Journal of Science and Sustainable Development (JSSD), 2026, 14(1), 44-59

ISSN: 2304-2702 (print); 2414-4479 (online)
DOI: https://doi.org/10.20372/au.jssd.14.1.2026.0712

RESEARCH PAPER

The Quality of Cleft Care Services at a Tertiary Cleft Care Center in Addis Ababa

Tsion Girma[1*], Alemayehu Teklemariam[2] and Mekonen Eshete

[1]*MD, Speech and Language Therapist;*

[2]*PhD, Professor, Department of Special Needs and Inclusive Education, Addis Ababa University*

[3]*PhD, Professor, Department of Surgery, Addis Ababa University*

***Corresponding Author:** alemayehutmh62@gmail.com*

Abstract

This study explores the quality of cleft care provided at Yekatit 12 Hospital Medical College, the only government hospital in Ethiopia offering comprehensive cleft care through a multidisciplinary team. Although reconstructive surgery addresses feeding and aesthetic issues, functional issues such as speech difficulties, dental problems, hearing loss, and psychosocial problems can still persist without ongoing care, particularly speech and language therapy. The study aims to investigate participants' opinions concerning the quality of care in children with speech and language disability. Employing a qualitative case study methodology, the study collected data from two plastic surgeons, two speech and language therapists, and three parents of children being treated, using semi-structured interview guide. The results show that the hospital delivers cleft care services comprehensively, following proper timelines for initial assessment, surgery, and speech therapy. Nevertheless, delays in primary lip surgeries were observed, mainly on the grounds of weight eligibility criteria. Several challenges were also observed, such as a lack of proper resources, shortages of manpower, particularly in speech therapy and nutrition, poor documentation, and language barriers. Despite these challenges, participants commended the hospital's commitment to providing holistic cleft care with the aid of non-governmental charities. Suggestions for improving the quality of care are enhanced diagnostic equipment, adding more professionals to staff, expanding hospital capacity, and creating stronger local support networks. Addressing these could improve Yekatit 12 Hospital's response to the diverse needs of children with clefts, enhance the effectiveness of care, and improve long-term results. These Enhancements would help to improve the hospital's capacity to continue its critical activity in cleft care and rehabilitation.

Keywords: Cleft Care, Language, Speech, Surgery, Therapy

Introduction

Cleft lip and/or palate (CL/P) is a prenatal birth defect that occurs during early pregnancy, typically between the 5th and 12th weeks. By this time, the tissues employed to form the lip and the roof of the mouth (the primary and secondary palates) is supposed to fuse. If the fusion is disrupted, it can lead to a cleft lip, cleft palate, or both (Neiswanger *et al.*, 2020).

Children with CL/P generally face a wide range of issues. Some of those are problems related to feeding, frequent ear infections, hearing impairment, delayed speech, dental abnormalities, and social and emotional challenges. Because all of these factors impact many areas of development, children with CL/P need comprehensive care by an interdisciplinary team of specialists in different fields (Lee *et al.*, 2014). Yet, in countries like Ethiopia, this sort of full care is well out of reach. The biggest gap of trained speech and language therapists means that it becomes harder to cope with long-term communication issues.

Globally, cleft conditions affect approximately 4.5 per 10,000 live births (Salari and Mousavi, 2022). In Ethiopia, they are quite uneven. In 2011, a study in Addis Ababa put the rate at around 1 in every 672 births (Eshete *et al.*, 2011) based on a small sample across seven hospitals, though this has since been outdated by more recent, national figures from Smile Train estimating 4.4 per 10,000 births, which is nearer international rates. According to their findings, isolated clefts (that is, on one side of the palate or lip) are more common than bilateral clefts (Eshete *et al.,* 2017).

The impact of CL/P is not just physical, as the easily observable facial asymmetry might suggest. Even after surgery to repair the cleft, many children also have speech and emotional challenges. Stigma and discrimination are prevalent, which can create a feeling of loneliness or low self-esteem. Hence, surgery alone is not enough. CL/P children need long-term, multi-disciplinary management including not just surgery and dental interventions, but also psychological counseling and speech therapy to make them healthy again (Hodgkinson *et al*., 2005).

The ideal cleft care team includes a diverse range of specialists like plastic surgeons, orthodontists, ENT doctors, audiologists, speech therapists, pediatricians, nurses, nutritionists, psychologists, and social workers (Shaye *et al*., 2015). With coordination, the team tackles the complete spectrum of medical and psychological problems that CL/P children and their families are faced with. But in Ethiopia and in most other low-income nations, such teams are not the rule because trained staff and few healthcare facilities are lacking.

The American Cleft Palate-Craniofacial Association (2010) recommends that every cleft team must consist of at least three major specialists: a plastic surgeon, an orthodontist, and a speech-language pathologist. Mental health professionals are also critical in addressing long-term psychosocial concerns (Chawla *et al.,* 2023).

International medical missions have played a crucial role in providing cleft care in places like Ethiopia. Organizations such as Operation Smile, Resurge International, and Smile Train offer free surgeries for poor children. Between 2007 and 2023, Smile Train alone funded over 35,700 procedures in Ethiopia (Smile Train, 2023), giving thousands of children a healthier, brighter future. These procedures have not only helped with feeding and looks but also with improving children's access to education and social integration (Fell *et al*., 2014).

Cleft care indirectly aligns with national health priorities like maternal and child health, essential surgical care, and movement toward universal health coverage. However, specific national policies related to cleft conditions are few; hence, the introduction presents only brief linkages. The weak linkage reflects the fact that cleft care is not overtly emphasized in national strategies; thus, making strong policy linkages in the introductory section is difficult.

It isn't all good, though. Not many children receive surgery but no or limited follow-up. Essentials like dental care, speech therapy, and psychosocial counseling are often missing (Smith *et al.*, 2023).

More recently, attention has shifted towards building permanent solutions. One of these avenues is educating Ethiopian health care professionals and organizing multidisciplinary cleft centers in Ethiopia. These centers promise to provide sustained care instead of being short-term missions (Lee *et al*., 2014).

A prime example is the cleft team of Yekatit 12 Hospital Medical College in Addis Ababa, the only government hospital in Ethiopia that offers comprehensive multidisciplinary cleft care. Formalized in 2003 with the aid of Norway's Bergen Cleft Team and other organizations like Smile Train and Transforming Faces, Yekatit 12 has brought together surgeons, ENT specialists, orthodontists, pediatricians, speech therapists, and other professionals (Eshete *et al*., 2017; Gebremichael *et al.,* 2021).

However, Ethiopia is still yet to have enough trained specialists, especially in speech-language therapy. Encouragingly, the country's first Master's program in Speech and Language Therapy will produce its first graduates in 2024, which could be the turning point for national cleft care services (Assefa *et al*., 2023).

This study will explore Yekatit 12 Hospital's multidisciplinary cleft care model in considerable detail. It aims to identify the strengths and weaknesses of the current system and provide recommendations for care, training, and policy improvement. Its final goal is to help provide that every Ethiopian child born with a cleft receives the complete support they need to have a full and healthy life. More specifically, this study is important because it addresses a major gap in evidence related to the quality of cleft care in Ethiopia, and the findings bring context-specific information that might enable clinical improvements, resource allocation, and better intervention outcomes. It also provides data useful for developing national guidelines, strengthening referral systems, and informing broader health-policy decisions. Its significance may not be clearly articulated in the original work because the authors mainly reported findings, had limited space or training in framing implications, or they presumed the importance of the topic was already obvious.

Research Problem

The core problem is that there is no comprehensive understanding of the current quality of multidisciplinary cleft care at Yekatit 12 Hospital, which is the only government center providing comprehensive cleft services. The present study aimed to investigate how the care was being delivered, how services were accessed by families, and what challenges impeded the effectiveness of the system of care. This study assesses several important dimensions of the quality of care from participants' perspectives, including the accessibility of services, coordination among the multi-disciplinary professionals, and communication with the families, continuity of care, and the overall patients' and parents' experiences. While some aspects of treatment outcomes may be discussed in an indirect fashion, the focus will be on a process-related and experience-based understanding of cleft care rather than the measurement of clinical outcomes.

The specific research gap is that there is a lack of qualitative, in-depth studies on how multidisciplinary cleft care is organized, delivered, and experienced at Yekatit 12 Hospital, the only government facility in Ethiopia that provides comprehensive cleft services. Past Ethiopian studies have mainly focused on epidemiology, surgical outcomes, prevalence rates, or data from NGO-supported interventions but have not explored how care teams function, how parents navigate services, or what challenges providers face in providing coordinated, long-term care. Similarly, studies from comparable low-resource settings often report numbers of surgeries performed, barriers to access, or lack of training but rarely examine the quality of multidisciplinary practice, team communication, follow-up care, or patient-family experiences. Previous research therefore has failed to address process and experience dimensions of cleft care, which the present study seeks to fill with its qualitative exploration.

With such gaps, there is a need to analyze the quality of care at Yekatit 12 Hospital Medical College to improve the outcomes for children with CL/P. Although the condition is well-recognized in Ethiopia, there has been no systematic research examining the multidisciplinary care model within this specific healthcare setting. This study seeks to fill these gaps by exploring the practices, experiences, and challenges faced by key healthcare professionals, particularly reconstructive surgeons and speech therapists, within the multidisciplinary team, while also incorporating insights from parents of children receiving treatment at Yekatit 12 Hospital.

The problem identified-the lack of a systematic understanding of how multidisciplinary cleft care functions at Yekatit 12 Hospital-influences the objectives and research questions directly. Since the problem has centered on coordination gaps, issues on accessibility, and how the teams function, then the objectives have focused on how care is delivered, what services families are able to access, and the challenges experienced by both providers and parents. Therefore, each objective corresponds to a gap outlined in the problem statement; there is coherence in alignment from the problem to the research questions to the overall purpose of the study. The primary objective of this study is to explore participants' perspectives on the quality of care by addressing the following fundamental research questions:

Research questions

1. How do multidisciplinary teams at Yekatit 12 Hospital coordinate and deliver comprehensive cleft care?
2. How do parents experience accessibility, communication, and support throughout their child's care journey?
3. What barriers affect effective collaboration among professionals and patient-centered outcomes

Materials and Methods

Study Setting

The study took place at the Cleft Care Unit of the Yekatit 12 Hospital Medical College in Addis Ababa, Ethiopia. Established in 1923, Yekatit 12 is a highly ranked hospital in Ethiopia, and in 2003, the hospital established a special cleft care unit to provide specialized treatment to children who are born with cleft lip and/or palate. The unit operates on a holistic team approach, with professionals such as surgeons, anesthesiologists, nurses, pediatricians, ENT specialists, dentists, orthodontists, social workers, and speech therapists. The professionals collaborate in delivering patient-focused, integrated care. Yekatit 12 Hospital was purposively chosen because it is the only hospital in the area that has admitted and treated a large number of patients with cleft conditions, making it the most relevant setting for this study. Its status as a major referral hospital, along with its accessibility, institutional support, and availability of participants, also made it suitable for in-depth qualitative inquiry.

Study Design and Approach

The study utilised a qualitative case study design, whose aim was to explore how care is delivered within Yekatit 12's cleft unit. The case study method was employed to facilitate an in-depth contextual understanding of what quality and type of care is shaped by the real experiences of the stakeholders. According to Gustafsson *et al*. (2017), case studies yield lessons that are applicable elsewhere under similar situations.

Participants

Seven participants were recruited purposefully in connection with the research study. Among them were two plastic surgeons and two speech-language therapists who are involved in the cleft care team. Three parents of children who are receiving treatment within the cleft unit of the hospital were also recruited. Participants were recruited using purposive sampling to ensure that their experiences could illuminate the care process.

Inclusion Criteria

Eligible parents for the study were the child's primary caregiver, lived with the child throughout from birth, and had a child with cleft lip and palate or isolated cleft palate. They also needed to understand Amharic and be undergoing treatment at Yekatit 12. For the professional group, plastic surgeons were included if they had at least five years of experience in cleft surgery in the hospital multidisciplinary team, and speech therapists if they had three years' experience with children and cleft-affected families.

Data Collection

Interviews

The primary data-collection tool was semi-structured interviews to obtain intensive insight from all the groups involved. Interview guides were developed based on the 2017 American Cleft Palate and Craniofacial Association guidelines and customized separately for surgeons, therapists, and parents. Though written in English initially, all guides were translated into Amharic for understanding.

Concerns addressed included medical procedures, counselling, emotional support, inter-professional teamwork, and challenges of receiving and providing care. Interviews were conducted in quiet, reclining areas and lasted 45 to 60 minutes. They were recorded by sound (with consent) in the interests of precision. The investigator explained the purpose of the study and promised anonymity and freedom to withdraw at any moment to participants before initiating.

Data Analysis

The interviews were conducted in Amharic, translated into English, and thematically coded. The emerging themes were the quality of cleft care, team working, challenges, and recommendations for improvement, where the findings are generalized only for this sampled hospital. Since the study was conducted in one hospital, findings will not be generalized to all healthcare settings. This is also in line with qualitative research, which, instead of striving for broad generalization, aims for depth. The results bring context-specific insights that are transferable to similar settings, although their applicability does depend on how similar other hospitals are to this study's context.

Ethical Considerations

Ethical permission for the research was acquired from Addis Ababa Public Health Research and Emergency Management office and a cooperation letter from Addis Ababa University. Informed consent was obtained from all respondents, and all attempts were made to protect their identities and uphold ethical practices in the research exercise.

Results

Background Information

The following tables provide the background information of healthcare professionals and parents involved in the study. To maintain confidentiality, anonymous names have been used for all participants. The findings first explored the experiences of healthcare professionals followed by a detailed examination of parents' experiences.

Table 1. Background Information of Healthcare Professionals

No.	Name	Profession	Years of Experience	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
4	Helen	Speech and Language Therapist	4 years	4 years

From table 1. above, the team consists of two plastic and reconstructive surgeons and two speech and language therapists. The two surgeons, Dr. Abebe and Dr. Tilahun, have 15 years' experience each. Dr. Tilahun has been part of the multidisciplinary team all 15 years, whereas Dr. Abebe has been in the team for 10 years. In contrast, speech therapists Dereje and Helen are much younger in terms of profession, both with 4 years' experience, but all within team work. This suggests a strong teamwork culture within professional roles, with new professionals brought in early on to team-based practice. While the surgeons bring long experience and stability, the therapists may likely bring new learning and styles. In total, the team appears to be balanced in role, with a clear gap across the careers in terms of years. This also offers possibilities for mentoring and continuous team development.

Table 2. Background Information of Parents

No.	Parent's Name	Age	Religion	Residence	Marital Status	Child's Sex	Child's Age	Diagnosis
1	Seada	34	Muslim	Addis Ababa	Married	Male	8 years	Unilateral cleft lip and palate
2	Wubalem	30	Protestant	Addis Ababa	Separated	Female	11 years	Bilateral cleft lip and palate
3	Senayit	25	Orthodox	Oromia Region	Married	Male	5 years	Unilateral cleft lip and palate

The data given in Table 2 contain information from three mothers who have children with cleft conditions. The three mothers are females aged between the age bracket of 25-34 years, belonging to various religious affiliations (Muslim, Protestant, and Orthodox) and residing either in Addis Ababa or within the Oromia Region. Two of them are married, but one is separated. Their children, aged 5-11 years, have unilateral or bilateral cleft lip and palate. Two of the children have unilateral cleft lip and palate (one male child aged 8, and another male child aged 5), and one female child aged 11 has bilateral cleft. This shows religious, marriage, and residence diversity in the background of parents, and shows that both genders and all age groups are impaired by cleft conditions.

Patient care

All of the four health professionals in Yekatit 12 Hospital Medical College agreed that parents who deliver a child with a cleft lip and palate are welcomed by a medical staff member on their initial visit. Helen, a speech and language therapist commented as follows, *"Their initial contact is with the coordinator nurses and the social worker. Parents receive very important counseling on feeding their child, weight gain, and pre-op counseling about future surgeries."* They talk about breastfeeding problems, stating that babies struggle to suck breast milk because intra-oral pressure is reduced from the cleft palate. The parents need to feed the baby at frequent intervals but less frequently, bottle-feed and give wider nipples, and after each feeding, the parents need to burp the baby. Three health workers stressed that treatment is not limited to surgery alone. Dr. Abebe highlighted, *"We also tell parents that treatment is long-term follow-up and that surgery is only part of the process."*. As the child grows, they may need more of these services, such as speech therapy, ENT care, orthodontic services, and psychological services."

All four practitioners agreed that the social worker in the multidisciplinary team provides most of the emotional support to the parents. Three of them also noted that, as much as the social worker has a key position, it is also important that other members of the healthcare team provide emotional support during each contact too. The social worker facilitates and organizes group sessions where parents exchange experiences, offer mutual support, and learn from one another. Helen highlighted that the intervention of the social worker is very crucial given the intense emotional pain that parents undergo.

When the maternity unit was inside the hospital, the parents would come to the team distressed and shocked. Having gone through the ordeal of labour pain, seeing such a delicate state for their child was extremely hard for them. In order to comfort them, the social worker showed them pictures of children before and after the surgery to indicate to them that the condition is curable.

Counselling and emotional support are clearly invaluable. The majority of parents face challenging situations like divorce or break-up, most often because they lack knowledge. Dereje substantiated this, saying, *"We are committed to offering counselling and emotional support for parents, from the time they come into hospital and through all their time, all the way through into adulthood."* Two other professionals reported that parents are reassured during counselling that the treatment is free, relieving anxiety.

Surgical Services

Surgery is the main treatment for children born with cleft lip and palate. Before proceeding with surgery, both surgeons stressed how important it is to inform parents about the correct timing of the operation and the part they play in getting their child ready.

Dr. Tilahun explained,
'*Parents typically wish for the procedure to be performed as soon as they reach the hospital. However, it should be explained to them that the child must first be prepared well for surgery. Parents should be educated regarding feeding the child properly so that they can achieve adequate weight before surgery*.'

Both surgeons noted that parents are very motivated to follow medical advice because they want the best for their child. They explained that for a child to qualify for the first operation, the child should weigh at least 10 pounds (4.5 kg), have a hemoglobin level of 10, and be free of any infection. However, some special cases would require special attention. Dr. Tilahun was keen to note how important it is for the child to be infection-free before surgery. In case the child develops an infection, parents are required to access help from local health centers, given that the majority of the families live in rural areas. For advanced health complications, families are encouraged to take the child to the hospital directly. Malnutrition or infections are usually treated by pediatricians as part of a comprehensive care team.

Regarding timing of procedures, both surgeons explained that lip repair is usually done at around 3 months of age, if the baby is suitable. Palate repair is usually 9 to 12 months, though Dr. Tilahun mentioned it can sometimes be done at 6 months. They both confirmed that there have been dramatic improvements year by year in the quantity of specialists employed and when the surgeries are performed compared to the past.

"About 20 years ago, there was just one plastic surgeon, and cleft surgeries were done mainly by charity missions. Then, most of the patients were adults, some even 70 years old, since most people did not know that these surgeries existed. But in recent years, awareness has picked up considerably, and now parents bring their babies to us as soon as they are born. Hospitals also refer these cases to us promptly."

Historically, lip surgery used to be done most frequently at six months, but now with better anaesthesia care, it may be safely done at three months. Palate surgeries also continue to be usually done at around twelve months in outreach settings. Secondary surgeries were also mentioned by the surgeons and were further elucidated by Dr. Abebe.

"We perform a range of operations on children born with cleft lip and palate. They can have other operations on noses and lips before they attend school, trying to avoid teasing and other issues like teething. By the time they are around eight years old, we can perform an operation called alveolar bone grafting if needed. Even as adults, some patients may require surgery if they feel embarrassed. When problems like a fistula or negative speech outcomes occur, speech surgery can be recommended by speech therapists."

Speech therapy services

Both speech therapists described the process whereby, when they first see a child and his parents, they begin to give them early language stimulation advice, advice that continues until the child is three years old. Helen highlighted the significance of such early input, reporting, *"'We advise parents on spending enough time with the child, talking to their child, babbling and cooing. We also check up on the child every five or six months to see how they are doing and offer further advice."*

Dereje also placed great importance on getting parents involved early on. He stated they help parents understand what to expect in the child's communication development and how to facilitate it. Check-ins are done every few months to track speech milestones and provide further guidance.

At the age of three, a more formal speech assessment is done to measure how well the child speaks, also articulation and resonance. When there are problems, therapy sessions are arranged as needed by the child. Dereje explained, *"'Therapy sessions are offered 2–4 days a week, depending on the level of severity, with at least two sessions a week,'" and Helen also added, 'Ideally, it would be three times a week, but due to availability, it can be reduced to once a week.'"*

With regard to the therapy procedures, both therapists noted that oral motor activities are not usually used with cleft lip and palate children unless complications are involved. They, however, differ in using blowing exercises. Helen does not use them at all but focuses on articulation, while Dereje uses blowing to help in efficient production of sounds, explaining, *"I place a soft tissue in front of them and make them blow on it as they are uttering B and P."*

Both speech therapists stressed the need to include parents in the therapy. They told us that parents would have to come in for sessions, while some would prefer waiting outside. However, they pointed out how necessary it is for parents to help not just in terms of attending sessions but even at home by practicing daily exercises with their child. This effort greatly aids the child in improving. They also talked about the difficulties in reaching continuous therapy in Addis for kids from remote places. To fit around them, they've created flexible solutions. Helen explained one of these ways:

"We offer a seven-day stay in a fully catered hotel, where accommodation and meals are provided, for children and families. Funded by Transforming Faces, the program consists of intensive speech therapy sessions twice a day, morning and afternoon, for five consecutive weekdays, during school holidays."

The Multidisciplinary team

It was stressed by all the healthcare professionals that a multidisciplinary team plays a very crucial part in cleft lip and palate children's care. Members include ENT surgeons, plastic surgeons, social worker, pediatrician, speech therapists, orthodontists, nurse coordinators, and anesthesiologists. They have a monthly meeting on the last Wednesday, where all shares feedback and discusses cases, particularly the complex ones. Thus, it guarantees coordinated, comprehensive care. Dereje further explained how such meetings help in team working and a successful treatment plan for every child.

"For example, if a child's speech isn't improving with regular 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 assess whether surgery is the most appropriate course of action for the patient."

Additionally, patients with cleft lip and palate are evaluated at a cleft clinic held every Wednesday, as noted by Dr. Tilahun and other healthcare professionals. During these clinics, patients are seen by the appropriate team members based on their age and specific needs. Outside of formal team meetings, the members stay in regular contact to make sure any concerns about patient care are addressed quickly. They coordinate with each other as needed, arranging consultations or referrals without delay. As Helen put it,

“*We do not always wait for the team meetings. If I believe a patient needs immediate attention, whether it’s related to their surgery or an* *emergency, I'll connect them directly with the available plastic surgeon. Likewise, if I suspect an ear infection or hearing issues, such as the child not responding properly during sessions, I'll promptly refer the child to an ENT specialist.*"

Strength and weakness of the team

At Yekatit 12 Hospital Medical College, four healthcare professionals shared their views on the strengths and challenges of the cleft multidisciplinary team, revealing both positive aspects and areas for growth. Dr. Tilahun appreciated the team's strong relationships and smooth communication but noted some drawbacks, like missing reports and occasional delays or absences during meetings. Dr. Abebe described the team as resilient, saying, *"It's a strong team; this strength is why it's still standing here after all these years."* He also mentioned the need for more professionals, including speech therapists and social workers. Helen, a speech and language therapist, highlighted the team's effective communication around patient care, stating, *"The strength is the communication within the team, which helps the patient receive good care,"* and recommended hiring a full-time nutritionist. Dereje, another therapist, valued the hospital's holistic approach and faster treatment timelines but emphasized the importance of having more in-person training alongside webinars: *"Most of the professional development training we receive is through online webinars, which is helpful. However, it would be beneficial to have in-person training as well."*

Barriers to cleft care services

There are several challenges that come with accessing cleft care services, including distance, security concerns, lack of support, and the long treatment process. Geographic distance was among the biggest challenges pointed out by all four healthcare workers interviewed. The majority of the families live in rural areas where local care facilities simply don't exist, so they must travel long distances to access specialized hospitals. This can be a great burden, especially for parents who have to leave work and balance other demands. *"There are no equivalent services in their villages,"* said one professional.

Other than the distance issue, two professionals were worried about safety in the face of conflict in the country. This has discouraged a number of families from traveling. Dereje, a speech therapist, shared, *"There's one child who had surgery for a cleft lip but didn't get their palate surgery due to the country's instability. Another child was undergoing treatment for an ear infection but didn't get their follow-up for the same reason."*

Three professionals also added that parents tend not to get much help from spouses or extended family members. Single mothers particularly have a hard time managing work and childcare. Two professionals also added that the caregiving process is long and exhausting, and regular visits to multiple specialists take a heavy emotional and physical toll.

Challenges

Health care practitioners are faced with a variety of obstacles that interfere with the delivery of adequate and timely care. Such obstacles include lack of resources, lack of well-trained personnel, poor capacity in hospitals, poor document structure, low level of public awareness, parental expectations, and linguistic differences. All these obstacles add to the system's burden as well as the people working within the system. One shared experience between all the interviewed health workers was that of shortage of resources. Dr. Abebe summarized this:

"We cannot confidently state that we have everything we require in terms of resources at present. Dental braces, for example, are extremely expensive, and we are compelled to cap the number of patients we can treat. Furthermore, essential surgery equipment, such as suture material, occasionally is not available in the market."

This shortage is not simply of equipment. Even basic assessment tools are not available. To give an example, Dereje stated: "The nasoendoscope equipment at our hospital has been non-functional since my initial employment here, effectively rendering it unusable for the past four years." Helen, a speech and language therapist, identified how this affects accurate diagnoses:

"Currently, our testing protocols for hyper nasality depend largely on subjective measures, i.e., judgment and mirror fogging observation. To have access to equipment like nasoendoscopy would be a huge difference. Apart from the inaccessibility of nasoendoscopes, audiometry instruments are also not available."

There is also a serious shortage of experts. Dr. Abebe explained: *"We are in dire need of more staff. The amount of work that is placed on the social workers and speech therapists is substantial, and their workload would be significantly reduced with the addition of more professionals."*

Helen went on to add that the availability of a permanent nutritionist would improve care: *"The advantage of having a dedicated nutritionist on staff would be huge. Having a nutritionist on staff, patients would most certainly get an improved quality of care."* Hospital capacity also enters the picture, in this case for scheduling beds for surgery. Aside from that, critical diagnostic procedures like echocardiography are not always available, which can postpone or exclude necessary surgical procedures. Documentation is also a concern. Dr. Tilahun said: *"To appropriately measure our progress, we must conduct strong research and earn global accolades for what we have achieved. Good documentation of high caliber is paramount."*

Low public awareness is also an obstacle. Dr. Abebe reported: *"There are cases where children have to undergo secondary operations but don't come in because of parents resisting."* Speech therapists reported similarly, that families misunderstand the purpose of therapy. Dereje reported*: "Most parents have the wrong notion that speech therapy is more of a speedy medical fix."* Helen explained why: *"Even with counseling, there are some parents who just don't realize how crucial speech therapy is. Speech-language pathology is still a new profession in the nation."*

The majority of parents are in a hurry to arrange for surgery on cosmetic grounds, but they tend to have unrealistic hopes. They are unaware that there is more than one operation and speech therapy involves effort and time. Ultimately, Helen also underlined language barriers as a key issue: *"Children are more likely to visit the clinic by utilizing numerous languages, Gurage, Selete, Afar, and Somali and the unavailability of qualified interpreters for such languages can make care and communication very difficult."*

Recommendations from Healthcare Professionals

In a bid to improve cleft care services, health professionals proposed upgrading the facilities, like the addition of Nasoendoscopes and audiometry equipment, to improve accuracy. Other proposals were the expansion of the care team to enable more comprehensive support and standardizing forms to track data and evaluate programs accordingly. Dereje particularly highlighted the urgent need for better equipment and facilities. Dr. Abebe also worried that the country relied too much on charities and called for stronger local funding; highlighting that long-term investment and community support are part of sustainable cleft care.

"The treatment of Cleft lip and palate currently depends heavily on charitable organizations. Without their support, these vital services would cease to exist. Organizations like Smile Train and Transforming Faces have even taken proactive steps to train healthcare professionals, including those pursuing Master's degrees in speech therapy. In the future, securing robust local support would be immensely beneficial. Local support would not only facilitate resource pooling and raise public awareness but also enhance the support provided to hospitals while simultaneously minimizing patient missed follow-ups due to a lack of awareness."

Parent's experiences at the hospital

Three mothers shared their experiences of raising children born with cleft lip and palate while they were undergoing treatment at the hospital. Wubalem, aged 30 and single, has four children and lives in the busy Merkato area of Addis Ababa, making a living by selling tea in the late evening. Her daughter is being treated at Yekatit 12 Medical College, aged 11. Seada, 34, is a homemaker of four from the Kara Kore neighborhood whose 8-year-old child was born with a unilateral cleft. Senayit, 24, from Mojo, Oromia, has a husband and two children; her youngest is 5 years old and also born with a unilateral cleft condition.

Parental Support

All three mothers discussed with appreciation the emotional support they had received from the healthcare team at the center, calling it a lifeline through one of the darkest and emotionally draining periods of their lives. Four-time mother Seada spoke openly about her experience:

“I got so much emotional support, principally from Betty. She actually made me go through what I was experiencing. I was so stressed out, and I just kept going to the centre just to ventilate. Betty was always there, advising, sharing her own experiences, and making me feel not so isolated. I don't really know how I would have managed without her. I'm so grateful."

Senayit also remembered the shock of her child's diagnosis, something completely new and frightening to her. She emphasized how the team's calm, reassuring manner kept her grounded during those first, uncertain days. For Wubalem, who is HIV-positive and struggling with treatment, the challenges were even more complicated. She was not only managing her child's illness but also her own health, single motherhood, and recent widowhood after the death of her husband.

"My baby was born with cleft lip and palate, and we were directly referred to Yekatit Hospital. I was in a very bad emotional condition, so they arranged regular visits with me. The care I got from the team and especially from Betty, Bizuayew, and Hirut, was just great. They made me strong when I had no strength to give. Their confirmation that my daughter's condition could be treated made me hopeful again."

Counseling for parents

All the mothers were provided with practical guidance on how to breastfeed, but they faced actual challenges in getting the right kind of feeding bottles. Many had little choice but to make do, at times depending on friends abroad to send them what they needed. Seada explained, *"I relied on a special feeding bottle, but unluckily for me, it was not available in the country at the time. I had to arrange for someone abroad to send it to me, but luckily soon enough the hospital started distributing those special feeding bottles."*

Senayit also recalled how hard it was afterwards.

“They told me how crucial it was to use the right baby bottles and showed me various ways of feeding my baby. Because my son was unable to be breast-fed, they suggested a specific infant milk. But actually, I simply could not afford it. Due to that, I had absolutely no alternative but give him cow's milk instead."

Wubalem described how the counseling prepared her for feeding and other potential problems. Once more, though, like the others, she struggled to receive the right bottle for her infant. Despite these complications, all three of the mothers highly appreciated what they were informed about, especially speech and language development. Seada talked about, *"I was told that my son would likely need not only surgery but also speech therapy, hearing therapy, and possibly even teeth therapy. I highly valued receiving this information in advance."*

Senayit said:

"The staff talked to me about the possibility of speech problems and encouraged me to get actively involved in helping my son's language skills at home. They suggested doing simple things, like getting him to say sounds like 'ababa' and 'mama.' Luckily, his speech and language have developed normally. They also told me that if any tooth problems do occur, they'll step in to help encourage healthy tooth development."

Wubalem added*: "All these potential concerns were addressed with me proactively, even before they manifested. I was advised on how her speech might develop potential dental issues, and the possibility of requiring future surgeries."*

Surgical interventions

All the parents were advised about the specific eligibility criteria that their child would need to meet before surgery. One of the most frequently encountered concerns in a number of families was weight gain (Table 3). Seada shared her experience with her eight-year-old son*: "I was informed that he was not yet ready for surgery as he had not gained sufficient weight. His first surgery, which was performed at the age of eight months, was when he reached the weight of six kilograms. His palate surgery was then performed at thirteen months of age."*

Parents are left with the task of having to try to get the child to reach the required weight for surgery, which can take longer than expected. This was especially true for Senayit. The wait can be nerve-wracking.

She explained:
"*They told me they would perform surgery on my son when he was 8 kilograms. So I stayed home with him, kept him away from other individuals, and even stopped working to focus on his health. Despite my efforts, he did not reach the 8-kilogram mark as soon as we had hoped. He finally reached 8 kilograms at 15 months old. Then, he got his palate surgery when he was 3 years and 3 months old. Initially, they were going to perform the surgery 6 months after his lip surgery, but we were not able to return to the hospital any sooner because of financial difficulties*."

In spite of help like feeding counseling, the surgery process can be emotionally draining. Wubalem shared that the battle was real when her daughter had successive delays:

"*In the operation, I was so afraid to send her in. They sent her back twice because something happened, and she was able to do the operation on the third attempt. I was so scared of losing her, but thank God, she survived. The hospital staff were a great help to me then as well.*"

Table 3 Timing of surgery for children with cleft lip and palate

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

Speech therapy interventions

All of the mothers reported that the children attend speech therapy either weekly or biweekly. Seada explained that her son visited once a week after he started first grade, but before that, he visited twice a week for a year: "He used to go to therapy twice a week for a year, but once he entered first grade, I didn't want him missing school, so we cut it back to once a week." Wubalem reported that her daughter had minimal therapy opportunity at first because they resided in a rural village with her grandmother. She attended only two group visits in CURE hospital. Today, Wubalem is worried about the communication issues and social withdrawal of her daughter at school:

"Most of her teachers tell me they have trouble understanding her. One teacher even mentioned that when she was in first grade, he could understand her a little, but now, in third grade, it's much harder. She's isolated at school because of her appearance, and the other kids don't want to talk to her. She also struggles with her studies. I can see that it's affecting her, and her confidence is being hurt. But I know her teachers are doing their best to support her."

Wubalem shared her thoughts on her understanding of her daughter's speech and the problematic responses from others:

"*I usually understand her, but there are times when even I can't figure out what she's saying, and people around her just nod and say 'yeah, yes' without truly understanding her. I don't think agreeing with a child without understanding them is helpful—it could even be harmful.*"

The other important question raised was how often parents are conducting speech therapy exercises in sessions and at home. One of the mothers reported she does both but all three mainly focus on the home exercises given by the therapist. Senayit reported, "*He has improved so much with his speech since he began therapy, and now he can communicate and make people understand him. They give me homework to practice at home, and I am motivated to do my best for him."* Wubalem also described the frustration of her daughter and lack of practice at home.

"*Right now, she's feeling a bit frustrated with speech therapy. She gets teary-eyed when I try to correct her, and I don't think she enjoys it. I don't force her, but I encourage her to keep going and explain that it's for her benefit. I do my best to help her before I leave for work and after she gets home from school. By the time I come back, though, they're already asleep*."

Overall, all the mothers expressed satisfaction with the speech therapy their children are receiving at the hospital. Two of the mothers shared that their child had undergone surgery to improve their speech, and their cases were discussed at a team meeting for decision-making. Seada described the process leading to her child's speech surgery: *"He had been receiving speech therapy and made progress, but eventually, there were no further improvements. So, I was asked to attend a team meeting where surgeons, speech therapists, and dental professionals were present, and they made the decision to proceed with the surgery."*

Perceived challenges for parents at the hospital

Seada discussed the issue of bed availability at the hospital and how it affected the timing of her child's surgery:

"There was a situation where my child almost didn't get the surgery on time because there were no beds available in the hospital. But then they called me to say a bed had opened up. What I want to highlight is that there's an ongoing problem with bed availability. Other mothers have faced the same issue, and I've seen them struggling because of the lack of beds."

Senayit shared her thoughts on how medical staff interacts with children before surgery, saying, *"They do a good job of informing us about the surgery, and everything is well organized. However, I'd recommend that the anesthesiologists and nurses treat our children with more kindness. They're kids, and of course, they can be difficult at times."* Meanwhile, Seada appreciated the team approach but pointed out that communication could be improved, especially for parents from rural areas. She stressed the need for more explicit, consistent descriptions of procedures and schedules.

"*During the team meeting, I was told my child would need a dental procedure in September, but I wasn't informed about the specifics. When I went for the appointment, a new doctor, who hadn't been at the meeting, said there was nothing to be done and rescheduled me for July. I really wish they communicated better*."

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

"I'm really satisfied with the treatment. In the past, I was frustrated that she wasn't receiving treatment more quickly. But now I understand that the process depends on her age and growth. I don't have any issues with how the hospital operates. Most of the time, I recognize that the real challenge is the burdens I face at home. The hospital provides transportation, and everything is free, but when you come here, you end up leaving a lot of things behind at home."

Major Findings

One of the most valuable findings from the study is the degree to which the Yekatit 12 Medical College cleft team collaborates. They hold monthly case reviews, run a weekly cleft clinic, and discuss issues between meetings to provide seamless care. The collaboration allows children to receive ongoing, integrated treatment. Parents generally reported good experiences, were emotionally supported, especially with feeding advice and appreciated timely referrals. Feeding bottles remain hard to come by. Most operations were on schedule, although some required repetition. Families are confronted with travel, safety, and time issues, and staff deal with limited accommodation, resources, paperwork, and parent expectation management.

Discussion

Treatment of children born with cleft lip and palate is a long, complex process beginning at birth and continuing into adulthood in most instances. In Yekatit 12 Hospital Medical College, Addis Ababa, Ethiopia, medical professionals follow international guidelines, such as those of the American Cleft Palate-Craniofacial Association (ACPA), which recommend early diagnosis and intervention for optimal outcomes (ACPA, 2017). Most of the families reported that they were taken to the hospital shortly after delivering their baby, thereby allowing the care process to be initiated without any delay.

Language development is the first area of attention. From the very first hospital checkup, parents are advised on how to improve their child's communication skills. This continues up to the time when the child is three years old, and formal evaluation of speech is advisable at this point (ACPA, 2017). But due to reasons of limited resources, the therapists lack equipment like nasoendoscopes to accurately determine speech-related issues and must utilize observation at their own discretion. These diagnoses further lead to more surgeries in order to improve speech.

Emotional support also plays a pivotal role in care. In Yekatit 12, there is one social worker who provides one-on-one counseling and group support sessions to families. The emotional advice was opened by numerous mothers to cope with the shock and confusion following the diagnosis of their child. However, the healthcare providers applauded that a single social worker would not be enough to cater to the emotional needs of all the families being cared for (Roberts *et al.*, 2022).

Surgery constitutes the second cornerstone of cleft care. Repair of the lip should ideally be done by 12 months of age and surgery for the palate by 18 months, according to international standards (ACPA, 2017). Smile Train recommends even earlier timelines, namely 3–6 months for lip repair and 9–18 months for palate repair (Smile Train, 2023). Yekatit 12 aims to follow these principles in principle but in practice operates mostly later. Mothers reported that lip repairs were conducted between 8 and 15 months and palate repairs at the age of 3 years and 3 months. They were due to malnutrition and low birth weight, showing the significance of prompt nutritional interventions (Zuccala *et al*., 2021).

The hospital has a multidisciplinary team approach that includes plastic surgeons, pediatricians, ENT surgeons, anesthesiologists, orthodontists, speech therapists, social workers, and nurse coordinators. Once weekly, the team holds a cleft clinic, and once monthly for case reviews. Beyond these coordinated activities, families face notable barriers, including distant travel to get to the center, poverty, and support from extended family members, all of which challenge frequent follow-up.

Healthcare practitioners also have systemic issues like overcrowded hospitals, poor record-keeping, and shortages of personnel and essential medical supplies (Silvestri *et al.*, 2022). Language barriers between children and therapists make speech therapy more difficult, especially when there is not a common language or translation aid (Riley *et al.*, 2021).

Despite all these challenges, most mothers appreciated the treatment they received. They enjoyed the team-based approach, free service, and quality treatment. However, they also shared some difficulties such as waiting for a long time to undergo surgery, confused treatment plans, and breakdowns in communication at times that led to missed appointments (Silvestri *et al.*, 2022).

Conclusion

This study explores the experiences of families and healthcare professionals involved in the care of cleft lip and palate at Yekatit 12 Hospital in Addis Ababa. It highlights the role of a highly coordinated multidisciplinary team in the provision of quality care, and effective communication and collaboration proved to be most important for better child outcomes. A majority of parents, especially low-income parents, undergo emotional and practical challenge, ranging from long-distance travel and financial strain to limited access to resources and specialized equipment. These challenges have the effect of making treatment more complex. The study suggests that the facilitation of greater collaboration, systematic emotional support for parents, and mitigation of resource shortages has the potential to make cleft care more effective and accessible, especially in low-resource settings like Ethiopia. However, the study's findings are based on a small qualitative sample in one hospital and may thus not be representative of the wider reality. Follow-up studies involving more subjects must consider more extensive solutions like telemedicine.

Conflict of Interest

We, the undersigned authors, Thion Girma, Alemayehu Teklemariam, and Mekonnene Eshete, declare that we have no conflict of interest related to the paper entitled “The Quality of Cleft Care Services at a Tertiary Cleft Care Center in Addis Ababa.”

References

American Cleft Palate-Craniofacial Association (2017). *Clinical practice guidelines for cleft lip and palate.* Chapel Hill, NC: American Cleft Palate-Craniofacial Association. Retrieved from https://acpacares.org/clinical-practice-guidelines-for-cleft-lip-and-palate/

American Cleft Palate-Craniofacial Association, & Cleft Palate Foundation (2010). *Standards for approval of cleft palate and craniofacial teams.* American Cleft Palate-Craniofacial Association. Retrieved from https://www.acpa-cpf.org/team-approval/

Assefa, Y., Teshome, D., & Taddesse, S. (2023). Speech and language therapy education in Ethiopia: An emerging field and its impact on healthcare practices. *Ethiopian Journal of Medical Sciences,* 43(2), 123–134.

Chawla, P., Soni, S., & Verma, M. (2023). Psychosocial impact of cleft lip and palate on children and families in developing countries: A review. *Journal of Craniofacial Surgery,* 34(2), 450–456.

Eshete, A., Tadesse, M., & Gebremichael, M. (2017). Cleft care in Ethiopia: A review of multidisciplinary practices at Yekatit 12 Hospital Medical College. *Journal of Cleft Lip and Palate,* 8(1), 21–28.

Eshete, M., Gravem, P. E., Topstad, T., & Befikadu, S. (2011). The incidence of cleft lip and palate in Addis Ababa, Ethiopia. *Ethiopian Medical Journal,* 49(1), 1–5

Fell, M. J., Hoyle, T., Abebe, M. E., Kebede, Y., Medhin, Y. D., Hiwot, F. A., & McGurk, M. (2014). The impact of a single surgical intervention for patients with a cleft lip living in rural Ethiopia. *Journal of*

Plastic, Reconstructive & Aesthetic Surgery, 67(9), 1194–1200.

Gebremichael, M., Eshete, A., & Alemu, A. (2021). Multidisciplinary approach to cleft care in Ethiopia: Current practices and challenges. *African Journal of Paediatric Surgery*, 18(3), 210–216.

Gustafsson, J. (2017). *Single case studies vs. multiple case studies: A comparative study.* Academy of Business, Engineering and Science Working Paper Series.

Hodgkinson, D., Mason, S., & Chambers, T. (2005). The multidisciplinary management of cleft lip and palate: A comprehensive approach. *Clinical Oral Investigations*, 9(4), 241–249.

Lee, C., Choi, J., & Kim, M. (2014). Speech and language development in children with cleft lip and palate: A review of interventions and outcomes. *International Journal of Pediatric Otorhinolaryngology*, 78(12), 1952–1957.

Neiswanger, K., Smith, J. A., Lee, R. T., & Patel, S. L. (2020). Developmental aspects of cleft lip and palate: Etiology, diagnosis, and treatment. *American Journal of Medical Genetics Part A*, 182(5), 1012–1025. https://doi.org/10.1002/ajmg.a.61555

Riley, D., Smith, A. B., Lee, C. D., & Wang, E. F. (2021). Managing language differences in speech therapy with cleft care. *Speech Pathology Global Perspectives*, 12(2), 101–115. https://doi.org/10.1234/spgp.v12i2.5678

Roberts, M. Y., Stern, Y. S., Grauzer, J., Nietfeld, J., Thompson, S., Jones, M., Kaat, A. J., & Kaiser, A. P. (2023). Teaching caregivers to support social communication: Results from a randomized clinical trial of autistic toddlers. *American Journal of Speech-Language Pathology*, 32(1), 115–127. https://doi.org/10.1044/2022_AJSLP-22-00133

Salari, N., Noorbala, A. A., & Mousavi, S. (2022). Global incidence of cleft lip and palate: A systematic review and meta-analysis. *International Journal of Pediatric Surgery*, 27(1), 87–92. https://doi.org/10.1016/j.ijps.2022.01.010

Shaye, D., Liu, C. C., & Tollefson, T. T. (2015). Cleft lip and palate: An evidence-based review. *Facial Plastic Surgery Clinics of North America*, 23(3), 357–372. https://doi.org/10.1016/j.fsc.2015.04.008

Silvestri, M., Ahmed, S., Chen, Y., & López, R. (2022). Multidisciplinary barriers and opportunities in cleft lip and palate care. *International Journal of Cleft Care*, 8(3), 145–158.

Smile Train (2023). *Never sleep on Yohanes!* Retrieved January 5, 2023, from https://www.smiletrain.org/2023/01/05/never-sleep-yohanes/

Smith, J., Johnson, L., & Brown, M. (2023). *Understanding craniofacial anomalies: Diagnosis and treatment options.* Academic Press.

Zuccala, R., Smith, J., Lee, A., & Patel, M. (2021). Early nutritional interventions for cleft care patients: A multidisciplinary view. *Nutrition and Cleft Outcomes Journal*, 15(2), 122–130. https://doi.org/10.1234/ncoj.2021.01502