

Barriers and Resources to Cleft Lip and Palate Speech Services Globally: A Descriptive Study

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Background: Although a number of international cleft organizations and cleft professionals in low- and middle-income countries (LMICs) have built and supported comprehensive cleft care and speech therapy models to address the shortage of speech services in LMICs, the specific speech needs of individuals with cleft lip and palate (CLP) in such countries remain unknown. The objective of this study was to evaluate the barriers to accessing speech services for patients with CLP as well as the resources and models of speech services that are currently available for individuals with CLP in LMICs, with the goal of better understanding the needs of this population.

Methods: Qualitative and quantitative methods consisted of Smile Train partner surveys that were distributed June 25th to July 31st, 2018 worldwide. Surveys were distributed through Smile Train's online medical database, Smile Train Express, which every Smile Train partner uses to report their Smile Train sponsored treatment outcomes. A total of 658 Smile Train partners responded to the surveys. Respondents included surgeons, speech therapists, orthodontists, administrators and nurses who represented non-governmental organizations, hospitals (private or public), hospital groups, and private clinics.

Results: Results indicated that lack of resources, including access to local speech providers and language materials, as well as financial constraints such as patient travel and speech treatment costs, are the most commonly reported barriers to accessing speech services across all geographic regions surveyed.

Conclusions: Improving access to CLP speech services in LMICs may require strategies that address lack of speech providers, language materials, and financial constraints.

Key Words: Barriers to speech services, low- and middle-income countries, smile train, speech therapy

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According to the World Health Organization, cleft lip and palate (CLP) is 1 of the most common congenital abnormalities, affecting 1 per 500 to 700 live births.¹ Children born with CLP may have feeding, speech, and hearing issues. An interdisciplinary team composed of surgeons, speech-language pathologists (SLPs), orthodontists, otolaryngologists, psychologists, pediatricians, nurses, geneticists, social workers, nutritionists, and audiologists treat patients with CLP. The stages of treatment include nutrition support as needed, primary surgery to repair the CLP, ongoing orthodontic treatment, speech therapy and psychosocial care when needed, and secondary and tertiary surgeries when warranted.^{2,3}

In low- and middle-income countries (LMICs), many children born with CLP may have a delay in care and surgeries due to the limited availability of qualified surgeons⁴ and other team professionals in CLP. This delayed surgical care is problematic as later surgical repair has been associated with poorer speech and resonance outcomes. Thus, the delay in early comprehensive care potentially increases the eventual need for speech therapy, which is also limited in certain LMICs.^{5,6} Those who receive surgeries may never receive much-needed speech therapy, as in many regions of the world, the profession of SLP does not exist^{7–9} or there are inadequate numbers of SLPs are available to meet the needs of individuals with CLP.¹⁰ Many children with cleft palate continue to have speech errors even after the cleft palate surgical repair. In 1 prevalence study, 68% of preschool-aged children with CLP had received speech and language intervention services,¹¹ whereas a separate study found that close to 67% of 5-year-old had received speech therapy.¹² These findings underscore the high need for speech therapy and SLPs to work with children with CLP.

Children with CLP may present with distinctive speech difficulties not seen in other groups of individuals. These difficulties manifest as compensatory errors, which are thought to be caused by the abnormal anatomy of the oral cavity when children are learning to produce sounds early on in speech development.³ Even after successful cleft palate surgery, compensatory errors still persist.¹³ Reducing and eliminating these compensatory errors is the primary objective of speech therapy.

Comprehensive Cleft Care in Low- and Middle-Income Countries

Comprehensive cleft care includes treatments that span infancy through adulthood. Comprehensive cleft care means that that every

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individual born with a cleft has access to a multidisciplinary cleft care team that can provide all the services they need to thrive. International and in-country programs aim to provide comprehensive cleft care in LMICs, where access to surgical repair and speech therapy is limited or nonexistent.⁷⁻⁹ Such programs have been established by Smile Train, the world's largest cleft-focused organization, which has provided training, funding, and resources for local medical professionals in more than 90 countries since 1999. Smile Train operates a sustainable model of CLP care by establishing mutual partnerships with local professionals to identify needs and provide training and financial support for comprehensive cleft care. Smile Train's partnership model identifies teams or hospitals within LMIC communities and sustains the safety and quality of sponsored CLP treatment. Protocols, built using international standards, are implemented and further supported by continuing education programs and grants for partner centers and teams. Smile Train grants cover the costs of training, treatment, equipment, awareness, research, and patient travel, with the goal of establishing self-sustaining centers in LMIC communities. Since its beginning, through its local, in-country partnerships, Smile Train has supported safe and quality cleft care for over 1.5 million children.^{14,15}

Present Problem

Although a number of international cleft organizations and cleft professionals in LMICs have built and supported comprehensive cleft care and speech therapy models to address the shortage of speech services in LMICs, the specific speech needs of individuals with CLP in such countries remain unknown. Identifying barriers to speech therapy for individuals with CLP in LMICs is needed to improve the existing resources. The primary goal of the present study is to determine the barriers in speech services in individuals with CLP to continue building successful approaches to improve access to CLP speech services globally. Additionally, it also aims at assessing the role of the SLPs in these countries.

MATERIALS AND METHODS

This study was approved by the Institutional Review Board at Long Island University, Brooklyn.

Smile Train Partner surveys were distributed June 25th to July 31st, 2018 worldwide. The survey was developed with input from Smile Train field staff as well as from feedback received from Smile Train partners in their regular grant reports. The questions were created to monitor trends in topics that were of utmost importance to Smile Train partners, patients, and the sustainability of Smile Train. Surveys were distributed through Smile Train's online medical database, Smile Train Express, which every Smile Train partner uses to report their Smile Train sponsored treatment outcomes. Smile Train partners include surgeons, speech therapists, orthodontists, administrators, and nurses represented non-governmental organizations, hospitals (private or public), hospital groups, and private clinics, all of that represent at least 1 site, where surgeries are funded. The survey contained 10 multiple choice questions that were available in 7 languages: English, Spanish, Portuguese, French, Mandarin, Vietnamese, and Indonesian. Questions were translated by translators without borders, a Smile Train partner, and translations were confirmed by Smile Train local field staff. Three of the survey questions focused on speech therapy barriers and represent the focus of this study as shown in Supplementary Digital Content, Table 1, <http://links.lww.com/SCS/D5>. Data were aggregated by world region and analyzed using Microsoft Excel and SPSS software (IBM Corp. Released 2019. IBM SPSS Statistics for Windows, Version 26.0. Armonk, NY: IBM Corp) for a descriptive examination. Results were reanalyzed by a second scorer for reliability.

RESULTS

Smile Train sent a total of 846 surveys to its worldwide partners, with 658 responses obtained. One survey was completed by each Smile Train center. Smile Train centers are located in different regions including Africa (Mali, Malawi, Cameroon, Ghana, Tanzania, Democratic Republic of the Congo, Somalia, Ethiopia, Nigeria, Rwanda, Uganda, Madagascar, Kenya, Burundi, Guinea, Senegal, Togo, Gambia, Mauritania, Côte D'Ivoire, Mozambique, Burkina Faso, Niger, Zambia, Guinea Bissau, Zimbabwe, Gabon, Chad, and Egypt), Americas and Europe (Haiti, Brazil, Ecuador, Mexico, Peru, Colombia, Panama, Nicaragua, Ukraine, Venezuela, Bulgaria, Bolivia, Honduras, Russian Federation, Guatemala, Chile, Argentina, and Dominican Republic), Asia (Laos, Vietnam, Cambodia, Palestinian Territories, India, Philippines, Indonesia, Bangladesh, Pakistan, Nepal, Thailand, Jordan, Sri Lanka, Afghanistan, Uzbekistan, and Myanmar), and North Asia (Mongolia and China). The total survey response rate was 78%, with most responses recorded in Asia. A breakdown of respondents by geographic region is presented in Supplementary Digital Content, Table 2, <http://links.lww.com/SCS/D6>.

Sixty-five percent of total respondents identified speech therapy as needing the most support within comprehensive cleft palate care. Regionally, 61.3% of respondents from African countries identified such need, whilst 54.8% of positive responses were gathered from American and European regions, 64.8% from Asian countries, and 78.6% from North Asian territories.

Qualitative comments on the need of speech therapists in such teams included "Speech therapists are limited. . .," "speech and nutrition are facets not readily available in the province. . ." or "there are no residential speech therapists in our country. A speech therapist from Kenya (2 countries away, as we count things in Somaliland) comes occasionally to the capital city".

Master's level training for speech and language therapists was seldom reported in the questionnaires, with most positive responses recorded in European and American countries (62.6%). African countries reported the lowest percentage of training at the master's level, 10.6%, followed by North Asian territories (19.8%) and Asia (25.6%).

Barriers to the delivery of speech therapy centered around 6 primary topics and included qualitative descriptions of the present gaps observed: having no connection to local providers (eg, "nous ne disposons pas encore de service d'orthophonie" [we do not have access to speech-language services yet]); having no local language materials (eg, "we do not have any materials to provide to patients in their local languages about cleft palate speech"); seeing no progress in speech therapy leading to speech not being prioritized (eg, "we do not see any progress with speech therapy so it is not prioritized"); families not being able to afford travel (eg, "almost all patients are coming from rural, far and poor areas"); families not returning after palate surgery (eg, "most patients do not comply with orthodontic and speech treatment follow ups because of the cost incurred"); and families not being able to afford to pay for speech services (eg, "presently speech therapy is not free of cost. But speech therapy and assessment would help us decide in terms of revision palatoplasties for better speech"). Figure 1 represents the distribution of barriers for speech services per main world region.

DISCUSSION

This study evaluated the barriers to speech services in individuals with CLP with the goal of better understanding the needs of this population globally. Results indicated that lack of resources, including access to local speech providers and language materials, as well as financial constraints, such as patient travel and speech treatment costs, are the most commonly reported barriers to accessing speech services across all geographic regions.

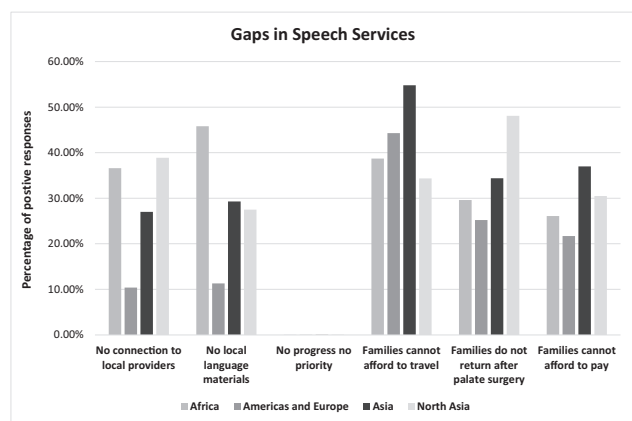


FIGURE 1. Distribution of barriers or gaps for speech services per main world region.

Access to Local Speech Providers

The lack of local speech providers was a reported barrier to speech services for individuals with CLP. The greatest number of respondents who identified this as a barrier were from North Asia, followed by respondents from Africa, Asia, and then the Americas and Europe. In many regions of the world, SLPs are scarce or unavailable^{7–9} to meet the needs of individuals with CLP.¹⁰ To address the lack of availability of SLPs, training other professionals in cleft speech therapy has been successful.^{16–19} In some countries, such as Uganda, for example, speech and language services have been traditionally provided by international healthcare professionals.²⁰ In Sri Lanka, individuals with a health or education background participated in a 16-week cleft speech and habilitation training program that was directed by British therapists, which included observation and practical experience in cleft speech therapy. Upon completion of the training program, trainees were judged to be skilled in providing speech therapy to individuals with CLP.^{21,22} Likewise, a program in rural India found that with periodic retraining, resource workers could provide speech services under the supervision of an SLP in places, where SLPs are not available.¹⁶

Smile Train works to identify local para/medical professionals connected to the Smile Train surgical partners and teams to build capacity so the children can receive competent cleft palate speech therapy.^{23,24} Training the local para/medical professionals to work on speech therapy is known as task shifting.²⁵ Task shifting models as part of global health development can be beneficial in distributing the number of medical providers for the medical services needed. For example, instead of having 5 nurses and no speech therapists, it might be beneficial to train 1 or 2 of the nurses to assess and treat speech in the absence of a trained SLP professional. This paradigm was recently explored in Nepal, where auxiliary nursing midwives were supervised by 2 licensed SLPs to provide cleft palate speech therapy during a one-week camp. Findings from this study indicated that task-shifted speech therapy resulted in significant speech improvements, hence contributing to improved postsurgery care.²⁶

To support speech therapy services, Smile Train and Teachers College, Columbia University developed and offer “Train-the-Trainer” courses to build local capacity for cleft speech therapy. This downloadable training was developed so that SLPs or local professionals, who had received cleft palate speech therapy training and were identified as potential trainers themselves, had a curriculum and materials to offer the training worldwide. This training

focuses on how to perform cleft palate speech therapy for patients’ postpalate repair and includes developing assessment and treatment skills as well as broader understanding of anatomy and physiology, cleft palate surgical procedures, feeding babies prepalate repair, and other foundational information. The Train-the-Trainer course includes a list of materials, an appropriate order for presenting the materials, the set of needed PowerPoints and videos, pre- and post-tests and daily quizzes, therapy materials in over 30 languages, and teaching strategies, all to ensure that the course objectives are targeted during the trainings.^{27–29} All the trainings are available in English, Spanish, and soon also in French for free download and copying at leadersproject.org, making them accessible and available in LMICs.³⁰

Implementation of international workshops to educate local SLPs on cleft palate speech therapy has also been developed to improve services and increase sustainability of cleft palate care in LMICs. Alighieri et al²⁰ reported on a 2-day free workshop conducted in Uganda for a group of 17 local SLPs. The contents of the workshop included anatomy and physiology, perceptual assessment of cleft palate speech, and multidisciplinary care to address the needs of this population. In general, SLPs reported increased knowledge and self-confidence in the assessment and treatment of cleft palate speech after training.

In 2015, Smile Train leveraged the aforementioned Teachers College training material to sponsor a workshop on cleft speech therapy in Addis Ababa, Ethiopia that included participants from the United States (US), Ethiopia, Nigeria, Kenya, Tanzania, and Ghana.¹⁷ In 2017, Smile Train held a workshop for SLPs, nurses, and social workers who work at Smile Train partner hospitals in the Philippines. The SLPs were primarily from Manila, whereas the nurses and social workers were from the more remote regions, where there were no speech therapists to provide speech therapy. The aim of the workshop was to empower these professionals and meet the speech needs of individuals who otherwise would not have speech services available.¹⁸ Additionally, in 2019 and 2020, Smile Train sponsored two 5-day capacity-building trainings focusing on cleft speech therapy for multiple disciplines including surgeons, SLPs, otolaryngologists, audiologists, psychologists, geneticists, dentists, pediatricians, nurses, and social workers in Abuja and Lagos, Nigeria.¹⁹ Since 2014, Smile Train has sponsored over 25 of these in-person Train-the-Trainer capacity-building programs in over 15 LMICs, most of that include ongoing follow-up, mentorship, and retraining, when needed, to ensure that the children receive quality speech services.³¹

Parent training is an important part of virtually all cleft palate speech therapy because the parent must provide feedback and support during the practice time at home, especially when limited services are available. Training videos have featured parents showing how others can do cleft speech therapy at home and attest to its effectiveness.^{32–34} Additionally, Smile Train has developed a free, interactive cleft palate speech application for parents in both Spanish, English, and Tagalog. With its stories, games, and songs targeting speech sounds, the app supports families with limited access to speech therapy and encourages children to practice target sounds.³⁵

Providing speech therapy services via teleconference has been successfully established in an attempt to extend speech services to individuals with CLP worldwide.^{36,37} In Nicaragua, individuals initially received telehealth speech therapy sessions with an SLP in Baltimore. The SLP also trained a health care provider in Nicaragua in CLP speech therapy. The health care provider then reinforced strategies between therapy sessions. Individuals demonstrated significant improvement in voice quality and speech intelligibility.³⁷ Similarly, Furr et al,³⁶ found improvement in overall speech intelligibility in individuals with cleft speech who participated in telehealth speech therapy sessions conducted between the

Pacific Northwest and Peru. In light of the COVID-19 pandemic, Smile Train partners in Brazil have successfully provided telehealth speech therapy to their patients and will continue to provide telemedicine beyond COVID-19 to patients who have no access to speech services.³⁸ Likewise Smile Train partners in the Philippines developed a virtual speech camp for patients during the pandemic.³⁹ Overall, telehealth is thought to be a potential solution to decreasing barriers to CLP care.⁴⁰

Training individuals to provide cleft palate habilitation via the cleft palate speech and feeding video tutorials^{41,42} has been an effective tool in teaching graduate students in speech-language pathology about CLP. The cleft palate speech and feeding video tutorials were developed for graduate students, parents, professionals, and SLPs to acquire the clinical skills to treat individuals with CLP. Additionally, they were created for medical providers in LMICs to learn about how to support speech development in children with CLP when there are no SLPs in the region or country. The cleft palate speech and feeding video tutorials are a free and easily accessible online CLP self-study course that includes a series of 17 video modules that cover the following topics: typical anatomy and physiology, pathophysiology of different types of clefts, submucous and occult clefts, velopharyngeal closure and nasoendoscopy, production of speech sounds, resonance, syndromes, surgical repair, feeding, oral examination and speech sound assessment, types of common cleft palate speech errors, and related strategies and treatment. Most importantly, there is an assessment with 75 multiple-choice questions that includes auditory questions using short videos. Those who pass the assessment with at least 80% correct receive a certificate of completion via email. Professionals who wish to attend a Smile Train cleft palate speech Train-the-Trainer course in an LMIC must provide a certificate showing that they have passed this online course. By requiring proof of passing the assessment for the online course, all participants come in with a minimum level of knowledge and skills about cleft palate speech therapy that can be built upon in the live train-the-trainer course. Even without an opportunity to take an in-person train-the-trainer course, by passing the online course, professionals can present the certificate and show that they have some foundational knowledge and skills for cleft palate speech therapy. This course may address the need to provide quality services and increase the number of trained SLPs in cleft palate habilitation internationally.⁴³

Additionally, efforts have been made to develop the profession of SLP in LMICs. For example, the University of Ghana initiated a Masters of Speech-Language Therapy program in September 2016. The first cohort of 12 speech-language therapists graduated in August 2018. The second cohort of 13 speech-language therapists is expected to graduate in October 2021.⁴⁴ Similarly in Togo, the Ecole Nationale des Auxiliaires Médicaux of Lomé has been offering a program in speech-language therapy for French-speaking students from African countries with new cohorts graduating every 3 years since 2003.^{45,46} In Ethiopia, Transforming Faces partnered with the University of Toronto and Addis Ababa University to create Ethiopia's first speech therapy university program and the first group received their degrees in 2019.⁴⁷ Uganda's first speech therapy university program was established in 2008 through collaborations with the Makerere University, the Mulago National Referral Hospital and the Voluntary Services Overseas.^{42,48} South Africa has 7 well-established SLT programs at Sefako Makgatho Health Sciences University, University of Cape Town, University of Fort Hare, University of KwaZulu-Natal, University of Pretoria, University of Stellenbosch, and University of Witwatersrand.^{49–55} Nigeria offers a speech therapy certificate as part of its special education degree at the University of Ibadan Department of Special Education.⁵⁶

Level of Training

The highest percentage of Master's level training is found in European and American countries, followed by Asian countries, then North Asian territories, and the lowest percentage of Master's level training found in African countries. It should be noted that a Master's level training does not necessarily equate to having the knowledge base or clinical skills needed to diagnose and treat individuals with CLP. For example, in the US, the majority of Master's level programs offer less than a full course on CLP and most Master's level students do not have clinical experience with this population.⁵⁷ As a result, many SLPs in the US have reported feeling insufficiently prepared to provide speech services to individuals with CLP.^{58–60} The shortage of highly trained SLPs with the skills to treat patients with CLP may explain the reported need for speech therapy to receive the most support within comprehensive CLP care services worldwide.

Unavailable Materials in Local Languages

Lack of access to materials in local languages was also identified as a barrier to speech services. The greatest number of respondents who identified this is a barrier were from Africa, followed by respondents from Asia, North Asia, and finally the Americas and Europe. Although the lack of materials in local languages continues to be a barrier, initiatives like the LEADERSProject at Teachers College of Columbia University have been developed to increase the availability of CLP materials in multiple languages. On its website, the LEADERSProject hosts CLP resources in multiple languages. This includes CLP assessment screeners in Mandarin, Igbo, French, Twi, Ewe, Ga, Shona, Nyanja, Ndebele, Chichewa, Spanish, and English; CLP treatment materials such as practice books and speech therapy sound games in English, Spanish, Hindi, Mandarin, Igbo, Italian, Portuguese, Korean, French, Twi, Hausa, Yoruba, Ewe, Arabic, Thai, and Amharic; and a CLP online training module, the cleft palate speech and feeding video tutorials,⁴¹ in Spanish, French, and English.^{34,60} Since the video tutorials are available on YouTube, the subtitle captions can be automatically translated into 1 of over 140 languages. These materials are supported and distributed by Smile Train⁶¹ and are hosted at leadersproject.org.

Financial Constraints

Lastly, financial constraints such as patient travel and speech treatment costs are commonly reported barriers to speech services. The greatest number of respondents who identified patient travel as a barrier were from Asia, followed by respondents from Americas and Europe, Africa, and then North Asia. Unaffordable travel costs may be due to lengthy distances to speech providers and poor infrastructure.^{26,62} Smile Train has recognized transportation as a need across all comprehensive cleft care areas and offers grants to local partner hospital/cleft teams to subsidize travel through their grant program called "Smile Grants".^{63–65} Since 2015, Smile Train and the Indonesian Army have partnered to provide free transportation for individuals with CLP to reach their nearest Smile Train partner hospital.⁶⁴ Smile Train also funds vans to help transport patients as part of their grants program called "Equipment Grants".⁶³ Additionally, sponsoring programs that target time-intensive camps can assist in reducing transportation costs in these countries.^{66–68}

Treatment costs were also a reported deterrent to receiving speech services. The greatest number of respondents who identified this as barrier were from Asia, followed by respondents from North Asia, Africa, and then the Americas and Europe. This financial burden may lead to significant delays in receiving speech services.

Both the shortage of providers and prohibitively expensive travel and treatment costs may be associated with families not returning after palate surgery. The respondents from North Asia reported the highest percentage of patients not returning for follow-up after palate surgery, followed by respondents from Asia, Africa, and Americas and Europe. Smile Train offers financial grants to partner cleft teams with capable speech therapy providers to cover the costs of speech therapy programs.⁶³ Although family responsibilities (eg, childcare, housework, and family health) were not directly addressed in this survey, it should be noted that these have been identified as a major barrier to follow-up for cleft palate care in some LMICs, such as Nepal.²⁶ Results from this survey indicated that overall families would not deem speech therapy as lacking priority.

Limitations

Although Smile Train is the largest cleft-focused organization, there are several other international and in-country organizations that support international treatment of clefts through different models of education and care. There may be barriers to speech therapy that are not reported in this paper. Additionally, this study was limited to a retrospective survey design, with multiple-choice responses and an option to further comment if needed; however, not all centers expanded on these comment boxes. Thus, there may be barriers beyond what is represented and reported in the questionnaires. Moreover, this research was solely representative of a snapshot in time (June 25th to July 31st, 2018). Future studies should analyze survey data longitudinally to assess if these barriers decrease, increase, or remain the same over time. Obtaining this information over an extended period of time will help better address these partners' needs and potentially improve patient care in the long term.

CONCLUSIONS

In sum, a lack of trained, qualified speech professionals, limited speech resources, and financial constraints are the most commonly reported barriers to accessing speech services worldwide. Identifying these barriers may assist the global cleft community and speech community in teaming together to continue to build successful approaches to improve access to CLP speech services globally. As availability to speech providers increases, the need to increase financial support to speech services is also warranted.

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