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Comprehensive
Cleft Care
Speech & Surgery Collaboration

REPORT

CURE Ethiopia Children's Hospital

Addis Ababa, Ethiopia | October 27, 2023





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A NOTE FROM TF

This is an exciting moment in the development of Comprehensive Cleft Care (CCC) in East Africa:

- The era of relying upon **foreign volunteers** to complete safe and effective lip and palate surgeries is waning, and an **inspiring generation** of young, locally trained cleft surgeons is on the rise.
- Speech and Language Therapy (SLT) is **increasingly recognized** as a critical health profession. For example, the dynamic first cohort of locally trained Masters in Speech Therapy students will graduate from Addis Ababa University in 2024, following the pathway of two successful undergraduate cohorts.
- The first CCC centres in East Africa are embracing the core challenges depicted in the CLEFT+ model (p.6), generating tools and locally-rooted insights. International Cleft NGOs such as **Smile Train, Operation Smile, and Transforming Faces** are committed to supporting a CCC approach.

The path ahead is not, however, straightforward. **Building the systems** that support strong multi-disciplinary teams is challenging; few families are yet **aware** of the benefits of CCC for their children's full rehabilitation, and the **distances** that rural families must cover in order to access care are daunting.

As SLT becomes more widely available in East Africa, we know that **effective collaboration** between Surgeons and SLTs is **essential** in unlocking the true potential of CCC to **improve patient outcomes**.

We are **thrilled** by the creative and intensive preparation completed by our wise and experienced faculty (p.5) in furthering our understanding of this topic.

Their **skillful facilitation** of our day, combined with the **active and thoughtful participation** of Surgeons and SLTs pursuing a CCC approach led to an amazing result:

- *100% of our 31 respondents rated the SSC conference as **VERY HELPFUL (4/4)** (p.15).*

We offer this brief report to participants in the hopes that you will extend the dialogue and learning with all of your colleagues interested in pursuing Comprehensive Cleft Care (CCC)!

On behalf of the faculty and Transforming Faces team we say: **onward**, with **gratitude**.

Hugh Brewster
Executive Director,
Transforming Faces

AGENDA RECAP

Morning

8:30

Context CCC in East Africa

9:30

Cleft Surgery & Cleft Palate
Speech Overview

10:30

Speech Therapy in Focus

11:30

CCC Clinic Collaboration

12:15

Lunch

Afternoon

13:15

Surgery Huddle OR
Speech and Language Therapy
(SLT) Huddle

15:30

Velopharyngeal Insufficiency
(VPI) Case Study

16:10

Debrief & Next Steps

16:30

CURE Ethiopia Tour (optional)



LEARNING OBJECTIVES



All Participants

- Deepen understanding of Comprehensive Cleft Care (CCC) in E. Africa
- Expand knowledge of cleft speech
- Consider the role of the speech therapist in a CCC team
- Explore ways that cleft surgeons and speech therapists work together
- Identify strategies for responding to VPI



Cleft Speech Therapists & SLT Students

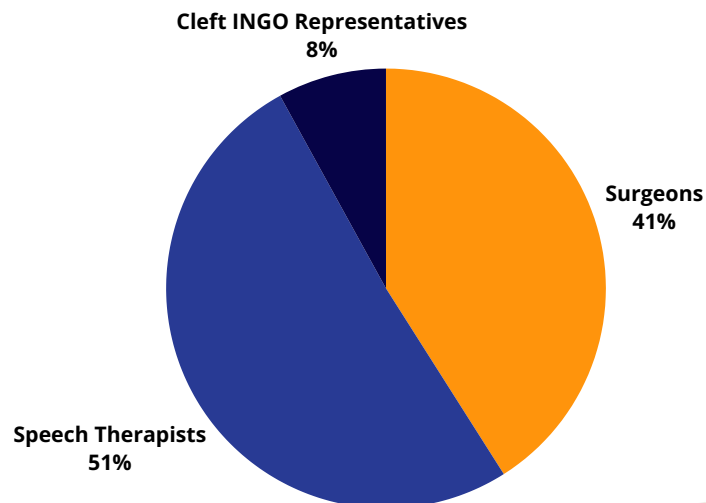
- Review speech therapy strategies
- Explore ways of documenting patient progress in speech
- Deepen understanding of assessment skills and listening practice



Cleft Surgeons

- Consider cleft surgery technical recommendations

SSC Conference Participants (n=37)





FACULTY



Berhane Abera
Speech and Language Therapist



Dr. Debbie Sell
Speech and Language Therapist



Dr. Triona Sweeney
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OPENING PLENARY

1. CCC CONTEXT: EAST AFRICA

What are the 6 key challenges in Comprehensive Cleft Care (CCC)?



Participants gathered in small groups to discuss each CCC Challenge.



Key participant insights and reflections about the CCC context and challenges in East Africa include:

Circle (C): In East Africa, there is a shortage of professionals capable of providing comprehensive care. Patients do not always perceive the value of interventions like Speech Therapy and retaining trained SLTs can be a challenge for teams.

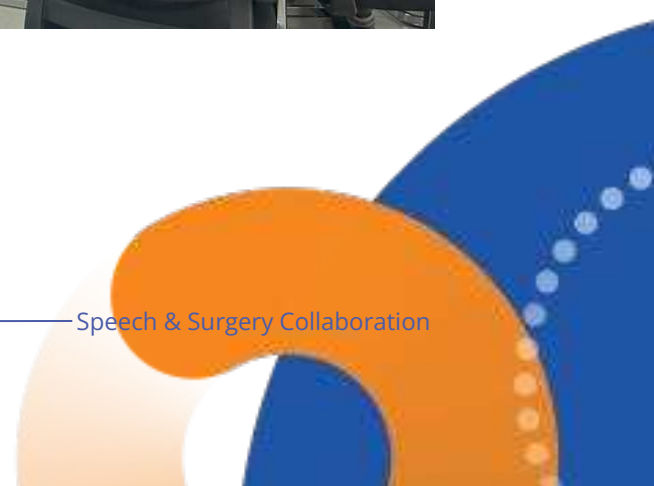
Local (L): Remote areas face challenges in accessing accurate information about cleft and its treatment. Providing services to patients far from central facilities remains a pressing concern. Expanding services beyond capital cities is essential.

Evidence-Informed (E): Access to relevant research is notably limited in East Africa. Sustaining CCC growth requires rigour in documentation and analysis of treatment results.

Fully-Inclusive (F): Truly inclusive care requires increased community awareness and outreach efforts to rural families.

Team (T): Good teamwork is crucial for providing ongoing care. Cleft professionals cannot work in silos. There are still only a few examples of CCC teams in East Africa to learn from.

Growth (+): Cross-center learning is critical. Inviting additional disciplines to contribute to CCC teams enhances the outcomes for patients and requires good communication among professionals.





WHY CCC?

“Cleft is a unique anomaly that impacts the entirety of an individual, encompassing psychological, social, speech, dental, eating, and various other aspects. Addressing it necessitates a comprehensive team approach as the interlinked issues cannot be effectively managed without collaboration across specialties.”

- Dr. Mekonen Eshete



CLEFT SURGERY & CLEFT PALATE SPEECH OVERVIEW



Dr. Mekonen and Dr. Hodges delved into the essential components of an effective cleft palate surgery, emphasizing anatomical considerations, the importance of timely procedures, tension-free repair to prevent fistulae, techniques for muscle dissection ensuring optimal length, and culminating with the fundamental principles guiding palate repair. Following this, Dr. Triona Sweeney facilitated an interactive session, guiding participants in discerning the attributes of cleft palate speech via various listening activities involving speech samples.

Principles of Palate Repair

- Palate should move with the dexterity of an eyelid
- Complete mobilization –tension free repair
- Gentle tissue handling – to minimize fibrosis
- Meticulous suturing
- Fistula free repair
- Minimize damage to maxillary growth





CHARACTERISTICS OF CLEFT PALATE SPEECH

Cleft palate speech is a complex problem which can include any or all of the following problems:

- Resonance/ Tone/ Nasality
- Nasal Airflow
- Consonant Errors (Articulation)

Some errors are due to structural problems which may require further surgery, while others are learnt patterns which will require therapy. Sometimes both surgery and therapy are required.



3. SPEECH THERAPY IN FOCUS

A. THE PATIENT PERSPECTIVE: INTERVIEW

Hugh Brewster and Ms. Berhane Abera conducted an interview with Hellina*, a patient born with an isolated cleft palate (ICP), who attended the session accompanied by her infant daughter, Rahma*, also born with a cleft lip condition.

Hellina's discovery of her own cleft condition was unconventional. Her parents adapted to her difficulty feeding as an infant, but were unaware that she was born with a cleft. A chance encounter as an 18-year old first led her to seek treatment. A stranger boldly commented upon his extreme difficulty in understanding her nasal speech and recommended she seek help at Yekatit12 Hospital.

Despite not receiving treatment for her palate as a child, Hellina vividly recalls her transformative journey post-surgery and speech therapy at Yekatit 12. Before treatment, she lacked confidence and avoided speaking whenever possible. However, after a successful palate repair and subsequent speech therapy, Hellina experienced a significant transformation. She now communicates effortlessly (including to a room full of strangers at our conference), expressing immense gratitude for the therapy's efficacy in aiding her speech improvement.

Reflecting on her speech therapy experience post-surgery, Hellina recalls exercises targeting specific sounds she found challenging to improve her speech. These exercises proved beneficial, especially when practiced at home.



Hellina strongly advocates for the integration of speech therapy in similar treatment programs, emphasizing its profound impact on her happiness, confidence, and ability to express herself effectively. Her journey not only underscores the importance of early detection and intervention but also highlights the transformative role of comprehensive care, including surgery and speech therapy, in empowering individuals with cleft conditions to lead confident and fulfilling lives.



**Names altered for confidentiality*

SLT'S ROLE IN A CLEFT TEAM

According to Dr. Debbie Sell, an SLT's responsibilities encompass screening, assessment, therapy, prevention, teaching, and research. Patient and family members play a key role in successful treatment. Investigations like nasendoscopy and videofluoroscopy require SLT input and contributions. Administrative tasks, including report writing and case-load management, are integral, alongside a commitment to education, training, and research. Dr. Sell emphasizes that effective collaboration between surgeons and speech therapists is vital in the comprehensive care of patients with cleft palate conditions.



SLT must give a **clear and confident message** to the surgeon about the nature of speech, its impact from the point of view of the patient and the family, contributing factors, and advise on management be it therapy, surgery or both

Aims of Speech Intervention

- Eliminate speech problem
- Diagnostic: therapy to inform if investigations/surgery are required
- To improve velopharyngeal function through articulation therapy
- Strategies for long-term unintelligibility
- Do not treat hypernasality directly/ use sucking and blowing games
- Vital importance of parents' supporting activities and patient's motivation





In small groups, all participants sought to identify and discuss the most effective treatment management approach using a series of hypothetical case scenario cards.

CCC COLLABORATION

Participants were prompted to recall a successful working relationship with a colleague and briefly outline its characteristics: *What factors contributed to its success.*

Two short role plays about professional interactions between a surgeon and a speech therapist sparked reflection and discussion in small groups.

Participants assessed a “Multidisciplinary Communication Checklist” that can help guide successful Surgery and SLT collaboration.

Multidisciplinary Communication Checklist:

1. **Active Listening:** Give full attention when colleagues speak and avoid interrupting
2. **Clear Communication:** Ensure medical terminology is understood and encourage colleagues to ask questions and seek clarification
3. **Timely Updates:** Provide prompt information about treatment updates and ensure accurate documentation of patient interactions
4. **Privacy and Respect:** Safeguard patient confidentiality and communicate respect through tone and body language
5. **Team Collaboration:** Encourage input from all team members about patient care



- Orofacial Clefts
- Anatomy: Hard & Soft Palate
- Cleft Palate Operative Techniques
- Surgical Tips for Successful Speech Outcomes



SURGERY HUDDLE

- *Perceptual Speech Assessment Unravellled*
- *Nasality and Nasal Flow*
- *Differential Diagnosis*
- *Therapy for Cleft Palate Speech*
- *Documenting Progress*

SPEECH THERAPY HUDDLE





CLOSING PLENARY

VELOPHARYNGEAL INSUFFICIENCY (VPI) CASE STUDY & DEBRIEF

The conference concluded with a joint surgeon-speech therapist presentation on the transformational journey of Kate*, who was born with cleft lip and palate in the Philippines. She presented with an unrepaired palate at the age of 18 years and was subsequently diagnosed with VPI post palate-repair.

Using photos, videos, and speech samples, Dr. Hodges and Dr. Sweeney walked participants through the Surgery and Speech Therapy implications of each step in her process toward clear and confident speech. The case study demonstrated how robust collaboration between the attending surgeon and speech therapist leads to inspiring results over time.

**Name changed for confidentiality.*





CONFERENCE FEEDBACK

"Interactive, informative, engaging" - Surgeon

"The conference allowed everyone to participate. The role plays and case studies were very helpful" - SLT

"I learnt that speech therapists and cleft surgeons have to work closely in evaluating patients with cleft palate to make good decisions and get good outcomes" - Surgeon

"It is interesting that you helped us see how collaboration can be like a miracle" - SLT

"It shows that the collaboration is not as strong and there is a lot to be done" - Surgeon

Most Appreciated

- The experienced faculty
- Participant-centered; interactive activities and discussions
- Case-based discussions
- Meeting other surgeons, SLTs and the sharing of ideas
- Focus on the importance of SLT-surgeon collaboration
- Logistics and conference methodology
- Broadening knowledge; learning about new techniques and tools, new ideas and approaches.

Suggestions for Improvement

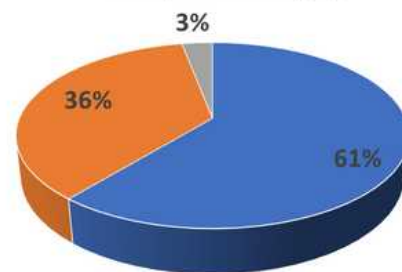
- Inclusion of practical engagement for participants with in-treatment patient sessions and team discussions
- Extend the conference schedule to at least 2 days
- Engage other CCC disciplines such as audiologists/ ENT specialists in future conferences

SSC Conference Experience



100% (n=31) respondents rated the 'Overall' conference experience as **Very Helpful!**

The conference deepened participant understanding of cleft speech and surgery



Strongly Agree Agree Strongly Disagree



ADDITIONAL RESOURCES

- A brief chapter overview of cleft communication issues in LMICs: Subramaniyan B. et.al. (2023). *Cleft Lip and Palate: An Overview with a Particular Emphasis on Communication Issues in Resource-Limited Regions*. In S. Levy, P. Enderby (Eds.), *The unserved. Addressing communication disorders in unserved and underserved populations*. J&R Press.
- Up-to-date comprehensive chapter on communication issues in cleft, including education, language, patient-reported outcomes, quality of life, cleft presentation: Sell, D., Pereira, V., Wren, Y. & Russell, J. (2021). *Speech disorders related to Cleft Lip & Palate & velopharyngeal dysfunction*. In J. Damico, N. Muller & M. Ball (Eds.). *Handbook of language and speech disorders*. (2nd edition). Wiley-Blackwell.
- Validated Intelligibility Scale for Use by Parents:
<https://www.csu.edu.au/research/multilingual-speech/ics>
- Useful website for good practice guidelines and training materials: www.clispi.org
- Importance of outcomes which are 'client centered' and measuring what matters to patients - Getting Started with Patient-Reported Outcomes: <https://solutions4ccc.com/wp-content/uploads/2023/06/SG-1-S4CCC-Guideline-Series.pdf>
- Mekonen, A. M. (2013). *Speech Production in Amharic - Speaking Children with Repaired Cleft Palate*. Accessible via author.





**Thank you to our amazing
volunteer faculty members,
and to the organizations that
made this conference possible.**

