

RESEARCH LETTERS

**Multidisciplinary Care of International Patients With Cleft Palate Using Telemedicine**

Cleft lip and palate is the most common congenital malformation, with an incidence of 1 per 600 to 1000 live births worldwide. In the developed world, the treatment and repair of children with cleft palate (CP) is multidisciplinary, involving care given by speech-language pathologists, otolaryngologists, plastic surgeons, nutritionists, dentists, and geneticists.<sup>1</sup> International volunteer groups routinely provide quality surgical care; however, the repair of the palate must be followed by speech therapy in order for these children to be able to speak normally. Currently, no effective strategy has been developed to address this disparity and provide postoperative speech training. The lifelong effects of speech deficits are profound and well documented.<sup>2</sup>

The American Speech-Language-Hearing Association (ASHA) has stated that telepractice (telehealth) is an appropriate model of service delivery for the speech-language pathology (SLP) profession. To date, only 1 (anecdotal) article<sup>3</sup> has described the use of telemedicine to deliver speech therapy to patients after surgery in the developing world; however, no objective measures were used. Although only 1 study<sup>3</sup> to date has addressed the use of telepractice to deliver speech therapy following the repair of CP, there have been numerous studies that have shown that providing SLP services for other speech disorders via telecommunications is both feasible and beneficial.<sup>4-6</sup>

**Methods.** Following institutional review board approval, 10 patients aged 3 to 17 years with velopharyngeal insufficiency (VPI) and other speech disorders secondary to repair of CP deformities were selected for this study. All 10 patients had both cleft lip and CP deformities, and informed consent was obtained from the parents of all participants. All patients had operations performed by surgeons from Greater Baltimore Medical Center and/or The Johns Hopkins University Medical Institutions (Baltimore, Maryland) as part of a humanitarian effort in Nicaragua in 2009 or 2010. Oversight of postoperative care was provided by our team initially and then transitioned to the team of physicians in Nicaragua.

The WebEx Internet-based, video-teleconferencing platform by Cisco Systems Inc (San Jose, California) was used for all therapy sessions. A Spanish interpreter was present in Nicaragua for all telehealth sessions; our speech-language pathologist (P. J. Bailey) was located in Baltimore. Methods of evaluation included perceptual judg-

ment of voice quality; a Spanish speech inventory, Contextual Probes of Articulation Competence-Spanish (CPAC-S)<sup>7</sup>; and a patient and parent quality-of-life (QOL) survey developed by our team. The CPAC-S assesses all Spanish phonemes and many frequently occurring phonological processes. In addition, it contains a full assessment that provides a comprehensive analysis of articulation and phonological skills.<sup>7</sup> Both the CPAC-S assessment and QOL survey were given during the first telehealth encounter and repeated during the final encounter; these scores were then compared. Each child underwent 2 or 3 monthly telehealth sessions with our SLP. Data from 8 of the 10 children who completed at least 3 sessions will be reported in this initial study. All data were analyzed using Microsoft Excel software (Redmond, Washington), and significance was based on a 2-tailed *t* test assuming unequal variance.

**Results.** In addition to improvement noted in voice quality and speech intelligibility throughout the telehealth sessions, the CPAC-S program was used to objectively measure improvement in speech as well as to serve as a therapeutic tool. The **Table** demonstrates a significant improvement in whole word, initial consonant, and total score ratios with *P* values of *P* < .03, *P* < .04, and *P* < .05, respectively, whereas total and final consonant sound ratios were not significant.

An extensive review of the literature did not elucidate an already established QOL survey specific to speech in the population of patients with CP. Therefore, we initially created a 16-question parent-caregiver survey to assess pre-treatment and posttreatment QOL in our patients. To decrease repetitive questioning and improve ease of administration, this survey was narrowed to 11 questions, all assessed using a typical 5-point Likert scale (**Figure 1**). Prior to administration, the survey was translated in its entirety to Spanish. The survey addresses many of the physical, emotional, and functional challenges dealt with by vali-

**Table. CPAC-S Scores**

Result	Score		<i>P</i> Value
	Pretreatment	Posttreatment	
Whole words correct	14 of 64	33 of 64	<.03
Total consonants correct	99 of 179	138 of 179	<.06
Initial consonants correct	84 of 160	123 of 160	<.04
Final consonants correct	12 of 19	16 of 19	<.13
<b>Total Score<sup>a</sup></b>	<b>211 of 422</b>	<b>309 of 422</b>	<b>&lt;.05</b>

Abbreviation: CPAC-S, Contextual Probes of Articulation Competence-Spanish.<sup>7</sup>

<sup>a</sup>Totals are not exact due to rounding.

Cleft Palate Speech-Related Quality of Life Survey					
Please answer the following questions regarding your child's speech and behavior using the following rating system:					
1 = Strongly disagree					
2 = Disagree					
3 = Neither agree nor disagree					
4 = Agree					
5 = Strongly agree					
1. I am more concerned about my child's speech than about his/her physical appearance.	1	2	3	4	5
2. My child talks as much as other children his/her age while at school.	1	2	3	4	5
3. My child is often asked to repeat him/herself.	1	2	3	4	5
4. My child gets frustrated when he/she is not understood.	1	2	3	4	5
5. My child appears more comfortable around our family than with peers.	1	2	3	4	5
6. My child avoid playing or socializing with other children because of his/her speech.	1	2	3	4	5
7. My child is teased about his/her speech.	1	2	3	4	5
8. My child is teased about his/her physical appearance.	1	2	3	4	5
9. My child is teased more often about his/her speech than his/her physical appearance.	1	2	3	4	5
10. My child is asked about why his/her speech is different.	1	2	3	4	5
11. My child's speech is improving.	1	2	3	4	5

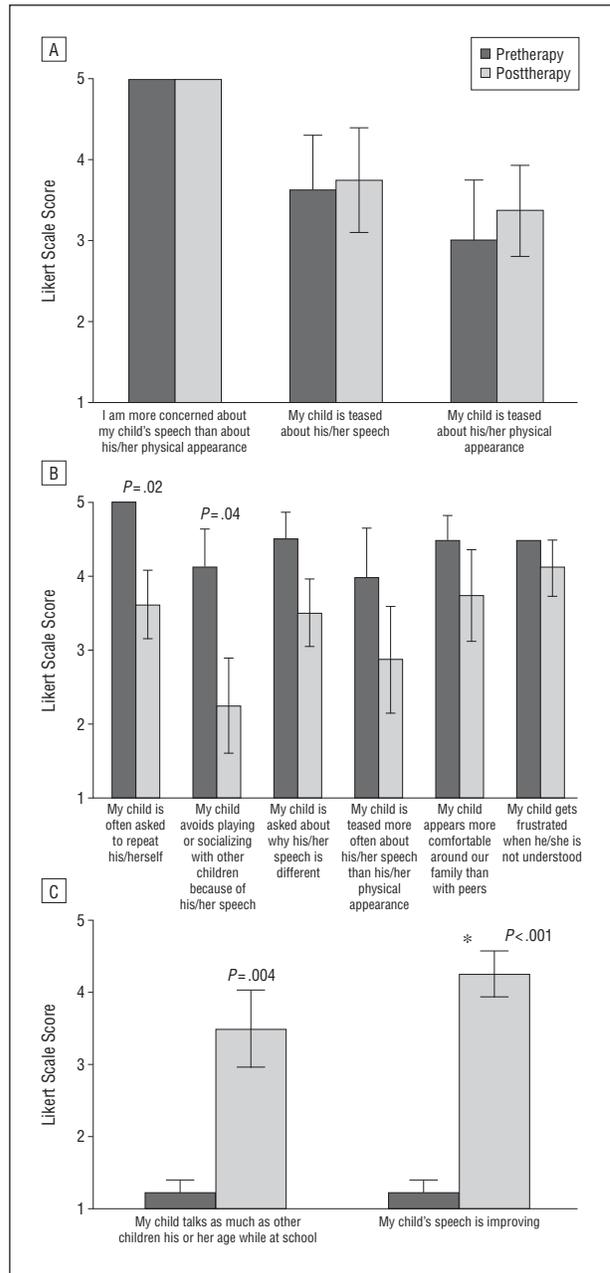
**Figure 1.** Cleft Palate Speech-Related Quality-of-Life (QOL) Survey. We developed a parent-caregiver QOL survey based on a 5-point Likert scale that attends to the unique challenges experienced by patients with cleft palate, who have both appearance- and speech-related concerns.

dated surveys, such as the pediatric Voice Handicap Index (pVHI) and the pediatric Voice-Related Quality of Life (pVRQOL) survey, but in addition addresses the unique challenges experienced by patients with CP, who have both appearance- and speech-related concerns<sup>8,9</sup> (Figure 1).

The pVHI and pVRQOL survey do not address parent-caregiver concern for his or her child, even though a parent-caregiver may comprehend the effects of the child's deformity better than the child himself. This has been identified as a possible weakness in these surveys, and thus our survey was modified to assess parent-caregiver concerns for his or her child's speech (Figure 1).<sup>8</sup>

Survey results show that the parent-caregiver continued to be more concerned about his or her child's speech than about physical appearance and that the parent's perception of whether the child was teased based on looks or communication did not change significantly (**Figure 2A**). After therapy, patients were asked significantly less often to repeat themselves, and, what is more important, patients after therapy were expanding their social networks and were significantly less likely to avoid social situations because of their speech ( $P = .02$  and  $P = .04$ , respectively) (Figure 2B). In Figure 2B, improvement is noted as a trend from 5 (strongly agree) to 1 (strongly disagree). Figure 2C shows significant improvement in the parents' perception of their children's speech as well as their perception that their children were speaking as much as other children of the same age ( $P < .001$  and  $P = .004$ , respectively). This improvement is noted by movement along the Likert scale from 1 to 5.

**Comment.** In this ongoing study, we objectively show, to our knowledge for the first time, that telemedicine offers the potential to extend SLP services following CP re-



**Figure 2.** Quality-of-life survey scores improved significantly following treatment. A, Parents continue to be concerned about their child's speech, more so than about physical appearance, and the parents' perception of whether their child was teased based on looks or communication did not change significantly posttherapy. B, After therapy, patients were asked significantly less often to repeat themselves and were significantly less likely to avoid social situations because of their speech ( $P = .02$  and  $P = .04$ , respectively). Improvement is marked by trend on a 5-point Likert scale from 5 (strongly agree) to 1 (strongly disagree). C, Parents' perception of their child's speech as well as their perception that their child was speaking as much as other children of the same age showed significant improvement ( $P < .001$  and  $P = .004$ , respectively). This improvement is noted by movement along the Likert scale from 1 to 5. Significance was based on a 2-tailed *t* test assuming unequal variance. Error bars indicate standard error of the mean. \*Significant improvement.

pair to rural, remote, and underserved populations in culturally and linguistically diverse locales. In this study, we have already shown that SLP provided via Internet-based telecommunications can significantly improve postoperative functional outcomes in the international popu-

lation of patients with CP. Another key component of this study has been the ability of our SLP to remotely train a health care provider who is not a speech-language pathologist to teach and reinforce SLP techniques on a weekly basis between monthly teleconference therapy sessions. This was accomplished through initial education in the anatomy of clefting and VPI as well as normal speech development during childhood. The chosen health care provider in Nicaragua had training in physical therapy but no specific training in SLP. After every monthly session, a postsession conference between our speech-language pathologist and their health care provider occurred in order to define future goals for each child, including therapeutic techniques to use to work toward those objectives. Parents were also instructed on exercises and goals to perform and reinforce on a daily basis with the children at home, much the same as we do for parents in the United States.

One limitation of this study is the use of an English-speaking speech-language pathologist to provide therapy for Spanish-speaking children through an interpreter. Prior to beginning this study, our speech-language pathologist studied the linguistics of Spanish speech development, reviewed the correct pronunciation of various Spanish phonemes with native speakers, and studied the proper mode, manner, and placement of Spanish phoneme production. The ideal situation would be to have a speech-language pathologist who was not only bilingual but also spoke in the dialect specific to Nicaragua. However, to our knowledge there is no such specialist in Nicaragua or the United States. Given the preliminary results shared in this article, we believe that, through an interpreter who speaks the native dialect, our English-speaking speech-language pathologist has been able to improve the speech of these patients. We believe this model is applicable to and more feasibly implemented by more health care providers performing this type of humanitarian work.

Our overall goal is to demonstrate the power of telepractice in overcoming longstanding disparities in the care of international patients.

Chad A. Glazer, MD  
 Patti J. Bailey, MS, CCC-SLP  
 Ivette L. Icaza, MD  
 Socorro J. Valladares, PT  
 Katherine A. Steere, MS, CF-SLP  
 Elizabeth S. Rosenblatt, BS  
 Patrick J. Byrne, MD

**Author Affiliations:** Department of Otolaryngology–Head and Neck Surgery, Division of Facial Plastic and Reconstructive Surgery Johns Hopkins Medical Institutions, Baltimore, Maryland (Drs Glazer and Byrne and Ms Rosenblatt); Milton J. Dance Head and Neck Center, Greater Baltimore Medical Center, Baltimore (Mss Bailey and Steere); and Hospital Metropolitano Vivian Pellas, Managua, Nicaragua (Dr Icaza and Ms Valladares).  
**Correspondence:** Dr Byrne, Division of Facial Plastic and Reconstructive Surgery, The Johns Hopkins University School of Medicine, 601 N Caroline St, Sixth Floor, Baltimore, MD 21287-0910 (pbyrne2@jhmi.edu).

**Author Contributions:** *Study concept and design:* Glazer, Bailey, and Byrne. *Acquisition of data:* Glazer, Bailey, Icaza,

Valladares, Rosenblatt, and Byrne. *Analysis and interpretation of data:* Glazer, Steere, Rosenblatt, and Byrne. *Drafting of the manuscript:* Glazer, Icaza, and Valladares. *Critical revision of the manuscript for important intellectual content:* Glazer, Bailey, Steere, Rosenblatt, and Byrne. *Statistical analysis:* Glazer and Byrne. *Obtained funding:* Byrne. *Administrative, technical, and material support:* Bailey, Icaza, Valladares, Steere, and Byrne. *Study supervision:* Glazer and Byrne.

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## Addressing Challenges of Cleft Lip and Palate Deformity in Afghanistan

The purpose of this report is to describe my experience with evaluating and treating cleft lip with and without cleft palate (CL/P) deformity in pediatric patients in Afghanistan from November 2009 to November 2010. Pediatric patients in Afghanistan are plagued by numerous challenges, including poor nutrition, limited access to health care, and lack of educational resources. The lack of plastic surgery care in Afghanistan was recently highlighted by *Time*.<sup>1</sup>

**Report of Cases.** The literature is deplete of reports of congenital malformations in Afghanistan. One older study<sup>2</sup> prospectively evaluated congenital malformations at birth among live-born infants. The incidence of major and minor malformations was 2.4% and 3.1%, respectively. This increased incidence reflected a higher occurrence of CL/P. The history of parental consanguinity was notably higher among parents of infants with major congenital malformations compared with unaffected control infants.<sup>2</sup> The Combat Support Hospital (CSH) at Bagram Airfield, Afghanistan, has been operational since 2002.<sup>3</sup> Most patients seen are Afghani local nationals (81%), of whom 35% are younger than 18 years. This facility represents