

# Empowering Volunteers at Tawanchai Centre for Patients with Cleft Lip and Palate

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**Background:** Cleft lip and palate (CLP) congenital anomalies have a high prevalence in the Northeast of Thailand. A care team's understand of treatment plan would help to guide the family of patients with CLP to achieve the treatment.

**Objective:** To examine the impact of the empowering volunteer project, established in the northeast Thailand.

**Material and Method:** The Empowering Volunteer project was conducted in 2008 under the Tawanchai Royal Granted project. The patients and family's general information, treatment, the group brainstorming, and satisfaction with the project were analysed.

**Results:** Participants were 12 children with CLP, their families and five volunteers with CLP; the participating patients were predominantly females and the mean age was 12.2 years. The treatment comprised of speech training, dental hygiene care, bone graft and orthodontic treatment. Four issues were addressed including: problems in taking care of breast feeding, instructions' needs for care at birth, difficulty in access information and society impact, and needs in having a network of volunteers.

**Conclusions:** Empowering volunteer is important for holistic care of patients with CLP which 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.

**Keywords:** Self-help and family support group, Community based model, Volunteer, Cleft lip-cleft palate

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Cleft lip and palate (CLP) is a group of birth defects of the face, which has high prevalence in the northeast of Thailand<sup>(1)</sup>. These congenital deformities have the impact on the health care, stress and anxiety for patients and their families<sup>(2)</sup>. Treatment of CLP requires the participation of a multidisciplinary team that has a wide range of expertise to provide care according to patient's age group. The management often requires a long period of time since pregnancy, birth and until the end of treatment at the age of about 19 years<sup>(3)</sup>. Therefore, an understanding of the

treatment and care plan is important and necessary for the care team and family. This would lead as a guide to management plan, to take their children to appropriately undergo medical treatment, surgery, follow-up, rehabilitation and eventually receive the best quality of care possible<sup>(4)</sup>.

A formulated treatment plan for CLP was introduced at the Srinagarind Hospital in 1986<sup>(5)</sup>. The Tawanchai Center (under the Tawanchai Royal Granted Project) was established through collaborative work as the first centre with a comprehensive interdisciplinary team for the treatment of CLP<sup>(6)</sup> followed by the development of a network system for the care of patients with CLP in Thailand<sup>(7)</sup>. Guidelines for long-term management and follow-up of patients with CLP were developed in conjunction with regular meeting in the clinic. The coordinator function with interdisciplinary

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team management and regular cleft clinic meeting is the most important in cleft management<sup>(8,9)</sup>.

The “Tawanchai Project” was initiated in 2002 as a special honor to the 48<sup>th</sup> birthday of Her Royal Highness Crown Princess Maha Chakri Sirindhorn, and intended to assist development of cleft lip and palate care in Thailand including these four activities: Khon Kaen University Cleft Lip-Palate and Craniofacial Center, Self Help and Family Support Group for Cleft Lip-Palate, “Tawanchai Foundation, Workshop for Self Help and Family Support Group and the Workshop for Development of Community Based Team for Cleft Lip-Palate Care. The community-based model<sup>(10)</sup> was then established.

Subsequently during the year 2012-2015, a comprehensive cleft care Project was introduced in as a special honor to the 60<sup>th</sup> birthday of Her Royal Highness Crown Princess Maha Chakri Sirindhorn. The empowering volunteer project was placed as the continuing work and activities of Self-Help and Family Support Group for Cleft Lip and Palate.

### **Objective of the project**

To examine impacts and assess benefits from empowering volunteers project of the Tawanchai Center.

### **Material and Method**

The Empowering Volunteers project “Camping for developing skills, mind and soul for caregivers of CLP bond of the Tawanchai” was held in July 2008 in Khon Kaen<sup>(11)</sup>. Two preliminary workshops “Improving the health care service system and holistic and sustainable care of CLP” were held in four provinces in the northeast, namely Khon Kaen, Roi Et, Kalasin and Mahasarakham in the year 2011 and 2012<sup>(12,13)</sup>. This project aimed to improve the health care service system of patients with CLP and congenital craniofacial deformities in the area of responsibility of the National Health Security Office (NHSO), region seven.

The Tawanchai Foundation supported the activities to help patients and their families in learning and sharing in order to rehabilitate and improve capacity of patients with CLP. The foundation launched a project for society entitled “Creating a network of voluntary family for caring of CLP patients in Roi-Kaen-Sarn-Sin: empowering volunteer at the Tawanchai Center” in Khon Kaen to develop voluntary family by expanding the network of care to four provinces: Khon Kaen, Roi et, Maha Sarakham and Kalasin. The project aimed to develop a network of holistic care to the

community and building up volunteer families as a mentor to a new family and to establish a relationship between the families of the patients with CLP and a multidisciplinary team.

The project’s summary report of “Creating a network of voluntary family in caring of patients with CLP in Roi-Kaen-Sarn-Sin: empowering volunteer at Tawanchai Center” held during December 21-22, 2012, Khon Kaen was reviewed. Participants were 12 children with CLP, 24 parents and five volunteers with CLP. Data of: 1) a form to record general information, 2) a treatment aspect, 3) a group-brainstorming aspect, and 4) satisfaction with the project implementation, were analyzed quantitatively and qualitatively by using percentage and content analyses, respectively.

### **Ethical approval**

This present study was approved by the Human Research Ethics Committee Khon Kaen University.

### **Results**

The study consisted of four aspects:

1) General information: There were 12 patients and families with CLP and five volunteers with CLP participated in the project (Table 1).

2) Treatment: Of the total of 12 participating patients, the females were predominated (66.66%), the mean age was twelve years and two month and 59% of those were unilateral CLP. The stage of current treatment was varied involving speech training, dental hygiene care, bone grafts and orthodontic treatment (Table 2).

3) The group-brainstorming and feedback to enhance volunteerism were divided into four sections as follows:

1) The challenges in breast feeding was the most common concern. Knowledge and information seeking in caring for children, guidance in care at birth was the most need for information.

2) Difficulties in access of information and assistance. For example, most families lived in remote areas and had difficulty to get the information, or a need for financial support for travelling costs and other costs. In addition, social stigma, as well as embarrassment caused by disfigurement had adverse impact on children.

3) The recommendations to enhance volunteer network: respondents wanted to have a representative network of volunteers that get easily access and through multiple channels. The details are presented in Table 3.

4) Participants’ satisfaction with participation

in the project: 50% of the participants had very good satisfaction and 46.43% had good satisfaction with the coverage of the project. Above half of the respondents reported having an opportunity in learning and sharing experience in caring for patients with cleft lip and palate (57.14%) and overall, they satisfied with the project (60.71%) (Table 4).

## Discussion

Feeding difficulties were the most common problem encountered by all families including holding the child, rhythm of feeding, a choked flow out through the nose, unfamiliar with the device used in feeding. This was supported by a study of Pathumwiwathana et al<sup>(14)</sup> that examined the promotion of exclusively breastfeeding for infants with CLP for the first six months after birth. Parents had received training in breastfeeding at the postpartum wards, Srinagarind Hospital. It was found that there were 20 cases could be achieved having breast feeding since at the hospital. However, after babies were discharged from the hospital, only two were breastfed for six months. This highlights the difficulties of mothers in breastfeeding when there was no assistance or supervision from nurses.

This study recorded the emotions of parents who delivered babies with cleft lip and palate immediately in their own “When I first saw my baby, I was scared and cried till death”, “I fainted when I saw my baby’s face”, “Having mixed feelings both love and feeling poor for my baby who was borne with deformities unlike other normal babies”. Providing information soon after the birth would greatly benefit the family as a whole as their feeling express after getting information as “but the doctor said it is curable. I then feel better<sup>(15)</sup>”. The present study revealed the mental problems of patients and their families who had stress, anxiety and difficulties in making their mind to accept the baby, which were consistent with the results from the home visit project by Augsornwan et al<sup>(15)</sup>.

A network with volunteers created by implementing camps provided opportunities for patients and their families to acquire knowledge, share their experiences and learning from the families with similar problems (Family group support). This would strengthen family bonding and form group of friends between families having similar facial deformities. This corresponds to results of the “Teaching life skills by the activities from the integration project<sup>(16)</sup>”. Teenagers faced bullying due to physical appearance and voice changes. This in turn stressed parents and children not to speak out, disclose the their inner thoughts and prevented them being photographed while travelling or on social occasions. The camp provided chanced to gain confidence and being assertive while facing society. After the implementation of the project, the satisfaction level varied among the families. However, the satisfactory levels were between high to the highest degree about the project on addressing an opportunity in learning and sharing experience in caring for patients with CLP.

**Table 1.** Demographic data of participants of the project

Demographic data	n (%)
Patients and families	12 (43)
Volunteers (CLP patients)	5 (18)
Mentor (nurses)	5 (18)
Lecturers and staff	6 (21)
Total	28 (100)

**Table 2.** Patient’s characteristics and current treatment

Gender	Mean age	Diagnosis	Current treatment	Address	
Male	4 (33.34%)	4 years	Bilateral CLP (2) Unilateral CLP (2)	- In the stage of speech training - Monitoring for ears and hearing examination every 6 months - Preparation for dental hygiene care and prevention of dental caries for orthodontic treatment.	Khon Kaen Kalasin Maha Sarakham (2)
Female	8 (66.66%)	12 years 2 months	Bilateral CLP (3) Unilateral CLP (5)	- In the stage of speech training. - Oral hygiene care, preparations for bone grafts and orthodontic treatment.	Roi-Et Maha Sarakham (2) Kalasin (2) Khon Kaen (3)

**Table 3.** CLP related problems addressed through the carers' brainstorming

Problems	Comments and suggestions
1) Caring for children/ grand children with CLP	<p>All participating families had commented on breast feeding a baby with CLP as follows: "There are many difficulties, do not know how to breast feed, breast milk flowing out of nose with air bubbles, sucking milk as well as air, do not know the best position for breast feeding, do not know how to use devices, difficulties in the use of equipment/devices, no weight gained, do not know how to raise baby correctly".</p> <p>Both patients and their families (90%) faced psychological issues including anxiety, stress and fear reflected in their words as follows: "could not make up my mind, lots of concerns, not look like other baby, mothers had stress and concerns for the growth of baby affecting state of mind of both father and mother whose baby with CLP whilst need to take care of siblings without CLP. This may create the problems in terms of warmth, bullying in school age. These may enable parents and children having poor mental health, do not want to speak or shoot photos, do not want to show up, other people stared at while travelling on the bus"</p> <p>The challenges from learning/work (50%) were also mentioned as follows: "Friends bullied for the figure and voice, difficulties when going out, facing people not known about facial deformities, fear of social acceptance, often have to miss a class or work to pursue treatment"</p>
2) To seek information and knowledge in caring for children/grandchildren	<p>"I want the staff's advice at birth about taking care of children with CLP. This is for peace of mind and reduces the anxiety of parents. Availability of information sources regarding treatment. Relatives who have experienced suggested to visit a hospital for treatment. Parents looking for information from the Internet, or from watching news".</p>
3) The barriers to access information and assistance, including the impact on children and families	<p>3.1 Information accessibility "Current information on CLP are greatly available. The data can be easily access, except people living in remote areas where having difficulties in accessing information. Community Hospitals advised not clear about the delay, postpone surgery".</p> <p>3.2 Resource accessibility "Difficulties in requesting for referral to Srinagarind Hospital; some families do not take the children for treatment because of long distances. The travelling fund from the Red Cross should have been continued".</p> <p>3.3 Impact on children and families: "To get questions from people around how this happened, we have no answer. Medical fee is quite high. Some families do not accept the fact. Do not want to reveal to the society that I have child with CLP. Children develop speech difficulties and embarrassment to enter to the society. Every visit of treatment contributes lots of money to spend including travel and food cost".</p>
4) Suggestions to enhance volunteerism	<p>"I want to have easy access to a representative of voluntary network, having their contact number, creating a network on Facebook in order to educate patients and their families. Exchange of information, experience and encouragement as well as sharing the problem to each other. Want to have volunteer for the village to spread knowledge (one village one volunteer). I would like this project to be conducted in every single province in order to have volunteers covering every province and spread knowledge to the community to get to know and understand more about CLP. As well as providing guidance that how and what to do while pregnant. Giving a symbol of being a volunteer. Collecting, storing and disseminating information. I want to build a network to the local administrators in order to get financial support for travel costs each time. I want to have the knowledge disseminate on the radio and television about the process of care and treatment. I want this to be advertised on the board in order to inform phone number and address of the Tawanchai Center so that patients can contact".</p>

**Table 4.** Participants' satisfaction with the project

Topics for evaluation	Very good %	Good %	Fair %	Little %	Poor %
1) The date and time of the project is appropriate.	42.86	46.43	10.71	-	-
2) The venue of the project is appropriate.	35.71	60.71	3.58	-	-
3) The project provides opportunity in learning and sharing experience in caring for patients with cleft lip and palate.	57.14	42.86	-	-	-
4) The project has made you ready to become a volunteer. Can provide counselling to families who need guidance further.	53.57	46.43	-	-	-
5) Are you satisfied with the overall project?	60.71	35.71	3.58	-	-
The overall average	50	46.43	3.57		

The appropriate care for patients with CLP needs to promote patients with CLP having a good quality of life and happily live in society<sup>(17)</sup>. Therefore, it is important that care must cover the treatment, information provided by a multidisciplinary team and learn and share experience of raising children in each family. This helps to understand each other feelings by using family voluntary group process and advises among families. These would help to promote knowledge and understand of child care over the course of treatment, create a warm love, accept the truth and conditions in the family and be able to use their potential in helping their children. Encouraging parents to participate in the care of mental rehabilitation, be able to improve personality and learn to prevent the problem by themselves. This is performed by having a group of parents who have experienced and are ready to care for or being a mentor to a new family. The families are encouraged to handle their anxiety in caring for their children and able to find ways to solve problems by the group that has a similar problem<sup>(15)</sup>. In addition, strengthening a network of volunteers to families with children having CLP will create a network to help between the families. This will extend to educate the community to further care for this group of children.

**Conclusion**

Empowering volunteer is important for holistic care of patients with CLP. The most important issue was to take care of breast/milk feeding and psychological problems of both children and family. Assisting and creating a volunteer network provides easy access and multiple channels to serve the needs of patients and their families. These should develop as part of the Self Help and Family Support Group, the Development of Community Based Team and Comprehensive cleft which are the program for CLP

care.

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

The appropriate care for patients with cleft lip and palate needs to promote the patients having a good quality of life and happily live in society. Therefore, it is important that care must cover the treatment, information provided by a multidisciplinary team and learning and sharing experience of holding children in each family. These would help to understand each other feelings by using voluntary family group process and advises between families.

**What this study adds ?**

The challenges in caring of the patients with CLP include: 1) taking care of breast feeding; 2) a need on instructions for care immediately after birth; 3) difficulty to access information and the impact on children in society; and 4) a need on having a representative network of volunteers for easy access and multiple channels.

**Potential conflicts of interest**

None.

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## รวมพลังจิตอาสา ศูนย์ตะวันฉายเพื่อการดูแลผู้ป่วยปากแห้งเพดานโหว่

สุธีรา ประดับวงษ์, ดารารวรรณ อักษรวรรณ, พรเพ็ญ ปทุมวิวัฒนา, เบญจมาศ พระธานี, บวรศิลป์ เชาวนชื่น

ภูมิหลัง: ปากแห้งเพดานโหว่ มีอุบัติการณ์สูงในภาคตะวันออกเฉียงเหนือ ประเทศไทย การเข้าใจแผนการรักษาของทีมสหวิทยาการจะช่วยให้ครอบครัวเข้าใจวิธีการดูแลเด็กอย่างเหมาะสมเพื่อการรักษา การผ่าตัด และการฟื้นฟูสภาพ โครงการนี้เป็นส่วนหนึ่งของโครงการกลุ่มช่วยเหลือตนเอง และกลุ่มช่วยเหลือครอบครัวผู้ป่วยรูปแบบการดูแลโดยใช้ชุมชนเป็นฐาน และแนวทางการดูแลที่สัมพันธ์กับวัฒนธรรมแบบของศูนย์ตะวันฉาย

วัตถุประสงค์: เพื่อวิเคราะห์ผลลัพธ์และผลกระทบที่เกิดขึ้นจากโครงการรวมพลังจิตอาสาในภาคตะวันออกเฉียงเหนือ ประเทศไทย

วัสดุและวิธีการ: โครงการรวมพลังจิตอาสาเริ่มดำเนินการในปี พ.ศ. 2551 ข้อมูลที่นำมาวิเคราะห์ประกอบด้วย ข้อมูลพื้นฐานของผู้ป่วยและครอบครัว การรักษา การระดมสมอง และความพึงพอใจต่อโครงการ

ผลการศึกษา: มีผู้ป่วยจำนวน 12 รายพร้อมครอบครัว และอาสาสมัครจำนวน 5 ราย พบว่าผู้ป่วยส่วนใหญ่เป็นเพศหญิงอายุเฉลี่ย 12.2 ปี การรักษาที่ได้รับคือการฝึกพูด การดูแลสุขภาพฟัน การปลูกกระดูกสันหลังอก และการจัดฟัน ประเด็นการดูแลที่มีความสำคัญ คือ การให้นม การดูแลระยะแรกเกิด การเข้าถึงบริการและผลกระทบด้านสังคม การมีตัวแทนจิตอาสาในชุมชนสิ่งที่กลุ่มต้องการ คือ การดูแลการให้นม และดูแลสภาวะจิตใจของผู้ป่วยและครอบครัว ความพึงพอใจของโครงการอยู่ในระดับที่สูงและสูงมากถึง 96.43%

สรุป: ตัวแทนจิตอาสาที่มีความสำคัญในการดูแลแบบองค์รวมในผู้ป่วยปากแห้ง เพดานโหว่ โดยเฉพาะด้านการเข้าถึงบริการและการสื่อสารข้อมูลต่างๆ ซึ่งควรพัฒนาให้เป็นกิจกรรมของกลุ่มช่วยเหลือตนเองช่วยเหลือครอบครัว การสร้างรูปแบบการดูแลแบบชุมชนเป็นฐานและการดูแลที่สัมพันธ์กับวัฒนธรรมแบบในผู้ป่วยปากแห้งเพดานโหว่ต่อไป

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