# Caregivers' Feedback after Enrollment in the Community-Based Speech Therapy Model

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***Background:*** *Khon Kaen University Community-Based Speech Therapy Model (KKUCSM) was conducted between 2012 and 2013 in Chiang Rai. Children with cleft lip and palate (CLP) and speech assistants (SAs) enrolled four-day intensive and five one-day follow-up speech camps that were run by speech and language pathologists (SLPs). KKUCSM focused on quantity of reduction of articulation errors. Therefore, it is necessary to find reflection sounds from children with CLP's caregivers for improving health care processes and services.*
***Objective:*** *To evaluate caregivers' reflection sounds after enrollment in the KKUCSM for a year.*
***Material and Method:*** *Data were collected by a focus group discussion and in-depth interviews among 20 mothers, 4 grandmothers, and 2 siblings. Participants were divided into two groups, i.e., caregivers who did and did not enroll in speech camps. Focus group discussions obtained 45 minutes per group. Content analysis was used for data summary.*
***Results:*** *Caregivers who enrolled in the KKUCSM told that their children with CLP were very happy with their peers. They had high self-esteem, self-confidence, good health, and academic achievement. Caregivers expected that their children could have independent living. On the other hand, caregivers who did not enroll in the KKUCSM felt that their children with CLP had low self-esteem and confidence to communicate with other people. The caregivers' concerns with their children involved image, family genetic, illness, psychosocial problems, relationship with other people, and articulation errors.*
***Conclusion:*** *KKUCSM mainly provided speech correction and indirectly supported children with CLP's quality of life (QOL) in psychosocial aspects and academic achievement. KKUCSM also relieved anxiety and improved family economic status.*

***Keywords:*** *Reflection sounds, Speech therapy model, Community base, Cleft palate, Caregivers*

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The majority of children with cleft lip and palate (CLP) suffer from speech and language anomalies after surgery for relieving stigma. Speech and language defects include delayed language development, articulation disorders, resonance disorders, voice disorders, and hearing abnormalities. Reviewing children with CLP revealed that most speech and language disorders ranged from 51 to 63%[1], followed by hyper-nasality at 20 to 30%[2], and voice disorders at 5.5 to 20%[3-5]. In Thailand, it is estimated that children with CLP have delayed speech and language development, articulation disorders, resonance disorders, and voice disorders of 16.33%, 88.56%, 43.26%, and 19.13%, respectively[5]. These problems need long-term care and treatment, particularly speech therapy. Children with CLP who have speech and language defects have low self-confidence to communicate with their peers when attending school that often leads to psychosocial, learning, and academic problems[6]. Children with CLP's and the caregivers' psychosocial problems and dissatisfaction should be a concerned for further support[7-9]. Speech therapy for normal articulation and communication might promote children's confidence. Psychotherapy might be needed for both some children with CLP and the caregivers. Therefore, for those children with CLP who have access to speech therapy on time, this does not only solve speech and language disorders[10,11] but also promote psychosocial development and satisfaction in both children with CLP and the caregivers.

Theoretically, children should be received speech therapy from speech and language pathologists (SLPs) for one to two sessions per week as soon as children with CLP are diagnosed with delayed speech and language development and/or speech disorders. However, most of them cannot access to speech services because of limitations in speech services or

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SLP in some developing countries.

Networking of Khon Kaen University Community based Speech therapy Model (KKUCSM) with Non Thong Tambon Health Promotion hospital, Borabue, and Maha Sarakham was good at enhancing speech therapy despite having limitations of speech services or lacks of healthcare professionals[12,13]. This KKCBSM was also an appropriate way to solve the problems in Chiang Rai, located in the northern Thailand[14]. Speech therapy for children with CLP applied the original model from KKUCSM[15]. It was conducted between 2012 and 2013 in Chiang Rai. This provided speech correction for 17 children with CLP who lived in Chiang Rai and Phayao provinces. They received speech therapy in a four-day intensive camp and five one-day follow-up speech camps at Chiang Rai's the Young Men's Christian Association (YMCA). Eight Speech Assistants (SAs) were trained to correct articulation errors with specific modeling by SLPs. SAs encouraged family members to do speech exercise every day at home. This model significantly reduced the number of articulation errors (mean difference = 1.5, 95% confidence interval = 0.5-2.5)[15].

In Thailand, community-based speech model has been extended to several areas. The results revealed the decreasing number of articulation errors[12,13]. Empowering volunteers is important for holistic care of patients with CLP. It provides easy access and multiple channels for patients and their families. It should be developed as part of the self-help and family support group, the development of community based team, and comprehensive CLP care program[16]. There were no evidences or feedback from participants, including children with CLP and caregivers, after enrollment in KKUCSM. The purpose of this study was to evaluate children with CLP's and the caregivers' feedback after one-year enrollment in the KKUCSM in Chiang Rai.

## Material and Method

This project was approved by the research protocol by the Khon Kaen University Ethics Committee for Human Research (The Project No.: HE 581088).

The evaluations were conducted by investigators during a workshop entitled "Family Camp" at YMCA, Chiang Rai on April 24 to 26, 2015 and were arranged by the Northern Women's Development Foundation. Data were collected by focus group discussions and in-depth interviews among 20 mothers, four grandmothers, and two siblings. The participants were divided into two groups. The first group had 12 caregivers who were enrolled to KKUCSM, including eight mothers, two grandmothers, one sister, and one brother. The second group included 14 caregivers who did not enroll at speech camp, including 12 mothers a grandmother and a grandfather.

Focus group discussions and in-depth interviews were performed according to the following questions: "Did you feel that children with CLP have disability, anxiety, or are unaccepted among peers?", "What did you do?", "Who were the supporters?", "Where did you get resources?", "Were your children's behaviors modified?", "How did they modify?", "What was children with CLP's ability improved?", "What did you want for support?", and "What did you plan for children with CLP in the future?". Each focus group discussion lasted 45 to 60 minutes.

### *Analysis*

Descriptive analyses were used for the demographic characteristics of the children. Content analyses were used to analyze feedback of speech and treatment outcomes for children with CLP after enrollment in the KKUCSM in Chiang Rai.

Twenty-six cleft families were in Family Camp between April 24 and 26, 2015. The characteristics of caregivers who did and did not enroll in the speech camp are displayed in Table 1.

Most caregivers were mothers in both groups and 88.5% of them were women. Majority of the caregivers were employed and had agricultural background.

Feedback from the focus group discussions and in-debt-interviews of the caregivers who enrolled in the KKUCSM are summarized as followings:

1) There was a good relationship of speech therapists and high value experience among caregivers who had children with CLP. After enrollment in the KKUCSM, their children had better articulation, communication, and could read a book clearly. They felt very glad and happy because their children could play confidently with their peers and had much more high confidence and self-esteem.

2) The caregivers had guidelines of correction for articulation errors in children with CLP and could advise other caregivers. They gained confidence to help their children to deal with social barriers and had spirit to support self-confidence, psychological adaptation, and academic achievement. They believed they could pass these skills to other caregivers because they were well-trained to practice from SLPs and SAs.

**Table 1.** The characteristics of caregivers

| Variables | Number | Number |
|---|---|---|
| Gender | Enrollment in the KKUCS | No enrollmentin the KKUCS |
| Males | 1 | 1 |
| Females | 11 | 13 |
| Age (years) | | |
| <18 | 1 | 1 |
| 18-25 | 5 | 4 |
| 26-35 | 2 | 6 |
| 36-45 | 2 | 1 |
| 46-55 | 2 | 1 |
| Education | | |
| Illiterate | 4 | 1 |
| Primary school | 4 | 7 |
| Secondary school | 1 | 2 |
| High school | 2 | 0 |
| Vocational education | 1 | 0 |
| Certificate | 0 | 3 |
| Occupation | | |
| Student | - | - |
| Employee | 8 | 6 |
| Agriculture | 3 | 6 |
| Merchant | 1 | - |
| N/A | - | 1 |
| Income/month | | |
| Mean | 5,333.33 | 10,769.23 |
| SD | 3,400.09 | 15,285.64 |
| Median | 4,750 | 7,000 |
| Min | 3,000 | 1,500 |
| Max | 15,000 | 60,000 |

KKUCSM = Khon Kaen Community-Based Speech Therapy Model

3) The caregivers increased their knowledge for looking after their children. They understood how to deal with children's psychological problems and behavioral disorders using family approaches. They would be able to continue taking care for their children in the community.

4) The caregivers who had children with CLP would be able to share their experiences and learn from each other. They had higher self-confidence for taking care of their children with illnesses using multi-disciplinary approaches.

5) Before enrollment in the KKUCSM, children with CLP were ashamed when facing their friends and other persons. After enrollment to the KKUCSM, their self-confidence increased and could express full potentials in daily life activities such as cooking, reading, playing with their peers, and washing their clothes by themselves. They were accepted by their peers, had higher self-esteem and higher confidence. They could also smoothly cooperate with their friends.

The caregivers and children with CLP had good impression with supporters, SLPs and SAs, as well as staff involved in this project. All caregivers were very impressed on speech services and would help their children to have positive attitudes on communication skills and increased self-confidence and psychosocial skills. The activities covered multi-disciplinary approaches. The outcomes showed increased in children with CLP's and caregivers' confidences and self-esteem for not only communication but also taking care of their children for both daily life activities and health care. The caregivers expected that their children would have success in highest education and could have normal living in the future.

Focus group discussions and indebt-

interviews for the caregivers who did not enroll in the KKUCSM, Chiang Rai were summarized as followings:

1) The children with CLP still had articulation defects and were teased by their friends at school. The children with CLP had low self-confidence, could not clearly speak, and did not do activities similar to other children. They isolated from their peers and did not like to play with other children. They had some behavioral problems. Some of them were headstrong kids and always wanted to behave in their own way. The caregivers felt anxiety and guilty.

2) The caregivers could not suitably take care for their children, and they worried about disability of children such as image, feeding, social interaction, communication, or speaking. Some caregivers were shocked, frightened, and anxious, and felt lost, angry, frustrated, guilty, or sin. Therefore, they still had to search for treatment, help, and family planning.

3) The caregivers lacked knowledge of speech correction or therapy and multi-disciplinary care. They still worried about looking after their children on feeding, social, inferiority, reconstruction treatment, and speech disorders. They suffered from their children's questions "Why is my nose not beautiful like yours?", "When will doctor correct my nose and mouth to normal like other people?" and "When will my nose and mouth to be normal?", "What can you do for your children?" The caregivers could not answer these questions. They confused a lot of their role and searching for knowledge and information for helping their children.

4) The caregivers had less experience for taking care their children when they got ill or had deviate behaviors. Most of them were worried with their children's health and learning in school. They felt hopeless at times. The problems that the caregivers' frequently complained included common cold, otitis media, allergy, voice hoarseness, conjunctivitis, and weeping. The caregivers were often forced to take off from their work, which affected their income.

5) The caregivers needed to support living expenses for transportation and children's cost for health check-up, and improving potential in daily life activities. They worried about the children's academic achievement and confidence to communicate with their friends at school.

**Discussion**

After enrollment_in the KKUCSM, the caregivers and children with CLP had positive feedback about the program. The KKUCSM provided speech correction as well as multi-disciplinary approaches, knowledge, and social skills for the children with CLP. The caregivers learned some experiences from each other. Therefore, they had high confidence to take care for their children. They could also provide continuum of care and practice their child to speak clearly. Families with CLP children could independently live without critical needs from health care support. For the caregivers who were not enrolled to the KKUCSM, they still searched for help and treatment for their children. The caregivers still had anxiety and stress about their children's communication, health, inferiority, daily living in school, and society. Their children with CLP still had articulation defects and were teased by their friends at school, and had low esteem, and self-confidence.

Regarding the speech camp activities, psychological and behavioral problems could be indirectly solved. The caregivers used guidelines of speech correction in real situation and passed their experiences to other caregivers. They felt proud and reduced their anxiety about their child. After enrollment to the KKUCSM, both the caregivers and children with CLP increased self-confidence and could express full potentials in daily life activities that improved their QOL. Their feedback for the program showed the effectiveness of speech camp to enhance the caregivers and children with CLP's potentials. For comparisons of psychological and self-confidence between the caregivers who did and did not enroll in the KKUCSM, this study revealed that the caregivers who enrolled in the KKUCSM had reduced anxiety and stress and a more stable mind than those who did not enrolled. The children with CLP who enrolled in the KKUCSM, unlikely those who did not enrolled in the KKUCSM, could reach high potential in academic achievement, as well as were accepted among their friends. These implied that the process of KKUCSM could reduce articulation errors and indirectly supported both the caregivers and children with CLP's psychological, self-confidence, and image.

The caregivers' feedback leads to understand the families of children with CLP who did and did not receive speech correction and multi-disciplinary approaches from the KKUCSM. This evidence indicated positive effects of the KKUCSM in Chiang Rai. It directly provided reduction articulation errors and indirectly supported the caregivers' and children with CLP's psychosocial and academic achievement. It should be provided in health care system and health services in the other areas where having limited speech services or people can neither afford nor are able to

access speech services from the nearest speech services centers. Non-Government Organization and funders should support the KKUCSM in providing speech, psychological, and academic services in developing countries that lacks these services.

Both positive and negative feedback from the caregivers who did and did not enroll in the KKUCSM were useful for the government health care units, health care providers, community nurses, and multi-disciplinary team in providing multi-disciplinary approaches for the children with CLP. Public health policy needs to be established to promote health and rehabilitation for children with CLP. It should also empower the caregivers and children with CLP to have normal life in society under holistic care (speech therapy, community nursing, and social support). Families having children with CLP need to be approached by the principles of community-based rehabilitation, primary health care service, and multi-disciplinary approaches[14,17,18].

Further study would be useful to evaluate the project by Context, Input, Process, and Product Model (CIPP model). Those studies could examine the caregivers' and children with CLP's reflection sounds and provide the needed support.

**Conclusion**

KKUCSM provides speech correction and supports the children with CLP's quality of life (QOL) in psychosocial aspects and academic achievement. For the caregivers, KKUCSM provides relief of anxiety and indirectly improves families' economic statuses. The networking of holistic care for children with CLP should be arranged by cooperation of community and local government.

**What is already known on this topic?**

Children with CLP had psychosocial problems from communication disorders or speech and language defects. Speech correction by the KKUCSM improves speech disorders, particularly articulation errors.

**What this study adds?**

KKUCSM provided reduction articulation errors and self-confidence in the caregivers and children with CLP. These were still the critical needs for both the caregivers and children with CLP who did not enroll in the KKUCSM. Health policy makers should provide speech services for the children with CLP as soon as possible to effectively encourage both speech correction, psychosocial support, self-confidence, as well as families' economic status.

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**Potential conflicts of interest**

None.

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## *เสียงสะท้อนของผู้เลี้ยงดูหลักหลังการเข้ารับบริการจากรูปแบบการฝึกพูดในชุมชน*

*รัชนี มิตกิตติ, เบญจมาศ พระธานี*

***ภูมิหลัง:*** *รูปแบบการฝึกพูดในชุมชนของมหาวิทยาลัยขอนแก่นได้นำมาใช้ในระหว่างปี พ.ศ. 2555-2556 ที่จังหวัดเชียงราย เด็กปากแหว่งเพดานโหว่และผู้ช่วยฝึกพูดเข้าค่ายฝึกพูดแบบเข้มข้น 4 วันและค่ายติดตามการฝึกพูด 1 วัน 5 ครั้ง ซึ่งดำเนินการโดยนักแก้ไขการพูด รูปแบบการฝึกพูดในชุมชนของมหาวิทยาลัยขอนแก่นนี้เน้นการลดจำนวนเสียงที่พูดไม่ชัด บทบาทของพยาบาลชุมชนเป็นสิ่งสำคัญในการดูแลแบบองค์รวมในเด็กปากแหว่งเพดานโหว่ ดังนั้นจึงจำเป็นต้องศึกษาเสียงสะท้อนจากผู้เลี้ยงดูหลักเพื่อปรับปรุงขบวนการและการบริการด้านสุขภาพ การสำรวจเสียงสะท้อนของผู้เลี้ยงดูหลักจึงเป็นสิ่งที่ควรทำ*

***วัตถุประสงค์:*** *เพื่อประเมินเสียงสะท้อนของผู้เลี้ยงดูหลักของเด็กปากแหว่งเพดานโหว่ หลังจากเข้ารับบริการจากรูปแบบการฝึกพูดในชุมชนของมหาวิทยาลัยขอนแก่น*

***วัสดุและวิธีการ:*** *ข้อมูลได้จากการสนทนากลุ่มและการสัมภาษณ์เชิงลึกผู้เลี้ยงดูหลักซึ่งประกอบด้วยมารดา 20 คน ย่าและยาย 4 คน และพี่ 2 คน ผู้เข้าร่วมโครงการถูกแบ่งเป็น 2 กลุ่ม คือ ผู้เลี้ยงดูหลักที่เคยและไม่เคยรับบริการจากรูปแบบการฝึกพูดในชุมชนของมหาวิทยาลัยขอนแก่น สนทนากลุ่มใช้เวลาประมาณ 45 นาที/กลุ่ม การวิเคราะห์เนื้อหาถูกนำมาใช้ในการสรุปข้อมูล*

***ผลการศึกษา:*** *ผู้เลี้ยงดูหลักที่เข้ารับบริการจากรูปแบบการฝึกพูดในชุมชนของมหาวิทยาลัยขอนแก่นสะท้อนความคิดเห็นว่าบุตรหลานที่มีปากแหว่งเพดานโหว่มีความสุขกับเพื่อนๆ วัยเดียวกัน มีความเชื่อถือในตัวเอง ความมั่นใจในตัวเองสูง มีสุขภาพและความสำเร็จในการศึกษาที่ดี ผู้เลี้ยงดูหลักคาดว่าบุตรหลานของตัวเองสามารถดำรงชีวิตได้ด้วยตัวเอง ในทางกลับกันผู้เลี้ยงดูหลักที่ไม่ได้เข้ารับบริการจากรูปแบบการฝึกพูดในชุมชนของมหาวิทยาลัยขอนแก่นรู้สึกว่าบุตรหลานที่มีปากแหว่งเพดานโหว่มีความเชื่อถือในตัวเองและมีความมั่นใจในตัวเองต่ำในการสื่อสารกับผู้อื่น ผู้เลี้ยงดูหลักยังคงมีความวิตกกังวลเกี่ยวกับปัญหาหลายอย่างของเด็กเช่น ภาพลักษณ์ การมีโรคกรรมพันธุ์ของครอบครัว การเจ็บป่วย ปัญหาทางจิตสังคม และสัมพันธภาพกับบุคคลอื่นโดยเฉพาะปัญหาด้านการพูดไม่ชัด*

***สรุป:*** *รูปแบบการฝึกพูดในชุมชนของมหาวิทยาลัยขอนแก่นมีวัตถุประสงค์หลักเพื่อแก้ไขการพูดและช่วยสนับสนุนทางอ้อม ในด้านคุณภาพชีวิตเกี่ยวกับด้านจิตสังคมและความสำเร็จในการศึกษา รูปแบบการฝึกพูดในชุมชนของมหาวิทยาลัยขอนแก่น ยังมีส่วนช่วยลดความวิตกกังวล และช่วยให้ด้านฐานะทางเศรษฐกิจของครอบครัวให้ดีขึ้นอีกด้วย*