

9 Cleft Lip and Palate: An Overview with a Particular Emphasis on Communication Issues in Resource-Limited Regions

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Key information for local and national policy and lawmakers

Cleft of Lip and Palate (CLP) is a congenital, heterogeneous group of conditions that involves multiple structures which present with varying degrees of severity. Depending on the time of interference with embryonic development, different types of clefts arise. Across the globe, individuals with CLP in resource-limited countries may have access to surgical intervention locally or through an international team. However, surgery often tends to be undertaken later than is optimum.

In most resource-advantaged countries, a multidisciplinary or interprofessional team is involved in the clinical care pathway, followed by a timeline for treatment, whereas in most low- and middle-income countries (LMICS), there is a shortage of qualified professionals who are able to provide comprehensive management for children with CLP, resulting in delayed or no intervention (Magee, Vander Burg, & Hatcher, 2010). Therefore, a challenge exists in the timely identification, reporting, and intervention of CLP. Early surgical intervention for the lip and palate is critical, ideally within the first 18 months of life. Significantly delayed palate surgery or an unoperated palate often results in a lifetime of poor speech with far reaching adverse consequences (Murthy, 2009). This, coupled with a delay in, or no possibility of, accessing speech therapy services creates a major problem in LMICs.

The planning and implementation of rehabilitation programmes needs robust action by the healthcare system. Each region requires an individualized rehabilitation programme that is appropriate to its own political system and geographical, linguistic, and cultural framework. This chapter aims to assist healthcare professionals and policymakers in creating improved access to rehabilitation for those with communication, language, and speech difficulties in LMICs to reduce the burden of care for individuals with CLP and their families.

The incidence and prevalence of cleft lip and palate

CLP is a congenital malformation which usually occurs during the first trimester of pregnancy. One of the causative factors could be a combination of TBXI gene that plays a role in formation of tissues and organs in embryonic development and environmental factors for maternal diet and lifestyle factors (Martinelli, Palmieri, Carinci, & Scapoli, 2020). It is estimated that, worldwide, a baby is born with a CLP every three minutes. Internationally, the prevalence rate is about 1 in every 700 live births with a greater likelihood of occurrence in certain ethnic groups and geographical regions (Mossey et al., 2011).

CLP is reported to occur more frequently (from 0.2 to 2.3 per 1000 births) than cleft of the palate alone (from 0.1 to 1.1 per 1000 births), although this varies according to race and ethnicity (Mitchell & Lupo, 2016). A systematic review conducted by Panamonta et al. (2015) documented the orofacial cleft prevalence per 1000 live births within continents: Asia 1.05 to 2.36, South America 0.99 to 1.00, and Africa 0.3 to 1.65. Documenting child births and using digital database platforms are fundamental to the healthcare system in order to inform healthcare-related policies.

Impact of cleft lip and palate in communication

Untreated CLP is a significant healthcare problem which can lead to abnormal facial development and severe speech and feeding difficulties, potentially impacting on functional and person-centered outcomes. Many factors such as the type and extent of cleft, age, and time of surgical correction of the palate, surgical techniques, surgeon experience, presence of fistula, status of the velopharyngeal port functioning, hearing status, and socioeconomic and linguistic status can potentially have an impact on speech and communication in individuals with CLP (D'Antonio & Scherer, 2008). One of the major goals of surgical correction of CLP repair is to provide the structure for the normal development of speech. The typical speech patterns observed in individuals with CLP clearly highlight the need for speech intervention in this population.

Key information for health practitioners, grass root level workers and caregivers

How to identify the presence of cleft lip and palate and issues related to communication

Cleft of the lip is easily identifiable. Cleft of the palate is more difficult to identify as it requires an examination of the oral cavity, and is diagnosed in the postnatal period. In contrast, a submucous cleft palate (SMCP) is usually diagnosed after the beginning of speech production, usually from around 3 years of age. The Speech and Language Therapist (SLT) is typically the first health professional to whom the child presents because of the communication difficulties. Therefore, the SLT plays a crucial role in the diagnosis of a SMCP and referral to a cleft team. A SMCP requires a more detailed

oral examination and there are guidelines on how to evaluate this (Caterston et al., 2014; Jamal et al., 2021; Massengill, 1966; Olin, 1966).

Engaging in conversation will often give sufficient cues to the listener to identify the presence of a speech disorder in individuals with CLP. Training methods and processes have been developed for identifying specific issues related to speech in individuals with CLP by paraprofessionals (Non-Speech Language Therapists) in LMICs, e.g., Thailand (Prathanee, Dechongkit, & Manochiopinig, 2006), India (Shunmugam et al., 2017), and Sri Lanka (Wirt et al., 1990).

Impact of cleft lip and palate in communication

The effect of structural anomalies on speech is complex. For example, individuals with CLP are at risk for disorders of language as well as speech domains. A delay in early vocabulary and language development has been documented in the literature (Chapman, Graham, Gooch, & Visconti, 1998; Scherer & D'Antonio, 1995). As the child starts to speak, issues related to articulation (pronunciation) and resonance (quality of speech) may be observed, leading to persistent speech errors in individuals with CLP, especially when there is no intervention. This can affect communication and can have a considerable impact on an individual's quality of life by limiting his/her activities and social participation, education, and psychosocial wellbeing (Havstam & Lohmander, 2011). In such instances, speech and language therapy is important and can determine the life chances and wellbeing of the patient.

Importance of identification of communication difficulties in individuals with CLP

Early assessment and intervention in infants and toddlers with CLP are crucial since young children with CLP are at risk of smaller phonetic inventories, later onset of babbling, fewer oral consonants, and less complex syllable and word structures than their peers without CLP (Chapman & Willadsen, 2011; Scherer, Williams, & Proctor, 2008). Early language development is also compromised in both receptive and expressive domains for young children with CLP when compared to their typically developing peers (Hardin-Jones & Chapman, 2014). Subtle difficulties can persist into the school-age years (Lancaster et al., 2020). Even following timely repair of the primary palate, children with CLP may develop cleft-related speech articulation errors and/or velopharyngeal insufficiency (VPI). VPI refers to the condition when the velopharyngeal mechanism does not close to separate the oral from the nasal cavities for production of oral consonants efficiently or consistently.

The speech features of VPI include hypernasal resonance, nasal airflow errors, and specific errors in articulation. Speech articulation errors tend to reflect an incorrect place of articulation, where typically a more posterior place is utilized. Errors can also be attributable to the presence of a palatal fistula, a class III occlusal status, and/or dental abnormalities. However, during the early years, speech errors could be similar to phonological patterns observed in speech of typically developing children and this needs to be differentiated (Harding & Grunwell, 1998). An estimated 25-35% of children with CLP present with velopharyngeal insufficiency (VPI) following palate

repair in the first 15 months of life (Britton et al., 2014; Sell et al., 2015), requiring secondary surgery. This is significantly elevated when palate repair is delayed into late adolescence and adulthood (Sell, 2008).

What to do after identification of communication difficulties in individuals with CLP

The aim of speech and language intervention focuses on communicative participation, encompassing the activity and participation components of the International Classification of Functioning, Disability and Health (ICF) model (Cronin, McLeod, & Verdon, 2020; Neumann & Romonath, 2012) as well as consideration of the impact of environmental and personal factors (WHO, 2007). Early speech and language intervention focuses on pre-empting potential speech and language difficulties by providing families with information about early speech and language development, strategies to encourage and facilitate the correct production of oral consonants, as well as early vocabulary development. Depending on the age of the child, later speech and language intervention can involve both direct and/or indirect intervention approaches, in which the involvement of parents or carers is essential (Sell, Pereira, Wren, & Russell, 2021). The continued involvement of the SLT in the school years is important, as children with CLP may have persistent speech disorders and subtle language difficulties that have an impact on academic achievement in reading and mathematics (Sell et al., 2021).

Support for individuals with CLP who exhibit issues related to communication

Services of speech and language therapy (SLT) are required to assess and provide intervention if any difficulties are noted in language, articulation, phonology, or speech development. Management of speech in individuals with CLP in LMICs faces unique challenges when compared to developed countries. One such challenge is the lack of availability of appropriate resources in LMICs. Sell, Nagarajan and Wickenden (2011) outlined the different models of delivery of speech services that have been adopted/ adapted worldwide. There is, however, a compelling (and challenging) need to formally and systematically identify the range of service delivery models implemented globally, and to explore the efficacy of such models of delivery in speech and language treatment for individuals with CLP.

Key Dos and Don'ts

During the routine visit for vaccination or other usual health interventions during the early years, the healthcare practitioner should ask the carer whether there are any feeding difficulties and check whether the baby's babbling sounds normal. Additionally, it is useful to enquire about other aspects of speech and language development. Refer the child to a cleft care team for surgery, feeding advice and early communication intervention if there are any concerns.

Information for Speech Language Therapists working with individuals with CLP

The SLT works collaboratively with all members of the CLP team, contributing to making an accurate diagnosis, formulating and delivering an appropriate treatment plan

in relation to feeding, speech (including velopharyngeal insufficiency) and language. Children with CLP have difficulty articulating high pressure oral consonants and speech will be hypernasal in the presence of an unoperated cleft palate, velopharyngeal insufficiency, or submucous cleft.

These speech difficulties may also be observed in children who have received surgical correction of palate before 1 year of age (Bessell et al., 2013). Cleft speech errors are classified and grouped under two broad categories: namely, obligatory errors (errors due to structural deformity) and compensatory errors (errors due to learned maladaptive articulatory placements). Obligatory errors are corrected through surgical/dental and orthodontic interventions. Compensatory errors are addressed by speech and language therapy which focuses on the establishment of correct placement of the articulators for speech sounds.

Speech assessment approaches

The role of the SLT begins with a comprehensive perceptual assessment of speech across the range of parameters of resonance, nasal airflow, and consonant production. Assessment involves: (i) identifying the nature of cleft-related speech errors and developmental speech errors; (ii) differential diagnosis of errors which are obligatory (due to structure in class III occlusal status or VPI); or compensatory in nature. Perceptual speech evaluation forms the basis of speech assessment in individuals with CLP (Lohmander & Olsson, 2004). The nature of the speech sampling and the phonetic content are important requirements (Henningson et al., 2008). There are international guidelines pertaining to articulation and non-articulation parameters, linguistic hierarchy (words, sentences, conversation), control of phonetic content, sampling methods as well as measurement methods (Henningson et al., 2008; Sell & Pereira, 2015; Sell et al., 2001).

Identification of perceptual speech features of VPI requires instrumental investigations, such as nasendoscopy and videofluoroscopy, for diagnosis of a structural problem and planning of secondary speech surgery (correction of velopharyngeal dysfunction). However, these services are not easily available in LMICs. Prathanee (2012) highlighted the need for both bottom-up and top-down models in sustaining services related to speech therapy for children with CLP in Thailand. The bottom-up development module comprises of community-based models that follow combined principles and emphasize the training of paraprofessionals in providing speech services. The top-down development module consists of developing a standard perceptual assessment, based on guidelines of universal parameters for reporting the speech outcomes in individuals with cleft palate (Henningson et al., 2004), and objective measurements from nasendoscopy and videofluoroscopy. These two modalities might be an effective way to resolve the problems of the lack of speech services in Thailand and other developing countries.

Evidence-based intervention

Several speech treatment approaches are currently used in CLP. The work of Scherer and colleagues provides strong evidence in favour of early intervention for speech and

language delay using Enhanced Milieu Training and focused stimulation (Scherer, 1999; Scherer, D'Antonio, & McGahey, 2008). Enhanced Milieu Teaching (EMT) involves modelling children's communication attempts and arranging the child's environment in order to develop his/her communication skills (Hancock & Kaiser, 2006). Focused stimulation refers to 'targeted parent stimulation to facilitate the child's consonant sound practice and provide feedback regarding the child's attempt at the sound (Scherer et al., 2008). These natural approaches aim to improve communication, as the teaching of speech and language occurs in response to the child's interest and intent to communicate (Kaiser et al., 2017).

There are two approaches that are gaining popularity in the UK: Multi-Sensory Input Modeling (MSIM), which involves providing the infant with high doses of models of speech articulation stimuli (Harding & Bryan, 2000) and MSIM+O (output), involving the use of novel but meaningful sound sequences and explicit verbal feedback (Calladine & Vance, 2019) which is based on elements of the Psycholinguistic Framework (Stackhouse & Wells, 1997). In terms of direct speech intervention, several treatment approaches are used: the Traditional Articulation approach (Van Riper & Erickson, 1996), Minimal Pair Therapy (Barlow & Gierut, 2002) and components of the Psycholinguistic Framework (Stackhouse & Pascoe, 2010; Stackhouse & Wells, 1997) as seen with MSIM+O above. The traditional articulation approach includes starting on the target speech sound in isolation and working across the linguistic hierarchy as well as encompassing elements of Motor Learning Theory (Maas et al., 2008), such as practice fraction (do not practise isolated movements). Such treatment approaches are also used with non-CLP children with speech sounds disorders (McLeod & Baker, 2017).

There is increasing interest in and evidence for combined phonetic-phonological approaches (Alighieri et al., 2020). These authors reported a larger increase in percentage of correctly produced consonants, and correct place and manner of speech production following intervention using a combined phonetic-phonological treatment compared to a motor-phonetic treatment. This has some logic as the physical constraints on articulation can affect a child's ability to signal the phonological contrasts essential to being meaningful (Harding-Bell & Howard, 2011). In fact, such phonological processes have been reported in young children with CLP (Chapman, 1993).

The use of nonspeech oral motor exercises (NSOME), such as blowing and sucking activities and exercises to strengthen the palate muscles, are contra-indicated in the treatment of cleft-related speech errors and/or velopharyngeal insufficiency (Ruscello & Vallino, 2020; Sell et al., 2021). There is strong and increasing evidence supporting parent-led, therapist-supervised articulation therapy for children with CLP (Sweeney, Sell, & Hegarty, 2017; Sweeney et al., 2020).

Key Dos and Don'ts

- Do undertake early intervention using naturalistic approaches such as Enhanced Milieu Teaching (with a phonological emphasis).
- Do involve parents or carers in speech and language treatment.

- Do use a combination of traditional articulation and phonological approaches in direct speech treatment.
- Do not use Non-Speech Oral Motor Exercises for cleft-related speech difficulties.

Resources

- There are certain resources which are useful for practitioners:
- the Circle of Cleft Professionals (CoCP) | Transforming Faces (leftcircle.org), worldwide network of cleft professionals and cleft charity leaders with an interest in promoting Comprehensive Cleft Care (CCC) in resource-constrained contexts
- Dropbox - Resources for CoCP - Simplify your life, FAQs from Cleft Palate and Craniofacial Committee | IALP: International Association of Communication Sciences and Disorders (IALP) (ialpasoc.info), and CLISPI - Cleft palate International SPEech Issues).

Discussion

The fundamental role of the speech language therapist in a comprehensive cleft care team is to provide a timely, appropriate, and continuous service. One of the barriers in providing this care is limited or non-availability of professionals and tertiary care centres close to the individuals living in remote areas in LMIC regions. For implementation of accessible speech services, models involving collaboration of public and private sectors could be a viable option in LMIC regions. With the advances in technology, it is possible to train SLTs in LMIC regions across the world and to be mentored by experts in the field. One recent initiative is the project initiated by IALP and Transforming Faces (2021). Such mentoring of SLTs in underserved regions will facilitate professional development and enable quality care for individuals with CLP.

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10 Speech Sound Disorders in Underserved and Unserved Populations

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Key information for local and national policy and lawmakers

the purpose of this chapter is to inform governmental bodies, professional organizations, health and educational service providers about the risk and consequences of speech sound disorders in children in underserved and unserved communities. Speech sound disorders (SSD) in children is a common reason for referral to speech-language pathology/phoniatric (SLP) services in many countries. SSD is a “persistent difficulty with speech sound production that interferes with speech intelligibility or prevents verbal communication” (American Psychiatric Association, 2013). It differs from other types of communication impairment such as developmental language disorder, autism spectrum disorder or social communication disorder and stuttering/stammering in that children with SSD have a specific problem with producing the sounds of speech in a clear and intelligible manner. In the majority of cases, the cause of SSD is unknown (e.g., Broomfield & Dodd, 2004; Shriberg, 2003). However, known causes are identified in a minority of children with SSD, which may include cognitive impairment, hearing loss, and craniofacial dysmorphias (such as cleft lip and/or palate, or cerebral palsy).

Incidence and prevalence of speech sound disorder

Estimates of prevalence of SSD vary depending on the definition and the assessment protocol used to measure speech. Rates ranging from 2.3% to 24.6% have been reported across a number of studies (Eadie et al., 2015; Jessup, Ward, Cahill, & Keating, 2008; Keating, Turrell, & Ozanne, 2001; Law et al., 2000; McKinnon, McLeod, & Reilly, 2007; Shriberg et al., 1997; Shriberg, Tomblin, & McSweeney, 1999; Wren et al., 2016) with clear evidence that rates decline as children get older. However, the prevalence studies to date have largely focused on children being brought up in Western countries where English is the primary language spoken. If one considers sub-Saharan Africa, for example, little is known about the prevalence of communication disorders. Pascoe, Rossouw and Mahura (2018) observe that prevalence of SSD has not been studied in South Africa. However, these authors contend that if the prevalence of children with