

Satisfaction of Speech and Treatment for Children with Cleft Lip/Palate in Lao People's Democratic Republic

Benjamas Prathanee PhD*,
Tawitree Pumnum BSc*, Pechcharat Jaiyong BSc*,
Cholada Seepuaham BSc*, Vieng Xayasin TN**

* Department of Otolaryngology, Faculty of Medicine, Khon Kaen University, Khon Kaen, Thailand
** Mahosot Hospital, Vientiane, Lao People's Democratic Republic

Background: Surgical treatment and speech therapy for people with cleft lip and palate (CLP) in the Lao People's Democratic Republic (Lao PDR) are either limited or not available in some areas. There continue to be patients needing surgical correction for abnormalities but they are past the age when surgery would be appropriate. Moreover, they have not been given speech services or received integrative multidisciplinary diagnosis and treatment.

Objective: To explore satisfaction on speech and treatment outcomes, as well as the further treatment needs for CLP in Lao PDR.

Material and Method: A literature review was undertaken and a background conducted on the problems of services for CLP in Lao PDR. A questionnaire was then developed to explore the magnitude of effects on speech and treatment outcomes as well as further treatment needs for CLP.

Results: Average scoring of children with CLP speech and configuration indicated that they have the least satisfaction with articulation and figure of lips. The majority of caregivers and patients agreed that correction of articulation defects was the aspect of their care most needing further treatment.

Conclusion: Satisfaction with speech and treatment outcomes was critical issues in Lao PDR requiring development of an appropriate therapy model for children with CLP.

Keywords: Satisfaction, Speech outcome, Treatment outcome, Speech service, Developing countries

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An estimated quarter of a million new babies with cleft lip and/or palate (CLP) will be born in the poorest parts of the world in the next decade. Of concern is that where resources are limited or non-existent the children will potentially go untreated past the time in their physical/psychosocial development for the best recuperative potential⁽¹⁾. The highest prevalences for CLP are reported for Native Americans and Asians⁽²⁾. Even though there is no direct estimate of the incidence in the People's Democratic Republic of Lao (Lao PDR), an estimate can be based on the incidence in neighboring countries: the possible rate of CLP in Lao PDR could be ~0.02/1,000.

Surgical care, including local and mobile units

from non-profit organizations (*i.e.*, Operation Smile, Smile Train, Interplast Australia and New Zealand, Center of Cleft Lip-Palate and Craniofacial Deformities, Khon Kaen University, in association with Tawanchai Project) have disappointingly resulted in an unintended stigma for individuals with CLP in Lao PDR. The reason: although access to care in developing countries has increased in recent years, the quality of care varies substantially⁽⁴⁾. The lack of the interdisciplinary cleft care approaches-particularly speech and language services-are not being addressed. This is concern since delayed speech and language development, compensatory speech disorders and velopharyngeal insufficiency are common problems for children with cleft lip and palate^(5,6). Moreover, there is considerable evidence of a high prevalence of speech disorders and structural disorders in patients with CLP in developing countries⁽⁷⁾.

Speech disorder treatment remains a high priority in some developing countries, particularly in

Correspondence to:

Prathanee B, Department of Otolaryngology, Faculty of Medicine, Khon Kaen University, Khon Kaen 40002, Thailand.
Phone: 043-348-396, Fax: 043-202-490
E-mail: bprathanee@gmail.com

Lao PDR. Whereas successful projects by training volunteers or personnel at the primary level have been proposed in Vietnam^(8,9), Sri Lanka⁽¹⁰⁾ and Thailand^(11,12), lack of accessibility is a persistent issue in Lao PDR. Patients with CLP in Lao PDR are therefore left unoperated or operated so late they suffer permanent compensatory articulation disorders (*e.g.*, glottal/pharyngeal quality of speech); thus, surgery alone is not sufficient treatment, whether timely or late, to address articulation issues⁽⁷⁾.

In Lao PDR, a long-term program or model for speech therapy is needed. The purpose of this study was to explore satisfaction with speech and treatment outcomes for children with CLP in Lao PDR. This article was approved the research protocol on January 12, 2011 (The Helsinki Declaration: HE 531344).

Material and Method

The principal investigator-associated with The Tawanchai Foundation for Cleft Lip, Cleft Palate and Craniofacial Deformities-explored the background of regional problems of speech services and treatment of CLP in Lao PDR by interviewing patients and other involved persons (*e.g.*, adult patients, caregivers and nurses). The survey was done while the team was conducting (a) a mission for CLP at the Luxemburg Hospital and Mahosot Hospital in 2008, (b) a collaboration with “Cleft Lip Workshop” at Mahosot Hospital in 2009, and (c) a collaboration with Multidisciplinary Care for Cleft Lip and Palate: Cleft Palate Surgery Workshop in 2010.

In order to evaluate the ‘present condition’ in developing countries where the use of a multidisciplinary approach is limited, the authors reviewed the literature vis-a-vis speech problems, therapy and treatment of children with CLP⁽⁸⁻¹⁴⁾. To study satisfaction with speech and treatment outcomes for CLP, a questionnaire was developed relevant to regional-based treatment for children with CLP in Lao PDR. With support from The Khon Kaen University Cleft Palate Craniofacial Center (Tawanchai Foundation) and Khon Kaen University, a workshop was conducted on Collaborative Multidisciplinary Care of Cleft lip and Palate at Khammouane Province Hospital, Thakhek, Khammouane province, Laos PDR from October 18-20, 2010.

The first draft of the questionnaire-on satisfaction with speech, overall treatment and further treatment needs for children with CLP-was introduced and clarified with the help of 8 paraprofessionals or nurses (representatives from 8 hospitals in Lao PDR).

Suggestions for revisions were reviewed and the final version amended. The questionnaires were comprised three parts: (a) satisfaction with speech outcomes (*i.e.*, articulation, resonance, voice and intelligibility), (b) satisfaction with overall treatments (*i.e.*, shape of face, lips, nose and teeth and (c) identification of further treatment needs (*i.e.*, for correction of articulation, resonance, voice and/or intelligibility).

Subsequently, 27 people were interviewed: 9 caregivers with children ≥ 2 years of age who had started saying meaningful words, phrases and sentences; 9 caregivers; and 9 patients ≥ 8 years of age, old enough to understand and respond to questions. Interviews were conducted in Lao for ease of communication, under the supervision of three speech and language pathologists (a principal investigator and 2 speech and language pathologists/coauthors) to explore the satisfaction level among caregivers and clients.

Analysis

Descriptive analyses were used for (a) the demographic characteristics of the children (b) the satisfaction with speech outcomes (c) satisfaction with overall treatments and (d) further treatment needs.

Results

Twenty-four children with CLP enrolled for surgery. Nine children were under 8 years of age, 9 were between 2 and 7 and 9 were < 2 . The majority (75%) of the 24 patients who enrolled in the project-particularly those needing chieloplasty-had not received their corrective surgery at an appropriate time.

The satisfaction with speech outcomes are presented in Table 1. Articulation got the least satisfaction while voice got the most.

Caregivers and patients rated the satisfaction with the configurative outcomes: the highest was for teeth alignment and the least for lips (Table 2).

Regarding further treatment needs, the greatest need was for correction of articulation defects while the least was for voice disorders (Table 3).

Discussion

Caregiver and patient satisfaction with the cleft care is one of the most important outcomes when evaluating corrective/rehabilitation programs in developed countries. However, most of studies related to speech therapy in developing countries^(10,11,15-18) make scant mention of the assessment of satisfaction of speech and treatment outcomes and further treatment needs. Possibly, this is because people lack

Table 1. Percentage of Satisfaction for speech outcome

Satisfaction items	Very much	Much	Moderate	A little	Very Little
Articulation	37.50	8.33	37.50	12.50	4.17
Resonance	40.74	22.22	14.81	7.41	14.81
Voice	59.26	7.41	18.52	0.00	14.81
Intelligibility	53.85	11.54	11.54	11.54	11.54

Table 2. Percentage of global appearance satisfaction

Satisfaction items	Very much	Much	Moderate	A little	Very little/No
Figure of whole face	24.00	12.00	12.00	8.00	44.00
Figure of lips	23.08	7.69	11.54	3.85	53.85
Figure of noses	30.77	7.69	11.54	11.54	38.46
Figure of teeth	37.04	3.70	7.41	3.70	48.15

Table 3. Percentages of the further treatment needs for speech defects

Treatment needs	Very much	Much	Moderate	A little	Very little/No
Articulation defects	53.85	11.54	3.85	0.00	30.75
Resonance defects	50.00	7.69	0.00	3.85	38.46
Voice defects	34.62	3.85	3.85	0.00	57.69
Unintelligibility	39.13	13.04	8.70	4.35	34.78

understanding about the full spectrum of speech services available for patients both pre- and post-surgery in CLP. The authors and international professionals directly concerned posit that the main problem is the lack of timely and on-going speech therapy services. Therefore, the authors work may represent pioneer research for persons with CLP in developing countries, focusing on current satisfaction and needs for further treatment.

The majority of persons studied had not received corrective surgery at an appropriate time, which explained why most of them still had articulation defects, resonance disorders and stigma from uncorrected or late corrected lips (Tables 1 and 2). Some patients did not attend school because of the social stigma of their abnormalities and speech defects. Psychological problems are likely to increase with age.

Evidently, the health education and care system remains limited in Lao PDR and one of the main reasons is that respondents live in remote areas or small communities, and parents can neither afford nor are able to travel to receive treatment. Surgical missions

provided by NGOs provide the best chance for receiving services because such programs provide support for transportation and living expenses.

Participants' interviewing revealed an awareness of further treatment; however, there was no speech therapy treatment available. Speech problems among children with CLP represent the current critical issue in Lao PDR. The establishment of a training program for trainers to help relieve problems is, therefore, urgently needed. Training must, however, be based upon shared attitudes and mutual awareness between/among international and local healthcare institutions and communities^(15,19). The training should include both prescriptive and activity-based training^(15,16). Community-Based Rehabilitation (CBR)-contextually relevant to the needs of Lao PDR-needs to be integrated with Primary Health Care (PHC). Employing both international and local health teams would be one of the best ways of solving the problem⁽¹¹⁾.

Conclusion

Lack of satisfaction with speech and treatment

outcomes remain critical issues in Lao PDR. In order to remedy speech therapy and overall limitations, there needs to be immediate development of a therapy model for children with CLP; such would be based on combining CBR, PHC and institutional approaches.

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Potential conflicts of interest

None.

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ความพึงพอใจของการพูดและผลการรักษาบุคคลปากแหว่งเพดานโหว่ในสาธารณรัฐประชาธิปไตยประชาชนลาว

เบญจมาศ พระธานี, ทวีตรี ภูมินำ, เพชรรัตน์ ใจยงค์, ชลดา สีพัวฮาม, เวียง ไชยาสิน

ภูมิหลัง: การผ่าตัดและการบริการด้านการแก้ไขการพูดสำหรับบุคคลปากแหว่งเพดานโหว่ในสาธารณรัฐประชาธิปไตยประชาชนลาวมีอยู่อย่างจำกัดและไม่มีเลยในบางพื้นที่ จึงยังคงมีผู้ป่วยบางรายที่ยังไม่ได้รับการผ่าตัดแก้ไขความพิการทั้งที่บุคคลเหล่านั้นได้เลยผ่านอายุที่เหมาะสมสำหรับการผ่าตัดไปแล้ว ยิ่งไปกว่านั้นผู้ป่วยเหล่านี้ไม่ได้รับการแก้ไขการพูดหรือการรักษาจากทีมสหสาขาวิชาชีพเลย

วัตถุประสงค์: เพื่อสำรวจความพึงพอใจด้านการพูด ผลการรักษาและความต้องการการรักษาเพิ่มเติมในบุคคลปากแหว่งเพดานโหว่ในสาธารณรัฐประชาธิปไตยประชาชนลาว

วัสดุและวิธีการ: การทบทวนวรรณกรรมที่เกี่ยวข้องและการสำรวจพื้นฐานของปัญหาในการบริการในสภาวะปากแหว่งเพดานโหว่ในสาธารณรัฐประชาธิปไตยประชาชนลาว การพัฒนาแบบสอบถามได้ถูกทำขึ้นเพื่อสำรวจขนาดของปัญหาของการพูด ผลของการรักษาและความต้องการการรักษาเพิ่มเติมในสภาวะปากแหว่งเพดานโหว่

ผลการศึกษา: คะแนนเฉลี่ยของความพึงพอใจด้านการพูดและรูปร่างหน้าตาของเด็กปากแหว่งเพดานโหว่บ่งชี้ว่ามีความพึงพอใจด้านการออกเสียงชัดและรูปร่างของฝีปากมีน้อยที่สุด ผู้ดูแลและผู้ป่วยมีความเห็นพ้องว่าการแก้ไขด้านการออกเสียงชัดเป็นสิ่งที่ต้องการมากที่สุด

สรุป: ความพึงพอใจด้านการพูดและผลการรักษา ยังคงอยู่ในสภาวะวิกฤตในสาธารณรัฐประชาธิปไตยประชาชนลาว ซึ่งจำเป็นต้องพัฒนารูปแบบการรักษาที่เหมาะสมสำหรับบุคคลปากแหว่งเพดานโหว่ต่อไป
