disorganized documentation, and language barriers.

Conclusion: The hospital's multidisciplinary team's dedication to providing comprehensive care, supported by charitable organizations, is commendable. In the future, addressing these challenges will be essential for improving the overall quality of cleft care at the hospital.

Recommendations: Key suggestions outlined for the hospital include providing essential diagnostic tools, recruiting more professionals, increasing hospital capacity, and enhancing local support groups.

1. Introduction

1.1 Background

A cleft lip and palate is a type of congenital birth defect that takes place during the first few months of pregnancy, particularly between the 5th and 12th weeks. This critical period is a window of time during which the primary and secondary palate fuse, thus failure of this process can result in a cleft lip, cleft palate or both (Neiswanger, et al., 2020). It is a condition that presents serious challenges across various domains including, feeding, dental, hearing, speech, and psychosocial development challenges. Therefore children born with this condition require assessment and treatment by several professionals for a long period of time (Lee et al., 2014). However in Ethiopia there is insufficient number of professionals, particularly speech and language therapists to provide the services for a majority of children needing this care.

The prevalence CL/P varies from region to region across different races and ethnicities. The global incidence of cleft lip and palate was estimated to occur in 4.5 out of 10,000 live births (Salari et al., 2022). In Addis Ababa the capital city of Ethiopia a study conducted in 2011, reported the incidence of cleft lip and palate to be 1 in 672 live births (Eshete et al., 2011). This incidence study might not be representative because it captures data of births from Addis Ababa seven delivery service providing institutions. In a more recent study retrieved from a database taken from smile train, the incidence of orofacial clefts in Ethiopia was estimated to be 4.4 per 10,000 live births which is close to the global finding however lower than the finding in 2011 (Eshete et al., 2017). The study also found 26.9% were bilateral CLP and 73.1% were unilateral CLP, showing the higher incidence of unilateral CLP.

The congenital visible appearance of orofacial cleft in a child, can present difficulties in feeding, and social stigma. Although these challenges are generally improved following surgical repair the functional consequences of the condition may still persist. (Lee et al., 2014). This condition also hiders the ability of the children to develop relationships, participate in social activities and express themselves verbally. As such the child and their parents will need guidance and support from all sorts of different practitioners. The most effective method of treatment is through a team or multi-disciplinary approach, where experts in different fields of specialization meet frequently to address the array of needs of the child and parent (Mossy et al. 2009, Hodgkinson et al. 2005).

Typical members of a cleft team include an audiologist, dentist, nurse, nutritionist, orthodontist, ENT surgeon, pediatrician, plastic surgeon, psychologist, social worker, and speech pathologist (Shaye et al., 2015). However, in many developing nations, the scarcity of resources and lack of professionals often presents obstacles to delivering comprehensive care for both children and their parents. The American Cleft Palate-Craniofacial Association (2010) has suggested that cleft palate teams should include at least the specialists from the three core disciplines of Plastic Surgery, Orthodontics and Speech-Language Pathology, and have access to professionals in other relevant disciplines.

In the past, the predominant approach to cleft lip and palate treatment in developing countries was through charitable medical missions such as, Operation Smile, Resurge International, and Smile Train. These organizations focus on providing surgical repair for children in various regions free of charge (Lee et al., 2014). Since 2007 to 2023 smile train only has sponsored more than 35,700 cleft surgeries in Ethiopia (Smile Train, 2023). These efforts have demonstrated good outcomes. A study conducted in a rural region of the country found that a single surgical repair had a positive impact on school attendance, marriage status, and reduced social stigma (Fell et al., 2014).

Despite the visible positive outcomes from interventions, notable gaps were identified. In the earlier missions, one significant challenge was the absence of long-term follow-up after surgery, which resulted in a lack of monitoring for post-operative complications. Without ongoing follow-up from an experienced surgeon, this could potentially lead to patient discomfort and, in some cases, even mortality. Additionally, these missions did not provide other essential services such as dental, hearing, speech, and psychosocial support for the children and parents (McQueen et al., 2009).

In recent times, as a result of extensive research in this field, there has been a noticeable shift in the approach of missions. There is now a greater emphasis on providing training to local health professionals to facilitate the development of independent care centers. This shift did not only focus on patient’s surgical treatment but also aims to establish long-term, comprehensive care options (Lee et al., 2014).

Currently in Ethiopia, Yekatit 12 Hospital Medical College is the sole government hospital providing comprehensive care in a multidisciplinary team. This center was established in 2003 through a partnership with the Cleft Lip and Palate Team in Bergen, Norway, and has received additional support from Smile Train and Transforming Faces throughout the years. The team at the Hospital includes coordinator nurse, surgeons, anesthesiologists, orthodontists, ENT surgeons, pediatricians, speech therapists, and social workers (Eshete et al., 2017).

A research that explores the practices of the health care professionals in the cleft care team was not accessible the researcher so far. There reason could be due to the new emerging working practice of a multidisciplinary cleft care team in Ethiopia. Another cause could also be attributed to the limited of professionals particularly in the field of speech and language therapy to conduct research. In the history of Ethiopia the first batch in Master of Science in Speech and Language Therapy is to graduate for the first time in July 2024. This huge gap enforced the researcher to inspire the present research.

1.2 Statement of the problem

It is important and beneficial to explore systematically the quality of care that is provided at Yekatit 12 Hospital Medical College. According to previous findings, cleft lip and/or palate (CL/P) is prevalent in the country, however to the knowledge of the researcher there were no available studies done on exploring the quality of care provided for children born with this condition in Ethiopia's context. Therefore, this study aim was explore the practices of two different healthcare professionals within the multidisciplinary team, particularly reconstructive surgeons and speech therapist's at Yekatit 12 Hospital. The experiences & challenges gathered will help guide efforts to improve services and patients quality of life. Additional insight will also be gained by studying the perspectives of parents of children born with cleft lip and palate that are being treated at the hospital.

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1.3 Research questions

- How do health care professionals in the team provide comprehensive cleft care at Yekatit 12 Hospital Medical College?
- How parents of children with cleft lip/palate access cleft care at Yekatit 12 Hospital Medical College?
- What are the main obstacles faced by professionals in providing cleft care and challenges for parents in accessing the care?

1.4 Significance of the study

The strengths and challenges of the current multi-disciplinary care approach at Yekatit 12 hospital Medical College can be better understood through the practices of healthcare professionals who are part of the team and experiences of parents who are receiving care for their child at the hospital. The findings of this paper could be used to improve care provision at the hospital, as well as serve as a guide to establish other multidisciplinary teams in other regional hospitals within Ethiopia. Furthermore, the study could also help narrow the research gap that currently exists and aid as a baseline for future researches on this topic.

2. Literature review

2.1 Overview of Cleft Lip and Palate

A cleft is an abnormal opening or a fissure in an anatomical structure that is normally closed. A cleft lip is the result of failure of parts of the lip to come together early in the life of a fetus. Cleft palate occurs when the sections of the roof of the mouth do not fuse normally during fetal development, leaving an opening between the oral cavity and the nasal cavity. A cleft lip presents with more serious cosmetic concerns than a cleft palate, but a cleft palate presents with more serious functional problems (Kummer, 2013).

Cleft lip and palate can present unilaterally or bilaterally and is further classified as syndromic and non-syndromic. Syndromic cleft lip/palate occurs when it is associated with other congenital conditions such as congenital heart disease, while non-syndromic cleft lip/palate arises in isolated instances (Abu-Hussein et al., 2011).

Various attempts at cleft classification have occurred throughout history because a common language was needed that could be understood by various professionals in the field. Kernahan and Stark (1958) recommended that clefts be classified as the primary palate, including structures found anterior to the incisive foramen (the lip and the alveolus), and clefts of the secondary palate, which includes structures found posterior to the incisive foramen, particularly the hard palate and the velum. Kernahan (1971) later introduced a more detailed and visual approach by proposing the "striped-Y" classification. The Kernahan "striped-Y" diagram was initially designed to simplify record-keeping, but it also facilitated the classification of severe cases more effectively (Allori et al., 2017).

The cause of CL/P may be linked to a combination of genetic and environmental influences, including maternal smoking, alcohol use, malnutrition, medication use, and exposure to teratogens in the workplace (Mossy et al., 2009; Vyas et al., 2020). Research conducted at Yekatit 12 Hospital involving 760 mothers revealed that exposure to diagnostic x-rays, maternal chronic illnesses such as bronchial asthma, and threatened abortion were associated risk factors for non-syndromic orofacial clefts (Eshete et al., 2020).

2.2 Longitudinal treatment of children with cleft lip and palate

Parents are generally worried about feeding their child born with cleft lip and palate after birth because the infant may find it challenging to suck milk due to the opening on the roof of the mouth. In most cases, if such a condition persists, then there is a likelihood of milk flowing through an infant's nose. Lack of counseling and absence of professional feeding bottles can lead mothers into a negative emotional state and disturb their emotional attachment with their child. Furthermore, if feeding complications are not addressed on time, the child could lose weight and become malnourished, hence rendering him unfit for any surgical treatment. Therefore, it is crucial that patients receive adequate counseling on feeding strategies for their child (Kummer, 2013).

Where surgical services are available children born with cleft lip and palate will eventually get surgery. The American Cleft Palate-Craniofacial Association strongly recommends that a child should have lip repair by the age of 12 moths and undergo cleft palate closure before they reach eighteen months old. These two procedures may be done at an earlier date given that safety is guaranteed (ACPA, 2018). After surgery, feeding and aesthetic concerns will be resolved to a greater extent however functional implications will still go on persisting. (Lee et al., 2014).

One of the functional difficulties that these children will face is speech impairment. It is possible for children born with cleft lip and palate to have speech deficits which may include nasal emission, hypernasality and sound distortions. Speech can be affected by obligatory or compensatory errors. Hypernasality that is due to an abnormal structure is an obligatory distortion as such requiring surgical intervention or other physical management for correction (pisek et al., 2014). On the other hand, compensatory articulation productions occur when articulation placement is changed in response to the abnormal structure which requires speech therapy intervention (kummer, 2011).

Oral hygiene and dental health can also be problematic for children born with cleft lip and palate. Having a cleft can make it difficult for them to adequately clean their teeth and gums, leading to a higher chance of tooth decay and gum disease (Evans, 2004). In addition to this children's teeth may not align properly because of the cleft, in such cases orthodontic treatment may be

necessary to rectify bite problems and align teeth properly. For good dental health, regular dental check-ups as well as good oral hygiene measures are valuable for these children (Evans, 2004).

Children with cleft lip and palate will also encounter hearing difficulties. The structural abnormalities associated with these conditions can affect the development of the middle ear and Eustachian tube function which can lead to a higher risk of ear infections, fluid buildup in the middle ear, and hearing loss. Consequently, if hearing impairment occurs it can lead to further complications as in delay to their speech and language development. Therefore children born with cleft lip and palate need regular checkup and an early intervention by an Ear, Nose and throat (ENT) specialist.

Due to their appearance and speech children with these conditions can be a victim of bullying and social isolation with can lead to having low self-esteem, feeling self-conscious and in severe cases depression. These challenges can impact their overall wellbeing and contribute to difficulties in forming relationships and participating in social activities. Furthermore, speech difficulties associated with cleft lip and palate can affect communication skills and hinder effective interaction with others, leading to frustration and a sense of inadequacy (hunt et al., 2005).

2.3 Guidelines on treatment of cleft lip and palate

The American Cleft Plate and Craniofacial Association (2017) have numerous core beliefs addressing the appropriate management of individuals with craniofacial problems, which are detailed below.

1. An interdisciplinary team of professionals can effectively manage individuals with craniofacial conditions.
2. Optimal care for patients with craniofacial conditions is provided by teams that see a sufficient number of patients each year to maintain diagnostic and treatment capabilities.
3. The best period for the first evaluation is during the first few weeks of life, preferably during the first few days. Referral for team evaluation and management is acceptable for patients of all ages.

4. From the first interaction with the child and family, every effort must be made to help the family adjust to the arrival of a child with a craniofacial condition, as well as the demands and stress that this places on the family.
5. Parents/caregivers must be provided with information on recommended treatment procedures, options, risk factors, benefits, and costs to help them (a) make educated decisions on their child's behalf and (b) prepare the child and themselves for all necessary procedures. The team should actively seek family input and involvement in treatment planning. When the child is grown enough, he or she should be able to make treatment decisions.
6. Treatment strategies should be created and implemented based on team recommendations.
7. Care should be coordinated by the team but delivered at the local level whenever possible; nevertheless, complex diagnostic and surgical treatments should be limited to centers with the necessary facilities and competent careers.
8. It is the responsibility of each team to be aware of language, cultural, ethnic, psychosocial, economic, and physical elements that influence the dynamic relationship between the team and the patient/family.
9. It is each team's responsibility to track both short-term and long-term results. Thus, long-term patient follow-up, including proper documentation and record-keeping, is critical.
10. Evaluation of treatment outcomes must take into account the satisfaction and psychosocial well-being of the patient as well as effects on growth, function, and appearance.

This guideline can be utilized as a reference to assess the performance of each team. It provides a structured framework to evaluate team functioning.

3 Research Method

3.1 Study Period

The study was conducted over a six month period specifically from January 2024 to June 2024.

3.2 Study setting

The study was conducted at Yekatit 12 Hospital Medical College cleft care unit in Addis Ababa, Ethiopia. The hospital was established in 1923 and since then has become a prominent medical facility in the country. In 2003, a cleft care unit was established at the hospital to provide comprehensive services to individuals with cleft lip and palate conditions. Professionals in the cleft team include coordinator nurse, surgeons, anesthesiologists, pediatricians, ENT specialists, dentists, orthodontists, social workers, and speech therapists.

3.3 Study method and design

A qualitative research approach was used for this study with a case study research design to explore the quality of care provided at Yekatit 12 Hospital Medical College.

"A case study can be defined as an intensive study about a person, a group of people or a unit which is aimed to generalize over several units (Gustafsson et al., 2017)."

3.4 Population sample

Purposeful sampling was used to select 2 plastic surgeons, and 2 speech language therapists who are working in the cleft team at Yekatit 12 Hospital Medical College. The same sampling technique was used to select 3 parents who are receiving care from the cleft team at Yekatit 12 Hospital Medical College. A total of 7 people participated in this study.

3.4.1 Inclusion and exclusion criteria

3.4.1.1 Inclusion criteria for parents

Parents who fulfilled the following inclusion criteria were included:

1. Parents who were the primary care takers (If the child has both parents the mother was chosen for the study)
2. Parents who lived with their child from birth to current year

3. Parents who had a child with either cleft lip and palate or cleft palate only
4. Parents who were receiving treatment for their child at Yekatit 12 Hospital Medical College.
5. Parents who were speaking Amharic as their primary language.
6. Parents who were willing to participate in the study and answer interview questions face to face for 45 – 60 minutes.
7. The parents who were willing to be audio recorded.

3.4.1.2 Inclusion criteria for surgeons

Surgeons who fulfilled the following criteria were included in the study

1. Surgeons who had at least 5 year experience with cleft lip and palate surgery in the multidisciplinary team at Yekatit 12 Medical College.
2. Surgeons who were willing to participate in this study and answer Interview questions for 45- 60 minutes.
3. Surgeons who were willing to be audio recorded.

3.4.1.3 Inclusion criteria for speech therapists

Speech therapists that fulfilled the following criteria were included in the study

1. Speech therapists that had at least 3 year of professional experience working with children and parents of children born with cleft lip and palate in the multidisciplinary team.

2. Speech therapists who were willing to participate in this study and answer interview questions for 45-60 minutes.

3. Speech therapists who agreed to be audio recorded.

3.5 Instruments for data collection

A semi-structured interview guide with open ended questions was developed by the researcher using the guidelines outlined by the American cleft palate and craniofacial association (2017) as a reference. The aim of this guide was to explore the working practices of surgeons and speech therapists and also explore the experiences of parents in the hospital.

The purpose of the semi structured interview guide was to provide a framework that is flexible yet organized enough to ensure all relevant topics are covered. Prepared interview guides were

tailored uniquely for each group of participants. It was initially prepared in English then translated in to Amharic so that participants who speak Amharic language, which is one of the national languages in the country, can fully understand and respond to the interview questions appropriately. This method should increase the reliability and validity of the collected data.

3.5.1 Interview guide for surgeons

The interview guide for surgeons covered topics such as patient care, counseling and emotional support provided for parents with children born with cleft lip and palate. In addition to this, working practice of the surgeons such as the timing of surgical services and follow up practices after surgery was included. Finally, the working of the multidisciplinary team, challenges encountered and recommendations were provided.

3.5.2 Interview guide for speech therapists

The interview guide for speech and language therapists included themes such as patient care, counseling, emotional support, speech therapy services, the working of multidisciplinary team, and challenges encountered as speech therapists. Perceived challenges for parents and other healthcare professionals in the team with recommendations were also listed out.

3.5.3 Interview guide for parents

Interview guide for parent's included the following major themes such as care provided by the hospital, counseling and emotional support received, challenges they encountered, and finally recommendations.

3.6 Data collection procedures

Semi-structured interviews that lasted approximately 45-60 minutes were conducted with each participant. All interviews were audio-recorded to capture the authenticity of the participant's narratives.

Procedure:

- All the necessary permission and consent was obtained from the participant's prior to the interview either by phone call or in person.

- An interview setting which was quite, well lit and comfortable was chosen to avoid any distractions.
- During entry to the interview setting the researcher familiarized themselves with the participants by warmly greeting them. Rapport was built with small talk to ease any initial discomfort as well.
- The purpose and the scope of the interview were explained before starting with the interview questions. The rights of the participants were briefly summarized as well.
- Smart phone recording equipment was used for the interview. It was checked beforehand to ensure it was working properly.

3.7 Data analysis

Thematic Analysis: The collected interview data was transcribed verbatim in Amharic and, translated to English. Afterwards, it was analyzed using thematic analysis. This involved identifying patterns in the collected data and developing themes that capture the essence of the participant's experiences.

Data Coding: Then transcripts were coded to identify recurring themes and categories which were related to topics such as cleft care, collaborative practices, challenges and finally, recommendations for future improvement.

Data Interpretation: Following data coding the identified themes were interpreted within the broader framework of cleft care. This provided insights into the provision of comprehensive care for children with cleft lip and palate at the hospital.

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3.8 Ethical Considerations

- **Ethical clearance**: was obtained from Addis Ababa public health research and emergency management (REF.N.O A/A/18017/227, DATE- 2/9/16)
- **Cooperation letter:** A letter of cooperation was secured from the special needs department at Addis Ababa University.
- **Informed Consent:** All participants were provided with detailed information about their rights, potential risks and benefits of the study. The study's purposes were also explained prior to obtaining their consent.
- **Confidentiality and data protection:** Measures were taken to ensure the privacy and confidentiality of participants. All personal identifiers were kept confidential, and data was stored carefully and was only accessible to the research team. Any information that could potentially identify the participant was made anonymous in the final analysis and reporting.
- **Respect for Participants:** Throughout the study the autonomy, dignity, and privacy of the participants was respected. They had the right to withdraw from the study at any point without consequences.

4. Result

4.1 Background information

A list of names of healthcare professionals and parents with their background information is outlined below. **Anonymous names were used for all participants.**

Table 4.1 Background information of healthcare professionals

No	Name	Profession	Years of Experience in the Field	Years in the Multidisciplinary Team
1)	Dr. Abebe	Plastic and reconstructive surgeon	15 years	10 years
2)	Dr. Tilahun	Plastic and reconstructive surgeon	15 years	15 years
3)	Dereje	Speech and language therapist	4 years	4 years
4l	Helen	Speech and language therapist	4 years	4 years

Table 4.2 Background information of parents

No.	Parents name	Age	Religion	Residence	Marital status	Sex of the child	Age of their child	Diagnosis
1)	Seada	34	Muslim	Addis Ababa	Married	Male	8 years	Unilateral cleft lip and palate
2)	Wubalem	30	Protestant	Addis Ababa	Separated	Female	11years	Bilateral cleft lip and palate
3)	Senayit	25	Orthodox	Oromiya region	Married	Male	5 years	Unilateral cleft lip and palate

4.2 Patient care

At Yekatit 12 Hospital Medical College all health care professionals stated that parents with a child born with cleft lip and palate are seen by a professional in the team on their first visit. Helen, a speech and language therapist mentioned,

> “Their initial interaction is with the coordinator nurses and the social worker. They will receive essential counseling and guidance on how to feed their child, the importance of weight gain, and detailed information about upcoming surgeries.”

The potential challenges with breastfeeding were also elaborated explaining that the child may struggle to suck breast milk due to the inability to generate sufficient intra-oral pressure caused by the opening on the palate. During counseling parents are advised to feed their baby more frequently with smaller amounts. They are also advised to use feeding bottles with wider nipple holes and burp the baby after every feeding session.

Comprehensive care for children with born with cleft lip and palate involves more than just the surgical procedure. Three of the health care professionals highlighted this key point when counseling parents. Among them Dr. Abebe particularly emphasized on the matter saying,

> "We also inform parents that the treatment involves long-term follow-up, and surgery is only a part of the process. The child may require additional services such as speech therapy, ENT treatment, orthodontic care, and psychotherapy as they grow older. "

Regarding emotional support all four professionals confirmed that the social worker on the multidisciplinary team provides the majority of this support. Three healthcare professionals also emphasized that while the social worker plays a primary role, it is important for other healthcare professionals to offer emotional support with every encounter.

The social worker in the cleft team organizes and facilities group sessions for parents as well. These sessions serve as a space for parents to share their experiences, provide support for other families and learn from one another. Helen further pointed out the role of the social worker, highlighting the emotional distress that parents often experience.

> "When the delivery center was located at the hospital parents used to come to us distressed and in tears. Imagine enduring the pain of childbirth and then seeing their child in that state, it can be an extraordinarily difficult time for them. The social worker shows the parents pictures of children before and after their surgeries so they can see that the condition can be successfully treated."

It is evident that adequate counseling and emotional support is important for these parents. Many parents often due to a lack of awareness may find themselves in difficult situations such as separating or divorcing with their spouses. Dereje who pointed out this matter also added,

> "We place great importance on providing counseling and emotional support to the parents. Our team is committed to being with them from the day they arrive at the hospital and continuing to guide them throughout their journey all the way to adulthood."

Two other healthcare professionals also highlighted that during counseling, parents are informed that the treatment is free of charge which decreases their financial burden.

4.3 Surgical Services

Surgical management is one of the main treatments for children born with cleft lip and palate. However before surgery, both surgeons underlined the importance of counseling parents about the timing of surgery and the roles parents have to take on to make the child suitable for the procedure. Dr. Tilahun mentioned,

> "Parents often want the surgery to be performed as soon as they come to the hospital. It's imperative to inform them that their child must first be fit for the procedure. Parents need to be guided on how to properly feed their child to ensure appropriate weight gain"

He went on to add that Parents generally follow their advice to the best of their abilities because they are eager for their child to receive the surgery. Both surgeons also mentioned the eligibility criteria that a child must fulfill. They stated that the child should weigh at least 10 pounds (4.5 kg), have a hemoglobin level of 10, and be free of infection to qualify for the first surgery. Although, there may be additional conditions to consider in some unique cases.

Ensuring the child is free from infection has a great significance as the presence of any infection contraindicates the surgery. Dr. Tilahun elaborated further on the treatment aspect of infections, stating that parents are advised to seek treatment at nearby healthcare centers if their child develops an infection. He acknowledged that frequent checkups might be challenging for families from rural areas, however, in cases where serious problems arise, they should still come and get treatment for their child at the hospital. He noted that issues such as malnutrition or infection are managed by a pediatrician from the multidisciplinary team.

The timing of surgery for both cleft lip and palate at Yekatit 12 Hospital Medical College was also elaborated by the surgeons. Both surgeons stated that currently, if a child meets the eligibility criteria, surgery for the lip will be done at 3 months of age. Regarding surgery of the palate, Dr. Abebe stated that palate surgery typically takes place between 9 to 12 months, while Dr. Tilahun mentioned palate surgeries are typically done at nine months, although sometimes as early as six months.

Both surgeons highlighted how the number of professionals and the timing of surgery have improved from the past. Dr. Abebe highlighted on the matter stating

> "About 20 years ago, there was only one plastic surgeon available, so cleft surgeries were performed by charitable organizations during missions. Many people were unaware that such surgeries existed, resulting in most patients being adults, some as old as 70 years old. There has been increased awareness among the population about this surgery. Parents now bring their children in as soon as they are born, and hospitals are more proactive in referring these cases to us immediately."

The age for lip surgery was six months. However, with improved experience from the anesthesia team, currently lip surgeries are done at three months and palate surgeries at twelve months in outreach settings. Other types of secondary surgeries were also mentioned by both surgeons, particularly Dr. Abebe elaborated,

> "We perform various surgeries on children born with cleft lip and palate. Before they start school, they might receive additional surgeries on their noses and lips to prevent bullying and teething. When children reach the age of eight there is a procedure called

alveolar bone grafting that we may perform if needed. Even in adulthood, surgeries may be necessary for individuals who are conscious about their appearance. In some cases, if problems such as a fistula or poor speech outcomes arise and if it is recommended by speech therapists, speech surgery could be undertaken."

4.4 Speech therapy services

Both speech therapists explained that during their first contact with a child and their parents, they provide counseling about early language stimulation which goes on until the child is three years old. Helen elaborated on the counseling of early language simulation stating

> "We advise parents on spending adequate time with the child, talking to their child, the importance of cooing and babbling. We also do a follow-up on the child every five or six months to track progress and offer more guidance."

Furthermore, Dereje added the following statements:

"To prevent communication problems as they get older, Parents are informed about what to expect in terms of their child's communication development and measures that can be taken to improve or prevent issues. During follow-up visits, parents are asked about their child's speech developmental milestones."

At the age of 3 years old formal assessment will be done which includes child's articulation, resonance, and speech understandability and after assessment if the child needs therapy, sessions will be provided accordingly. Dereje disclosed on this matter saying

> "Therapy sessions are given 2-4 days per week, depending on severity, with a minimum of two sessions per week" while Helen said," three times a week is ideal, but due to availability, it may be reduced to once a week."

Regarding using oral motor exercises and blowing exercises, both speech therapists mentioned that they do not use oral motor exercises for children with cleft lip and palate, except when there are additional disorders present. However, they differ in their approach to blowing exercises. Helen does not use blowing exercises for children with cleft lips and palate, stating that their speech problems are usually due to improper articulation and resonance issues. On the other

hand, Dereje uses blowing exercises to teach proper placement and create pressure in the mouth for sounds like "B" and "P." He explained,

> "I put a soft tissue in front of them and blow on the soft tissue by saying B and P."

Both speech therapists emphasized the importance of involving parents in therapy sessions. They also mentioned providing counseling to parents on the responsibilities and expectations of speech therapy and that it is mandatory for parents to be present during therapy sessions but some parents may prefer to wait outside. They highlight the need for parents to practice exercises with their child both in therapy and at home for good outcomes.

It was also mentioned that it is difficult to provide continuous therapy sessions for children who lives far from Addis they shared some of the ways therapy sessions is provided for these is children. Helen further disclosed,

> "For these children and their parents, we offer a one-week stay at a hotel where accommodation and meals are fully provided. Sponsored by Transforming Faces, this project includes intensive speech therapy sessions twice daily, once in the morning and once in the afternoon, for five consecutive days and for children who are in school, it can be challenging to attend regular therapy sessions. To accommodate this, intensive daily therapy sessions are offered for two to three weeks during their semester breaks."

4.5 The Multidisciplinary team

All healthcare professionals emphasized the importance of the multidisciplinary team that provides treatment for children with cleft lip and palate. When asked about the professionals involved, the following members were listed Two ENT specialists, five plastic surgeons, one social worker, one pediatrician, three speech therapists, three orthodontists, two nurse coordinators, and two anesthesiologists.

All four healthcare professionals provided similar insights into the team meeting of the multidisciplinary team treating children with cleft lip and palate. It was mentioned that the team meets once a month on the last Wednesday of the month. During these meetings, each team member reports their activities during the month. Patients who were sent by team members for possible discussion will be assessed at the team meeting. Patients with complex cases are

specifically discussed during these sessions to ensure a coordinated approach to their care. Dereje elaborated on this matter saying

> "For instance, if a child's speech does not improve with regular speech therapy and I suspect velopharyngeal insufficiency, I would schedule the child for our team meeting. During this meeting, we would consult with the entire team to determine whether surgery is the best course of action for the patient."

Furthermore, patients with cleft lip and palate are assessed in a cleft clinic held every Wednesday, as mentioned by Dr. Tilahun and the other health care professionals. During these clinics, patients are seen by the relevant professionals from the team based on their age and specific needs. Outside of formal meetings, the team members maintain direct communication to address any concerns about patient care promptly, allowing for consultations and referrals as needed. Helen elaborated on this matter, saying,

> "We don't always wait for the team meetings. If I believe a patient requires immediate attention, whether it's something related to their surgery or an emergency, I will connect them directly with the available plastic surgeon. Similarly, if I suspect an ear infection or hearing problems, such as the child not responding properly during sessions, I will promptly refer the child to an ENT specialist."

4.5.1 Strength and weakness of the team

The conclusions of four health care specialists at Yekatit 12 Hospital Medical College about the cleft multidisciplinary team's strengths and limitations reflect a mix of positive and negative elements. Dr. Tilahun emphasized the team's strength in positive connections and overall communication. However, he did identify flaws such as inadequate reports and occasional absences or tardiness during meetings.

Dr. Abebe emphasized the team's resilience as a major strength, saying, "It's a strong team; this strength is why it's still standing here after all these years." He recognized areas for improvement, including the need for additional experts such as speech therapists and social workers.

Helen, the speech and language therapist, identified the team's communication on patient cases as strength, adding, *"The strength is the communication within the team, which helps the patient to get good care."*

She recommended hiring a permanent nutritionist to increase patient care quality. Dereje, another speech and language therapist praised the hospital's comprehensive cleft care and pointed out advances in treatment time. He stated the following as an improvement,

> "Most of the professional development trainings that are provided to us are given online through webinars. That is good however; it would be nice to have face-to-face training."

4.6 Barriers to cleft care services

There are many barriers to obtain the services such as geographical location, insecurity, lack of support and long treatment process. All four healthcare professionals highlighted that distance is a significant challenge in providing adequate cleft care. They noted that many families come from rural areas where nearby services are often unavailable, requiring them to travel long distances to reach the hospital. This travel can be a major obstacle, particularly for those who have to take time off work and manage other family responsibilities. This is because there are no similar services in the hospital in their village.

In addition to distance barriers, security concerns due to the conflict in the country were mentioned by two healthcare professionals. As a result, only a few people are currently coming from distant regions. Dereje, a speech therapist disclosed his observations as follows*: "There's a child who received surgery for cleft lip but missed his palate surgery because of the country's instability. Another child was being treated for an ear infection but missed his follow-up for the same reason."*

Three healthcare professionals further pointed out that the lack of support can also hinder families from following up on services provided at the hospital. For some parents, especially for single parents, it was explained that it can be very hard to keep up with appointments. Single mothers who separated from their husband due to their child's health condition are common. Those mothers have to work to support their families and also take care of their children. This makes it very difficult for them to bring their child to the hospital for follow-up care. Finally, the journey of caring for a child with cleft lip and palate was described as a challenging and exhaustive process by two healthcare professionals. From birth to adulthood, parents face a continuous cycle of seeking support from various specialists, not limited to surgery. This prolonged and demanding journey can take a toll on parents.

4.7 Perceived challenges for health care professionals

The major challenges for health professionals include lack of resources, shortage of health care professionals, limitation of the hospital capacity, disorganized documentation, limited parental awareness and support, parental expectations and language barriers which each will be discussed in the paragraphs below.

All health care professionals emphasized on the limitations of resources in the hospital. Dr. Abebe explained:

"We can't confidently say that we have all the resources right now. Dental braces are very expensive, which forces us to limit the number of patients we can treat. Additionally, sometimes the suture material we need for surgery is simply not available in the market."

Three healthcare professionals also mentioned the lack of instrumental assessment particularly nasoendoscope in the hospital. Dereje emphasized on the matter saying*: "The nasoendoscope equipment at our hospital has been non-functional since I began working here, which means it has been out of service for the past four years."*

Helen a speech and language therapist added on the matter saying:

> "Currently, our method for assessing hypernasality is primarily subjective, relying on perceptual evaluation and observing mirror fogging. The availability of instrumental assessment would greatly reduce confusion and enhance the accuracy of our evaluations. Other than nasoendoscope there is also lack of audiometry"

Three health care professionals pointed out shortage of professionals. Dr. Abebe highlighted: *"We need more professionals. Especially there's a burden on the social workers and speech therapists if more professionals were added it would be very helpful."*

Two healthcare professionals also added the addition of a permanent nutritionist to the team. Particularly Helen said:

> "Having a permanent nutritionist on the team would be very beneficial. Currently, we do have nutritional support for cleft lip and palate patients however i would suggest one in

> the team. With a nutritionist on the team, patients would receive higher quality care. We need more professionals on the team to meet our patients' needs more effectively."

Two healthcare professionals noted, that in the past it was challenging to secure hospital beds even when a child required surgery. Furthermore, one healthcare professional highlighted limited diagnostic capabilities: mentioning certain essential investigations, such as echocardiography is not being available at the hospital, which is crucial for surgical procedures."

Dr. Tilahun, a healthcare professional emphasized that the documentation of outcomes is still lacking. He pointed out the importance of accurate documentation of results, given the vast and geographically dispersed population of our country. Dr. Tilahun said:

> "We need to assess our progress through research, and it must be recognized on an international level. For this, our documentation must be of high quality. This will help us identify our gaps and determine areas for improvement."

Three healthcare professionals mentioned limited of awareness in the community Dr. Abebe mentioned that there is still limited awareness about secondary surgeries:

> "There are children who needed secondary surgeries but don't come to the hospital because of their parents. After they get older, they know the impact therefore force their parents to come for their surgery. This shows that there is also a lack of awareness among the community about surgical interventions."

Both speech therapists highly emphasized about decreased awareness about speech therapy services and how it can be challenging. Particularly Dereje said:

> "Many parents may view speech therapy as a straightforward process similar to taking medication, where they entrust the child to us and anticipate a cure. However, speech therapy is more of a rehabilitation process, which needs active involvement from parents. It is essential for every parent to be present during therapy sessions. However, some parents might prefer to wait outside. If parents do not practice with their child at home, it can negatively impact the child's progress."

Helen on the other hand mentioned the possible causes for decreased parental attention to speech therapy services,

> "Occasionally, we observe limited parental engagement despite our efforts in counseling. This could be due to a lack of awareness about the significance of speech therapy and its impact on a child's overall well-being, including psychological aspects, as the profession is still relatively new in our country."

One challenge on the surgical side is that parents are often eager to have their child's cleft repaired as soon as possible, primarily due to concerns about the child's facial appearance. However, the actual surgical process can only be done if the child is eligible for surgery, and they may need to wait. Additionally, their child may also require multiple surgeries over time. This can lead to frustration for some parents who are expecting immediate results.

Also on speech therapy, it appears that many parents hope for quick improvements in their child's speech and language skills. However, a speech therapist highlighted the importance of understanding that therapy is a continuous process and parental involvement is the key. The therapist also mentioned that there seems to be a general lack of awareness about what speech therapy entails.

One healthcare professional, Helen also mentioned language barriers:

> "There is a language barrier when children who speak different languages come to us, and we don't have a translator for those languages. A lot of people who speak other languages, like Gurage, Selete, Afar, and Somali, come to the clinic and since we don't speak their languages it is hard to treat these children without a translator."

4.8 Recommendations of health care professionals

The healthcare professionals provided valuable insights into the improvements needed for multidisciplinary cleft care at the hospital. The key recommendations include

- updated diagnostic instruments and materials
- expanding the team with additional professionals,
- implementing structured, organized documentation and reporting, and
- Cultivating local financial support

Dereje emphasized the importance of updated diagnostic instruments and modernized facilities, highlighting the need for Nasoendoscope and audiometry equipment.

Dr. Abebe stressed the reliance on charitable organizations for financial support and advocated for widening local support, emphasizing the need for sustainable treatment, stating:

> "The treatment of Cleft lip and palate currently relies heavily on charitable organizations, and without their help, such services wouldn't exist. Charitable organizations, such as smile train Transforming Faces; have even taken steps to train professionals, including those enrolled in speech therapy master's programs. In the future, if our country could garner local support, it would be immensely beneficial. Local support could also help to pool resources and raise awareness. It would enhance the support provided to hospitals while also minimizing patients missing their follow-ups due to lack of awareness"

4.9 Parent’s experiences at the hospital

Three parents were interviewed about their experiences. Wubalem is a 30 year old mother of four children. She lives around Merkato, which is one of the biggest market place in Addis. She is a single mother who supports her children serving tea in the evenings. Her daughter receiving treatment at Yekatit 12 medical college is currently 11 years old and was born with bilateral cleft lip and palate.

Seada is a 34 year old married mother with children of four. She is a housewife who lives in Addis Ababa city around Kara Kore. Her child is currently 8 years old and was born with unilateral cleft lip and palate.

Senayit is 24 year old married, housewife. She lives in Oromya region around Mojo and is a mother of 2 children. Her child, who was born with unilateral cleft lip and palate, is currently 5 years old.

4.9.1 Parental support

Parental support that this thesis focused on included emotional support and counseling.

4.9.1.1 Emotional support

All three mothers mentioned receiving emotional support from the healthcare professionals, at the center. They expressed gratitude for the emotional support they received during a challenging and emotionally distressing time. Seada, a mother of four talked about the support she got by saying

> "Yes, I received emotional support especially from Betty. They really helped me so that I was not psychologically hurt. I used to go there frequently because I was really stressed at the time. Betty used to give me counseling taking her as an example and they really made me feel better at the time. I can't thank them enough"

While Senayit also had the same type of feeling pointing out that she never had seen a case like this before and was initially shocked, she thanked the team for calming her. Wubalem on the other hand who is a known RVI patient who is taking antiretroviral medications talked about her emotional and financial struggle at the time emphasizing the support she got from the team.

> "My daughter was born with an opening in both her lip and palate. They referred me to Yekatit immediately. At the hospital they scheduled frequent appointments with me because I was emotionally unstable at the time. I was dealing with my illness; i had no family support, and was separated from my husband. There was a time I even tried to take my own life, but it failed. I'm glad it did because my daughter has only me. The support from the people here is the reason I'm standing today. I want to thank Betty, Bizuayew, and Hirut at Yekatit 12 hospital. They cried with me and calmed me down when I was in shock after seeing my daughter. They even supported me financially when I had no money for milk. They also told me that it can be treated."

4.9.1.2 Counseling for parents

All mothers were informed about specific feeding strategies, but they faced challenges accessing feeding bottles at the time. Consequently, they had to rely on alternative methods such as sourcing bottles from other countries. Seada shared her experience on the matter stating,

> "I used to feed using a special feeding bottle. I couldn't find any in the country at the time so I had someone send it to me from abroad. The feeding bottle was available at the hospital after me, though."

Senayit mentioned some of the financial challenges she faced after the counseling:

> "They informed me about feeding bottles and strategies for feeding. In that time since he couldn't feed on my breast milk, i was supposed to give him canned milk but due to financial constraints, I had to give him cow's milk instead of canned milk."

Wubalem received counseling about expectations, feeding her child, and potential future problems. She also mentioned needing to obtain a feeding bottle from alternative sources. All three mothers also spoke about the additional counseling they received including guidance for their children's speech. Seada elaborated:

> "They informed me that my son might need not only surgical treatment but also care for his teeth, hearing, and speech. They also told me in the future he could have difficulty pronouncing certain words and that he might talk through his nose. They advised me to help him at home by making eye contact during interactions and stressing sounds especially those made with our lips to aid his speech development. All of this was communicated to me before his speech problems even manifested."

Senayit: "They also discussed potential speech issues and advised me to encourage him to say 'ababa' and 'mama' at home. Thankfully, he is now fine and able to talk. Additionally, they mentioned that if his teeth do not grow properly they would need to intervene."

Wubalem: “All these issues were communicated to me before they actually occurred. They advised me on how she talks, her teeth, and also mentioned that she might need other surgeries in the future.”

4.10 Surgical interventions

Counseling was given for all parents about the eligibility criteria that needed to be achieved for each specific child. Parents were more specifically concerned about the weight gain of their child. Seada recalled how it was for her eight-year-old son,

> "They informed me that he can't have the surgery at this moment and needs to gain more weight. He underwent surgery when he weighed 6 kilos at 8 months old and had his palate surgery at 1 year and 2 months."

There are instances where Parents ensuring that their children reached the required weight for surgery takes longer than expected as in the case of Senayit. This delay can be quite stressful for any parent, Senayit elaborated on the matter,

> "They informed me that my son would undergo surgery once he reached 8 kilograms. Until the surgery, I stayed at home with him and kept him from being seen by anyone. I even stopped working because of this. Despite my efforts, he didn't reach 8 kilograms as quickly as expected. He finally weighed 8 kilograms when he was 15 months old. Afterwards, He had his palate surgery at 3 years and 3 months. Originally, they planned to perform the surgery 6 months after his lip surgery but we couldn't return to the hospital due to financial constraints"

Other than feeding counseling giving up your child for surgery can also be a hard time for parents especially with Wubalem's case where there was repeated delay

> “During surgery i was afraid to send her to the operation, because they sent her back twice because something failed and she got the operation on the 3rd time. And at that time i was really scared i would lose her but thank God she was better. The hospital staff really supported me at that time too.”

No.	Mothers name	Fulfilled weight criteria for eligibility	Age of the child during lip surgery	Age of the child during palate surgery
1.	Seada	6 kg	8 month	14 month
2.	Senayit	8 kg	15 month	3 year and 3 month
3.	Wubalem	Unknown	10 month	14 month

Table 4.3 Timing of surgery for children with cleft lip and palate

4.11 Speech therapy interventions

All mothers mentioned that their child's speech therapy frequency which is at least once or twice a week. Seada explained changes that were made in the speech therapy frequency after her son started school.

> "He used to have therapy twice a week for a year, but since he joined first grade I didn't want him to miss class so we reduced it to once a week."

Wubalem also explained that her daughter did not have frequent speech therapy interventions in her younger years as she was living with her mother in a rural area and at that time she took two group therapy sessions at CURE hospital. She also stated her concerns regarding her daughter's current struggles with communication and social isolation at school.

> "Most of her teachers tell me they don't understand her. One of her teachers even told me that when she was in first grade he used to understand her a bit, but now in third grade it has gotten harder to understand her. Now she is at school, and she is isolated because of how she looks. The other kids don't want to talk to her. She struggles with her studies as well. I feel like she is hurt, and her confidence has been affected. But I know her teachers try to support her as much as they can."

Wubalem talks about her own understanding of her child's speech and the problematic responses from others.

> "I usually understand her, but there are times that even I don't, and people around her just tell her 'yeah, yes' without even understanding her. I don't think agreeing with a child without understanding what they are saying is good. It could be harmful."

The other main concern was if parents were practicing during their speech therapy sessions and at home. One mother noted that she practices both during sessions with the speech therapist and at home, all three mothers revealed that they try to help their child only at home with the home exercises that were given to them. Senayit talks about this experience stating,

> "He has improved his speech a lot since starting speech therapy and is now able to communicate and make people understand him. They give me things to work on at home, and I'm motivated to help him as well."

Wubalem on the other hand expresses her daughter's frustration with speech therapy and also the challenges she faced with helping her daughter practice at home.

> "Currently, she is feeling a bit frustrated with speech therapy. She becomes teary-eyed when I attempt to correct her, and I don't think she enjoys it. I don't force her, but I encourage her to study and explain that it's for her benefit. I do my best to assist her before leaving for work when they return from school. When I come back home they are already asleep."

Overall all mothers are satisfied with the speech therapy they are receiving at the hospital. Two of the mothers elaborated that their child has received surgery to improve their speech and were presented at the team meeting for decision. Seada recounts the decision-making process for her child's speech surgery.

> "He was taking speech therapy and had made progress, however at some point, they couldn't make further improvements. So I was asked to be present at a team meeting where the surgeons, speech therapists and dental professionals were present, and they decided on the surgery."

4.12 Perceived challenges for parents at the hospital

Seada discussed the issue of bed availability at the hospital and the impact on surgery scheduling.

> "There was an instance where my child almost didn't get the surgery he was supposed to get in a timely manner because there was no bed available in the hospital. But afterward, they called me telling me a bed was found. What I want to say is that there is a problem with bed availability at the hospital. Other mothers also had to deal with the same thing. I see other mothers struggling because of the lack of beds."

Senayit expresses concerns about how medical staff treats children during surgery preparation.

> "They do inform us well about the surgery and everything is organized. However, I recommend the anesthesiologists and nurses treat our children more nicely. They are kids; of course, they are going to be difficult at times."

Seada appreciates the team approach but notes issues with communication. She pointed out a communication gap affecting parents from rural areas regarding surgery details. She stated more thorough explanations should be given so that parents fully understand the procedures their children will undergo. She also stressed the importance of clear and consistent communication regarding medical procedures and schedules

> “During team meeting I was told there would be a dental procedure for my child in September but I didn't know what it was. When I went for the appointment, a new doctor that wasn’t present at the time said there was nothing to be done and scheduled me for July. I wish they communicated better.”

Wubalem reflects on her past frustrations and current understanding of her child's treatment process.

"I'm really satisfied with the treatment. In the past, I used to be frustrated that she wasn't getting the treatment faster. But now I understand that the treatment is dependent on her age and her growth. I don't have a problem with the way the hospital works. Usually, I know it's the burdens

I have at home that are the main challenge for me. Here at the hospital, they provide transportation, and everything is free. But when you come, you leave a lot of things at home."

5. Major Findings

One major finding based on the research question is the way the multidisciplinary team works in the hospital. The healthcare professionals in the multidisciplinary team provide comprehensive cleft care at Yekatit 12 medical college in three ways.

a) Team meetings: The team meets on the last Wednesday of the month. During these meetings, each team member reports their monthly activities and patients who were sent by team members will be presented on the team meeting for a joint decision on future interventions.

b) Cleft clinic: A cleft clinic is available weekly on Wednesdays, where patients born with cleft lip and palate are appointed for their follow up and seen by the appropriate professionals based on their age and specific needs.

C) Direct communication and Referrals: Outside of formal meetings, the team members communicate directly to address any concerns about their patient care. Consultations and referrals between professions are present based on the need.

Another main finding of this research is parent's access to care at the hospital. The focus of the thesis was on services related to emotional support, counseling, surgical care, and speech therapy services. Interviewed Parents of children born with cleft lip and palate conditions mentioned that they were referred to the hospital as soon as possible for intervention by the cleft care team. From the data gathered, parents also informed that they received satisfactory emotional support and were also counseled on the functional problems their child could potentially face in the future. Counseling on feeding support was also provided however securing a feeding bottle in the country was a challenge for all mothers.

Surgical intervention of cleft lip and palate were provided for all children of parents who were interviewed at varying ages specifically at the age of 8 to 15 month for lip surgery and at 14 month for palate. One mother in particular received the palate surgery at the age of 3 years and 3

months old, secondary surgeries for the improvement of their speech was also done for two children as stated by their parents.

Speech therapy services were also provided for parents included in the research. They received therapy services with the frequency of 1 to 2 sessions per week. Two mothers were satisfied with the speech therapy provided while one mother mentioned that her child was finding speech therapy challenging.

Finally, the main barriers identified for parents of children born with cleft lip and palate were geographical challenges, security problems, lack of support and long treatment process. While challenges faced by healthcare professionals include lack of resources, shortage of health care professionals, limitation of the hospital capacity, disorganized documentation, limited parental awareness and support, unrealistic parental expectations and language barriers.

6. Discussion

The treatment of children with cleft lip and palate is a longitudinal process that spans from birth to adulthood. At Yekatit 12 Hospital Medical College, all healthcare professionals mentioned that children are seen as soon as they come to the hospital, which is also recommended by the ACPA guidelines, where optimal care is given within the first weeks of life or as soon as possible (ACPA, 2017). All parents who were interviewed had similar experiences; they were referred to the hospital immediately within days.

Regarding emotional support given to parents, which is a crucial part of cleft care, the social worker provides most of the support at the hospital offering individual counseling and group training. The mothers are also grateful for the emotional support they received, mentioning the challenging emotional states they were in, such as being shocked, depressed, anxious, and confused, and how the support they received alleviated most of their concerns. Due to the following reasons, it is safe to assume that the support provided was adequate. However, two healthcare professionals also mentioned, there are limited professionals providing support when only one social worker is working on the team.

Concerning Primary surgery of the lip and palate, the American Cleft Palate - craniofacial Association (2017) recommends lip surgery to be done within 12 months and palate surgery within 18 months. While this is a broader timeframe, Smile Train organization's recommended timeline suggests lip surgery to be done specifically within 3 to 6 months of age and palate surgery within 9 to 18 months (smile train, 2021). At Yekatit 12 Hospital Medical College, surgery, as stated by the plastic surgeons interviewed, lip surgery is done as early as 3 months and palate surgery within a range of 6 to 12 months, depending on the safety for the child. Mothers interviewed in this research had variable timeframes for their child's lip and palate surgery. Lip surgery was done from 8 months to 15 months, and palate surgery was done at 14 months for two mothers and at the age of 3 years and 3 months for one particular mother. The reason for the disparity in the findings is because of the eligibility factor, as mentioned by the mothers. They were told their child has to be at least 6 to 8 kilos to get the first surgery, and stated that they couldn't meet that weight criteria as soon as they hoped. This shows us how adequate nutrition, implementing feeding strategies and the role of infection prevention are vital for children with cleft lip and palate.

During Interviews with the speech therapists valuable insights were gained on how they work. Counseling on early language stimulation is a vital factor for these children and is started for the parents when they come first to the hospital and goes on until the age of 3 years, formal assessments will also be done at the age of 3 years. This strategy follows the recommended guideline which states speech and resonance assessment should be done between the ages of 3 to 4 years (ACPA, 2017). All the interviewed mothers stated that they have received counseling for their child speech at an earlier age, and were told about their responsibilities as a parent.

Instrumental assessment is required for all patients with resonance disorders and audible nasal air emissions to check for velopharyngeal function. However 3 healthcare professionals mentioned that the there are no instrumental assessments available for assessment velopharyngeal function at Yekatit 12 hospital medical college and two of the speech therapists interviewed mentioned they use perceptual assessments to check problems with resonance. There are also two mothers who were provided for surgery to improve their child speech as their child progress halted and

problems with velopharyngeal function was identified by the speech therapists. Consequently surgery was decided at the team meeting.

While the major factor stated by the speech therapists as a challenge was lack of awareness about speech therapy, unrealistic expectations and lack of support by parents. During the interview of the mothers all three mothers stated that they practiced with their child at home. One mother in particular had a hard time supporting her child due her work conditions and also being a single mother.

The members of the multidisciplinary team included ENT specialists, plastic surgeons, social worker, pediatrician, speech therapists, orthodontists, nurse coordinators, and anesthesiologists. Not only does the team include all the healthcare professionals from the core team (plastic surgeons, orthodontists and speech and language therapists) but also other healthcare professionals which are crucial for the treatment of cleft lip and palate.

One of the guidelines of the American cleft lip and palate association (2017) is that the team must see sufficient amount of patients every year at least to maintain clinical expertise in the field. The multidisciplinary team at Yekatit 12 hospital medical college meets once a month to discuss cases that needs team decision and also has a cleft clinic on Wednesdays every week where patients are seen by various professionals on their follow up.

Some of the barriers faced by parents were also mentioned by healthcare professionals, the most common challenges being distance and security challenges due to conflict, for parents coming from rural areas. The other challenge is that Parents may face financial difficulties due to time off work when they visit the hospital and other expenses related to treatment. Three healthcare professionals also mentioned that parents may lack support from their spouses and extended families in caring for their child and could be a barrier for them to attending appointments and coming for follow ups. The last point stated was the toll of the long treatment process of children with cleft lip and palate can be exhaustive for parents and may lead to decreased adherence to follow ups.

Perceived Challenges in the hospital for Health Care Professionals included the hospital lacking essential resources such as, dental braces and suture materials for surgery. The absence of

instrumental assessments such nasoendoscope and audiometry equipment was also mentioned, which limits the accuracy of evaluations and diagnosis. Shortage of healthcare professionals was stated by three healthcare professionals, especially social workers, speech therapists, and nutritionists. This shortage can hinder the comprehensive care that children with cleft conditions require. The hospital's capacity is also limited, as noted by both healthcare professionals and a concerned mother that at times it can be challenging to secure hospital beds for children who need surgery. The documentation of patient outcomes is also lacking, making it difficult to assess progress and identify areas for improvement this point was mentioned by one healthcare professional.

Language Barriers in Speech Therapy is also a challenge that was mentioned by one speech and language therapist. Language barriers can pose significant challenges in the provision of speech therapy services. When a child speaks a language that is different from the therapist's, it can be difficult to assess the child's speech difficulties and provide appropriate treatment.

The findings from the interviews with mothers highlight both strengths and challenges in the provision of cleft care at the hospital. The Strengths mentioned are good Team approach where Healthcare professionals work together in a team to provide comprehensive care to patients. The other strength mentioned was the availability of free services in the hospital. Surgery, transportation, and other services are provided free of charge to patients. Overall, the mothers interviewed were satisfied with the quality of care they receive and mentioned some areas of improvement such as shortage of hospital beds, which can delay surgeries and other procedures, Lack of detailed information about treatment plan and Communication issues where there were instances of miscommunication between healthcare professionals and patients, leading to confusion and delays in treatment.

7. Conclusion

The findings of this research indicate that Yekatit 12 Hospital Medical College provides comprehensive cleft care services, with adherence to the recommended timeframe for initial assessment and surgical interventions. Though there is overall satisfaction with the quality of care among healthcare professionals and parents interviewed, some challenges were identified and areas for improvement were highlighted. These include limited resources, a paucity of healthcare workers, inadequate capacity of hospitals and lack of instrumental assessment for velopharyngeal function.

The hospital's multidisciplinary team working together with charitable organizations that offer free medical services shows a remarkable commitment to access to care that is comprehensive in nature. Additionally, establishment of local support groups and health care associations will ensure sustainability and guarantee long-term success of these services. By developing and strengthening local support networks, the hospital can tap into a valuable resource for parents and families of children with cleft lip and palate. These support groups have numerous advantages including emotional assistance as well as education about the condition itself.

Moving forward, addressing the following gaps will be essential for improving the overall quality of cleft care at the hospital. By securing necessary resources, increasing staffing levels, and overcoming language barriers, the hospital can augment it's already strong team approach and free service provision. Ultimately, these efforts will contribute to improve care and outcomes for children with cleft lip and palate, furthering the hospital's mission of providing high-quality, accessible healthcare.

8. Recommendations

Here specific recommendations are outlined from the data gathered from the healthcare professionals and parents.

- Enhancing local support by creating local financial backing can help alleviate resource challenges at the hospital and help in creating more awareness in the community.
- Providing essential diagnostic tools, such as nasoendoscope and audiometry, to the hospital.
- Expanding the healthcare team by adding more professionals, particularly social workers and speech therapists.
- Including a nutritionist and a translator on the team
- Introducing initiatives to enhance parental awareness about speech therapy services and the significance of parental participation.
- Providing Training to team members on organized reporting and documentation
- Increasing hospital capacity by expanding the number of available hospital beds to reduce waiting times for surgery and other procedures.
- Implement systems to ensure that patients and their families receive clear and accurate information about their child's treatment plan.
- Provide training to healthcare professionals on how to interact with children and families in a sensitive and respectful manner.
- Foster better communication and coordination between healthcare professionals to avoid miscommunications and delays in treatment.

9. Limitations of the research

- **Limited Insight from Other Professionals in the Team**: The research did not involve interviews or insights from other professionals within the cleft care team, for example orthodontics, nursing and social workers. It would have added to more depth of the research.
- **Geographical limitations:** this study is confined to Addis Ababa and did not include opinions of healthcare professionals and parents residing in other places which might have added more depth in its findings.

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Appendix 1: Interview Guides

1.1 Interview Guide for Parents

I. Demographic information

1. Name
2. Age
3. Sex
4. Religion
5. Place of residence
6. Occupation
7. Family size
8. Name of your child
9. Age of your child
10. Dignosis of your child

II. Main interview questions

1. How do you first find out about your child's condition?
2. How the process of your child being referred to yekatit 12 Medical College?
3. What services did they you receive in the hospital after a referral?
4. Can you tell you what you've been told about your child's condition at the hospital?
5. Do you feel that the questions you had at that point were answered adequately by the health professionals?
6. How important do you think emotional support is for parents with children born with cleft lip and palate?
7. What emotional support have you received from the health professionals at the hospital?
8. Can you describe to me the types of treatments that your child received in the hospital?
9. Are you satisfied with the follow-up and appointment methods at the hospital?
10. Is there a gap you saw while attending the hospital for your child's treatment?
11. Is there any other support that you've received besides the hospital's treatment?
12. How do you describe your relationship with the different professionals in the team?
13. How do you describe the coordination of medical delivery within the team?
14. Can you share any positive or negative experiences you have with the team?
15. Can you express your level of satisfaction with the treatments you provide at the hospital?
16. Based on your experience, can you share any recommendations or changes you suggest in the Cleft Care Service at yekatit 12 medical college?

ለወላጆች የ ቃለ ማጠይቅ መመሪያ

1. አጠቃላይ ሚጂ

1. ስም
2. ዕድሜ
3. ፆታ
4. ሃይማኖት
5. የ መኖሪያ ቦታ
6. ሥራ
7. የ ቤተሰብ ማጠን
8. የ ልጅዎ ስም
9. የ ልጅዎ ዕድሜ
10. የ ልጅዎ ዲግኖሲስ

2. ዋና የ ቃለ ማጠይቅ ጥያቄዎች

2 ስለልጅዎ ከነ ፈር ወይምላንቃ ሁኔታ መጀመሪያ እንዴት አወቁ?

3 ለልጅዎ ወደ የ ካቲት 12 ሜዲካል አንዴት ነ በር ሪፈር የ ተደረጉት?

4 ሪፈራል ከተደረገ በኋላ በሆስፒታል ወስጥ ምን አይነ ት አገ ልግሎቶችን አገ ኙ?

5 በሆስፒታል ወስጥ ስለልጅዎ የ ተነ ገ ሮትን ሊነ ግሩ ኝ ይችላሉ?

6 በዛን ወቅት የ ነ በሮት ጥያቄዎች በጠፍ ባለሙያዎች በበቂ ሁኔ ታእንደተመላሱ ይሰሙታል?

7 ለነ ዚህ ልጆች ወላጆች ስሜታዊ ድጋፍ ምን ያህል አስፈላጊ ነ ውበለውያስባሉ?

8 አርሶ ስ በሆስፒታሉ ባሉ ጠፍ ባለሙያዎች ምን አይነ ት ስሜታዊ ድጋፍ አግኝተዋል?

9 ልጅዎ በሆስፒታል ወስጥ ያገ ኘወን/የ ገ ኘችወን የ ህክምና ዓይነ ቶች ሊገ ልፀልኝ ይችላሉ?

10 በሆስፒታሉ ወስጥ በሚሰጠውቀጠሮ አሰጣጥ አና ክትትል ረክተዋል?

11 በሆስፒታሉ ወስጥ ለልጅዎ ህክምና ሲከታተ ሉ ያዩት ከፍተት አለ?

12 ከሆስፒታሉ ከሚሰጠውሕክምና ወጪያገ ኙት ሌላ አርዳታ አለ?

13 በቡድኑ ወስጥ ካሉ ልዩ ልዩ ባለሙያዎች ጋር ያለዎትን ግንኙነ ት እንዴት ይገ ልጹታል?

14 በቡድኑ ወስጥ ያለወን የ ህክምና አሰጣጥ ቅንጅት እንዴት ይገ ልጹታል?

15 ከቡድን ኑ ጋር ያጋጠሙዎትን ማነኛወንምአወንታዊ ወይምአሉታዊ ልምዶችን ሚጋራት ይችላሉ?

16 በሆስፒታሉ ወስጥ በሚሰጠዎት ህክምናዎች የ እርካታዎን ደረጃ መግለጽ ይችላሉ?

17 ካጋጠሙዎት ልምድ በማ ሳት በየ ካቲት 12 ሜዲካል ኮሌጅ በሚ ኘውየ ከላፍት እንከብካቤ አገ ልግሎት ላይ ማሻሻያዎችን ወይም ለወጦችን ማካፈል ይችላሉ?

1.2 Interview guide for speech therapists

II. Demographic information

1. Name
2. Age
3. Sex
4. Level of education
5. Occupation
6. Year of experience

II. Main interview questions

1. When do you first see the child with cleft lip and palate for initial evaluation?
2. Can you tell me about the topics you cover during counseling for parents?
3. How is emotional support provided for parents of these children?
4. At what age do you consider providing speech therapy services for these children?
5. How many sessions do you see patients with cleft lip and palate conditions per week?
6. What are the main speech therapy techniques you use for these children?
7. What is your opinion on blowing exercises and oral motor exercises for children with cleft lip/palate?
8. Have you encountered any challenges in providing speech therapy services for these children?
9. What do you think is the role of parents who are bringing their child to speech therapy services?
10. How do you communicate with parents about their child speech therapy progress?
11. What kinds of supports are available at the hospital for parents with children with cleft lip/palate?
12. What challenges do you think there is for parents in accessing care at the hospital?
13. Can you tell me the role of charitable organizations in the treatment cleft lip/palate conditions?
14. Who are the members of the multidisciplinary team at the hospital?
15. Can you tell me how the multidisciplinary team works in the hospital?
16. Who sets appointments and coordinates patients to be looked by the team?
17. How do communicate with the other team members regarding your patient? For surgical management? For orthodontic care?
18. What do you feel like are the strength and weakness of the team?
19. Are you satisfied with how the team works?
20. Do you have any recommendations on how to improve the team in the future?

የ ንግግር ቴራፒስቶች የ ቃለ ማጠይቅ መመሪያ

1. አጠቃላይ ሚጃ

1. ስም

2.እድሜ

3. ፆታ

4. የ ትምህርት ደረጃ

5. ሥራ

6. ልምድ ዓመት

2. ዋና የ ቃለ ማጠይቅ ጥያቄዎች

1. ለአንድ ከንፈር አና ላንቃ መሰነ ጥቅ ላለውልጅ የ መጀመርያወን የ ንግግር እና ለቋንቋ ግምገማበሰንት ዓመቱ ላይ ያደረጋሉ?
2. ለልጃቸው ከትትል ለሚሳጡ ወላጆች ምክር አገለግሎት በሚሰጡ ጊዜ የሚፍፍኗቸወን ርዕሰ ጉዳዮች ልትነግሩኝ ትችላላችሁ?
3. የ እነዚህ ልጆች ወላጆች ስሜታዊ ድጋፍ እንደሚየስፈልጋቸው ይሰሙታል? እንዴት ነው ሰሜታዊ ደጋፍ የ ምያረጉላቸው?
4. ለእነዚህ ልጆች የ ንግግር ሕክምና አገልግሎት ለመሰጠት በየ ትኛውዕድሜላይ ያስባሉ?
5. የ ከንፈር መሰንጠቅ እና የ ላንቃ ችግር ያለባቸወን ለጆች በሳምንት ስንት ጊዜ ቴራፒ ይሰጣሉ?
6. ለእነዚህ ልጆች የ ሚጠቀመሳቸውዋና ዋና የ ንግግር ሕክምና ዘይዎች ምንድን ናቸው?
7. ከንፈር/ላንቃ መሰንጠቅ ላለባቸው ልጆች የ አየር መንፋት እና የ አፍ ስፖርት ሕክምናን በተመለከተ የ እርስዎ አስተያየት ምንድን ነው?
8. ለእነዚህ ልጆች የ ንግግር ሕክምና አገልግሎት በመሰጠት ረገድ ምንምዓይነት ፈተናዎች አጋጥመውዎታል?
9. ልጃቸወን ወደ የ ንግግር ሕክምና አገልግሎት የ ሚያመጡወላጆች ኃላፊነት ምንድን ነው?
10. ስለ ልጃቸውየ ንግግር ሕክምና ሂደት ከወላጆች ጋር እንዴት ይነጋገራሉ?
11. ለወላጆች በሆስፒታሉ ወስጥ ምን አይነት ድጋፎች አሉ?
12. በሆስፒታሉ ወስጥ ሕክምና ለሚያገኙ ወላጆችስ ምን ዓይነት ፈተናዎች አሉ ብለውያስባሉ?
13. በሆስፒታሉ ወስጥ ለከነፈር አና ላንቃላላቸውልጆች ህክምና የ ሚሰጡውቡድን አባላት እነማን ናቸው?
14. ሰለቡደኑ አሰራር ልያብራሩልኝ የ ችላሉ?
15. ቡድኑ ምን ያህል ጊዜ ይገናኛል?
16. ቀጠሮዎችን የ ሚያዘጋጅ እና ታካሚዎችን በቡድኑ እንዲታዩ የ ሚያስተባብር ማነ ው?
17. ታካሚን በተመለከተ ከሌሎች የ ቡድን ሞመራት ቢፈለጉ እንዴት መገናኘት ይቻላል? ለቀዶ ጥገና ወሳኔ ? ለኦርቶዶቲክ እንክብካቤ?
18. ሰለቡድኑ ጥንካሬ እና ድክመት ሊነግሩኝ የ ቸላሉ?
19. አርሶስ በቡደኑ አሰራር ረከተዋል?
20. ወደፊት ቡድኑን እንዴት ማሻሻል እንደሚቻል ላይ ምንምምክሮች አሉዎት

1.3 Interview guide for surgeons

II. Demographic information

1. Name
2. Age
3. Sex
4. Level of education
5. Occupation
6. Year of experience

II. Main interview questions

1. When do you usually first see the child with cleft lip and palate for initial evaluation?
2. Can you tell me about the topics you cover during counseling for parents?
3. How is emotional support provided for parents of these children?
4. When is surgery done for these children at the hospital?
5. How often is there follow up process for these children?
6. What challenges do you think there is for parents in accessing care at the hospital?
7. What are the main challenges in providing surgery for these children?
8. What do you think is the responsibility of parents who are bringing their child for surgery?
9. What kind of supports is available at the hospital for parents with children with cleft lip/palate?
10. What challenges do you think there is for parents in accessing care at the hospital?
11. Who are the members of the multidisciplinary team at the hospital?
12. Can you tell me how the multidisciplinary team works in the hospital?
13. Who sets appointments and coordinates patients to be looked by the team?
14. How do communicate with the other team members regarding your patient? For speech therapy? For orthodontic care?
15. What do you feel like are the strength and weakness of the team?
16. Are you satisfied with how the team works?
17. Do you have any recommendations on how to improve the team in the future?

የቀዶ ጥገና ሐኪሞች የቃለ መጠይቅ መመሪያ

1. አጠቃላይ መረጃ

1. ስም
2. ዕድሜ
3. ፆታ
4. የትምህርት ደረጃ
5. ሥራ
6. ልምድ ዓመት

2. ዋና የቃለ መጠይቅ ጥያቄዎች

1. ከንፈር እና ላንቃ ለተሰነጠቀ ልጅ የመጀመሪያ ግምገማ መቼ ነው የሚሰሩት?
2. ስለልጃቸው የምርመራ እና የሕክምና ዕቅድ ለወላጆች ምን ርዕሶችን ይሸፍናሉ?
3. ለእነዚህ ልጆች ወላጆች (በቀዶ ጥገናው ዙሪያ) ስሜታዊ ድጋፍ የሚሰጠው እንዴት ነው?
4. በሆስፒታል ውስጥ ለእነዚህ ህጻናት ቀዶ ጥገና የሚደረገው መቼ ነው?
5. ከንፈር እና ላንቃ ለተሰነጠቀ ህጻናት የምታደርጓቸውን ልዩ የቀዶ ጥገና አይነቶች መግለፅ ይችላሉ?
6. ለነዚ ለጆች ምን ያህል ጊዜ ክትትል ይደረግላቸዋል?
7. ለእነዚህ ህጻናት ቀዶ ጥገና አቅርቦት ላይ በተመለከተ የገጠሞት ችግር ወይም ያዩት ክፍተት አለ?
8. ልጃቸውን ለቀዶ ጥገና የሚያመጡ ወላጆች ምን ኃላፊነት አለባቸው ብለው ያስባሉ?
9. ከንፈር/ላንቃ የተሰነጠቀ ልጆች ላሏቸው ወላጆች በሆስፒታሉ ውስጥ ምን ዓይነት ድጋፎች አሉ?
10. በሆስፒታል ውስጥ እንክብካቤን ለማግኘት ለወላጆች ምን ችግሮች አሉ ብለው ያስባሉ?
11. በሆስፒታሉ ውስጥ የመድብለ ዲሲፕሊን ቡድን አባላት እነማን ናቸው?
12. ሁለገብ ቡድን በሆስፒታል ውስጥ እንዴት እንደሚሰራ ልትነግሩኝ ትችላላችሁ?
13. ቀጠሮዎችን የሚያዘጋጅ እና ታካሚዎችን በቡድኑ እንዲታዩ የሚያስተባብር ማነው?

14. ታካሚዎን በተመለከተ ከሌሎች የቡድን አባላት ጋር እንዴት ይገናኛሉ? ለንግግር ሕክምና? ለኦርቶዶቲክ እንክብካቤ?
15. የቡድኑ ጥንካሬ እና ድክመት ምን ይመስላል?
16. ቡድኑ እንዴት እንደሚሰራ ረክተዋል?
17. ለወደፊት ቡድኑን እንዴት ማሻሻል እንደሚቻል ላይ ምክሮች አሉዎት?