

# Community-Based Network System and Interdisciplinary Management for Children with Cleft-Lip/Palate

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**Objective:** To propose a community-based network system and interdisciplinary management for children with cleft lip/palate, applicable to Thailand and other developing countries.

**Material and Method:** A network was developed for the care of patients with cleft lip/palate by combining primary health care, community-based rehabilitation and institutional expertise (Tawanchai Center). Five workshops were conducted, including: 1) network development for cleft lip-palate care in the new millennium; 2) a multi-center study on the incidence and etiology of oral clefts and associated abnormalities in Northeast Thailand; 3) establishment of a Network for Children with Cleft Lip/Palate care in Northeast Thailand, including: 3.1) Skill development in cleft lip/palate care for parents and family; 3.2) a community-based model for speech disorders for children with cleft lip/palate in developing countries and for holistic nursing care for children with cleft lip/palate in developing countries; and, 4) development of interdisciplinary team system and network for holistic care for community-based quality of life, health promotion, speech and language intervention for Thai cleft lip/palate.

**Results:** A community-based network system model with interdisciplinary care was developed.

**Conclusion:** A community-based network system model with interdisciplinary care can be applied for children with cleft lip/palate in Thailand and developing countries where there exists a lack of coordinated multidisciplinary services. We plan to implement such a system in the near future.

**Keywords:** Community-based, Network, Interdisciplinary, Cleft lip, Cleft palate

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Almost a quarter of million new babies with cleft and/or palate live in the poorest parts of the world where resources are limited or non-existent compared to 17,000 in developed countries<sup>(1)</sup>. The birth incidence of cleft palate in Thailand was 1.10-2.49<sup>(2)</sup> and most of the children with cleft palate are from the impoverished Northeast. Estimates of the annual occurrence of cleft-births in this area was 745 live-births each year<sup>(3)</sup>.

Children with cleft lip/palate can be devastating to the family, which has to face many psychological, medical, economic and financial problems. A successful program and treatment requires

the early involvement of many professionals working together as a multidisciplinary team. Such teams have been organized in many developed countries; however, this is not the case in most developing nations which commonly lack interdisciplinary care, healthcare professionals or resources, including Vietnam, Indonesia, India, Laos, Burma, China and Thailand<sup>(4-6)</sup>. The creation of a multidisciplinary team for cleft and craniofacial care in developing countries will take significant resources and many years of cooperative, determined effort.

Recently, Thailand made a commitment to increase the availability of surgical care for cleft and craniofacial defects. Several domestic volunteers have joined the task.

The first group, the Royal cleft Projects conducted a campaign for cleft repairs in remote areas.

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This was a work done by the Society of Plastic and Reconstructive Surgeons of Thailand (SPRST) as a tribute to His Royal Highness, the Crown Prince between 1987 and 1988. This campaign was continued by the Princess Mother's Medical Volunteer Foundation and the Ministry of Public Health between 1989 and 1991. The third Royal Project was launched in honor of the 72<sup>nd</sup> birthday of his Majesty the King of Thailand in 1999. Currently, many volunteer projects work in rural areas throughout the country, especially to celebrate the King's Birthday (December 5<sup>th</sup>)<sup>(2)</sup>.

There are projects by domestic volunteer missions in Thailand, such as: the Duangkaew's Foundation, the Thai Red Cross Council and the Project of the Royal College of Surgeons of Thailand. Most volunteer projects emphasize surgery and do not cover supplemental care, such as: speech, language, hearing and dental concerns.

In 2007, National Health Security Office, Ministry of Public Health, Thai Speech and Hearing Association, and Thai Red Cross Society realized the importance of having interdisciplinary teams and raised funds to help people with cleft lip/palate get services via the "Smart Smile & Speech Project", established in celebration of the 50<sup>th</sup> birthday of Her Highness, the Royal Princess Sirinthorn. This Project focuses on surgery, speech and language therapy and dental management for patients with cleft lip/palate.

The objective of this article is to present a snapshot of the community-based network and interdisciplinary management for children with cleft lip/palate, particularly as applicable to Thailand. The study protocols were reviewed according to the Declaration of Helsinki and approved by the Ethics Committee of the University of Khon Kaen.

#### **Material and Method**

The community-based network system and interdisciplinary management for children with cleft lip/palate has been under development since 1998. Development has included many processes, including the following:

##### ***Establishment of interdisciplinary team and center for cleft lip/palate and craniofacial deformities***

Cleft and craniofacial care in Thailand has recently implemented the concept of centers for management with interdisciplinary team care in a few tertiary hospitals. The hospital-based collaboration for cleft and craniofacial anomalies was developed, then initiated in 1990, by the Thai-American Plastic Surgery

and the ACPA Ambassador program to improve the quality and range of care for children with cleft at the Queen Sirikit Institute of Child's Health<sup>(2)</sup>. The programming was extended to Khon Kaen University in 2001.

The need for interdisciplinary team management for hospital-based treatment has been increasing in this area. "The Center for Cleft Lip/Palate and Craniofacial Deformities, Khon Kaen University", the first interdisciplinary center in Northeast Thailand was established in 1998<sup>(7)</sup>, and was subsequently associated with "The Tawanchai Project/Center", established at Khon Kaen University in 2006. The objectives of the center are to provide a coordinating center for the interdisciplinary care of patients with clefts, to conduct research into the prevention of clefts and to improve relevant healthcare services. The challenge is how can the center actively support and strengthen its key communities and how can it determine areas for involvement, related to its core competencies. Thus, in 2009 "The Tawanchai Foundation for Cleft Lip/Palate and Craniofacial Deformities" was formally established.

As a first step, the center developed a protocol for regional care of patients with clefts and conducted a workshop in 1999 on the role of nurses in the management of patients with clefts. There were forty in attendance, including hospital-based nurses from tertiary, secondary and primary healthcare units. A summary from the workshop suggested proceeding with regional development of care for patients with clefts including: 1) cleft-specific training sessions and workshops; 2) establishing a coordinating group for care; 3) organizing a special clinic; and, 4) developing good public relations regarding the care of patients with clefts. From this workshop, The Center for Cleft Lip/Palate and Craniofacial Deformities, Khon Kaen University realized that development of interdisciplinary in Thailand contexts should include cooperative efforts from institutional, regional and community functions and networks. Therefore, strategies for establishment a community-based network system and interdisciplinary management for children with cleft lip/palate were performed via continuing workshops and action researches from magnitude of problems in regional areas through the development of the network or model to reach the objective of this article as follows:

##### ***Developing networks on the care of cleft lip/palate for the new millennium***

In 2000, this center partnered with Smile Train.

Some professionals in the team had more experiences on the international interdisciplinary approach regarding cleft care. In February 2001, a related cleft symposium, "System and networking development of cleft lip-palate care in the new millennium", was organized in collaboration with the Faculties of Medicine and Dentistry, Khon Kaen University, the Thai Ministry of Public Health and the Smile train Organization.

The organization of interdisciplinary approach for cleft care still, however, faced too many obstacles such as a lack of: 1) resources, 2) funding, 3) professionals (particularly speech and language pathologists), special cleft nurses and nurse coordinators. Management of cleft care in this area therefore needed capacity development.

#### ***Multi-center study of incidence and etiology of oral clefts and associated abnormalities in Northeast Thailand***

Many developing countries do not have an appropriate system to assess needs in order to develop an appropriate cleft care system. Thus, a workshop was conducted on, "Multi-center study of incidence and etiology of oral clefts and associated abnormalities in northeast Thailand"<sup>(2)</sup>. The purpose of the project was a population-based, multicenter study in three provinces of Northeast Thailand (*viz.*: Khon Kaen, Buri Rum and Loei), the area most likely to have the highest incidence of cleft lip/palate. In addition, three other provinces in other regions were conducted, (*viz.*, Saraburi, Pisanulok and Songkhla). An outcome of the multi-center study was the establishment of collaboration and networking *vis-à-vis* the care of patients with cleft as a model that could be adopted for all regions of Thailand.

During a 3-month period in 2003, workshops were conducted to set the diagnostic criteria and to reach a consensus on treatment guidelines, a referral system, data collection and reporting, for all of 6 provinces. The data collection phase for the delivery of infants with cleft lip/palate was a 12-month period between 2003 and 2004. There was some variation in the reporting of birth incidence from each province which may reflect problems in the referral system because of remote locations and lack of transportation. The reporting delivery of infants at the community hospital level was mostly done by the parents from the same district while deliveries at the provincial hospital level may have been done by parents from a different district or province. Geographic Information System

(GIS) analysis was used and the high prevalence in one area indicated the need for more investigation. The community-based model and self-help support groups were developed during the period.

The objectives of the workshops in three provinces of the Northeast (*i.e.*, Khon Kaen, Loei, and Buri Ram) were to provide knowledge and information on the interdisciplinary approach to the management of clefts and to encourage healthcare professionals to improve the quality of life for cleft patients. Despite these efforts, we have still not reached the goals set for better cleft care. Some cleft patients still have to survive without access to the interdisciplinary team at the Khon Kaen University Center. Some special services such as speech therapy, dental care, feeding care, and coordination system are still not available in many hospitals.

#### ***Network System for Children with Cleft lip/palate care in Northeast Thailand***

Establishing interdisciplinary care for clefts is still the critical issue in the Northeast; thus, we created the "Community-Based Model of Network System for Children with Cleft Lip/Palate in the Northeast".

##### ***Description of Northeast Thailand***

The 21 million people of the Northeast are widely dispersed throughout the region. This population represents one-third of the population of Thailand, the poorest on a per capita basis in the country. Agriculture is the major occupation. Major roads are good and bussing the primary mode of transportation. Secondary and tertiary roads are not paved or maintained so persons depending on these types of roads can be quite isolated. Some cleft palate families have to travel a long distance (200-300 km) to get to a service center.

The only interdisciplinary service is provided at the Khon Kaen University Cleft Palate and Craniofacial Center, because it is a tertiary healthcare centre at Khon Kaen University. Some professionals are limited in number: there is only one speech and language pathologist, a few special nurses and orthodontists for cleft palate in this region. A training program for community rehabilitation workers for cleft palate and craniofacial defects has not been initiated.

##### ***Skill development in cleft lip/palate care for parent and family in Northeast Thailand***

First we tried to find information and encourage the community to participate in development

of the model. Khon Kaen University Cleft Palate and Craniofacial Center conducted a workshop entitled, "Skill Development in Cleft Lip/Palate Care for Parents and Families in Northeast Thailand" between May 11 and 13, 2003<sup>(8)</sup>. In sum, the information from workshop suggested many reasons for getting only a little or no interdisciplinary service(s) from the Center including:

1. Many parents, families had misconceptions regarding both the cause of the impairment and the availability of treatment. They believed that surgery was the end-all and be-all of treatment so did not concern themselves with any complementary services. Family needed and expected to get more information about cleft care than they were getting.

2. Most patients lived in a remote area where an interdisciplinary approach was not available. Families had to travel a long time and distance to get to services. Frequently, they could not afford the expense of coming to the treatment center.

3. The public health system and educational center put little emphasis on a community-based model for interdisciplinary cleft care.

4. Healthcare providers and para-professional had little basic knowledge and information regarding the interdisciplinary approach (*i.e.*, when, where, how and which services were available for children with cleft palate).

#### ***Community-Based Model for Speech Disorders, and for Holistic Nursing Care of Children with Cleft Lip/palate in Developing countries***

Information from professionals from two international consensus meeting workshops were summarized (*i.e.*, 1. The first International Congress on Interdisciplinary care for Cleft Lip/palate 2003, 1-4 December 2003: "Community-Based Model for Speech Disorders for Children with Cleft Lip/palate in Developing Countries" and 2. "Community-Based Model for Holistic Nursing Care for Children with Cleft Lip/palate in Developing countries"). Attendees included speech pathologists, doctors, nurses, special educators, dentists and para-professionals from Pakistan, Singapore, Australia, Hong Kong, Taiwan, Srilanka, and Thailand. The strengths and weaknesses of the healthcare systems in other developing countries were adapted for use in Thailand<sup>(9)</sup>.

#### ***Community-Based Model of Network System***

It was challenging to establish a "Community-Based Model for Network System for Children with Cleft Lip Palate in Thailand" based on the philosophy

to: 1) promote development of healthcare with community; and, 2) share knowledge, skills and generally seek to develop and strengthen the community's capacity to care for itself. Our projects were put forward: 1) to ascertain the needs of a community and 2) implement the principles of community-based rehabilitation (CBR) and primary health care (PHC). Ultimately, a community-based model had more effective service delivery<sup>(10)</sup>, cost less and provided service directly in the community by training healthcare providers or personnel at a basic level.

#### ***Development of Interdisciplinary Team System and Network for Holistic Care in Quality of Life, Health Promotion, Speech and Language Intervention for Thai Cleft Lip/palate in Community***

The Center for Cleft Lip/Palate and Craniofacial Deformities, Khon Kaen University, the only interdisciplinary team in northeastern Thailand, coordinated the workshop entitled, "Development of Interdisciplinary Team System and Network for Holistic Care in Quality of Life, Health Promotion, Speech and Language Intervention for Thai Cleft Lip/palate in Community", between June 3-4, 2004. Healthcare providers and non-para-professionals (from all healthcare unit levels and communities) in three provinces, with the highest incidence of cleft birth in the Northeast were invited to meet and build a consensus. One-hundred and five persons were invited to be panelists (including doctors and nurses from healthcare providers in primary, secondary and tertiary healthcare units, as well as leaders of communities, teachers and parents of children with cleft lip/palate).

The workshop was conducted for two days. The first day, specialists on the interdisciplinary team provided basic knowledge and background for children with cleft lip/palate. The following day, attendees were divided into four small groups to address the first priority of the project in promoting and developing the health care services to improve quality of life and holistic care by an interdisciplinary approach for cleft lip and plate. Another big group was set to discuss the development of a "Community-Based Model of Network System for Children with Cleft Lip/Palate in Thailand". Professionals from The Center for Cleft Lip/Palate and Craniofacial Deformities, Khon Kaen University were facilitators in each group. Panelists from all levels of health care units and communities were included in each group.

Panelists agreed that the first priority for



project which should be implemented was ‘healthcare promoting for cleft lip/palate care’. They also proposed a network system for development of an interdisciplinary team to provide holistic care from the perspective of quality of life and health promotion, speech and language stimulation for Thai cleft lip/palate children in their community<sup>(9)</sup>.

In sum, the consensus of the workshop was that members of The Center for Cleft Lip/Palate and Craniofacial Deformities, Khon Kaen University or Tawanchai Center should provide a training workshop for healthcare providers and community para-professionals to: 1) increase their capacity to function as an interdisciplinary team under the supervision of a specialist; 2) establish an effective referral system; and, 3) to improve the communication between facilitators and supervisors. In addition, there should be effective follow-up to ensure on-going quality improvement the system.

## Results

The Model of community-based network system and interdisciplinary management for children with cleft lip/palate based on combining PHC, CBR and institutional cooperation from workshops and action researches were discussed. A modification of the networking was reproduced based on the original system<sup>(9)</sup>, the result is shown in Fig. 1.

From this model, Tawanchai Center implemented the network system based on health care unit and functions including para-professional training to identify speech, language, hearing problems, and provided early intervention, parental and caregiver training for cleft care, developed a manual for cleft care, a manual for early speech and language intervention for Cleft lip/palate, etc. However, the network system is still incomplete because it needs to reach to the community level. Therefore, consensus of the implementation in the community level was done and prepared according to these following processes:

1. Community-based network and interdisciplinary management workshop for tertiary, secondary, and primary health care providers
2. Community-based network and interdisciplinary management workshop for community health care providers or local key persons
3. Assessment of the needs of interdisciplinary management for individuals with cleft lip/palate in local areas *i.e.* Kantharawichai, Kosum Phisai, Muang district, Maha Sarakham province, and Phon Thong district, Roi-et province

4. Interdisciplinary management for children with cleft lip/palate by community health care providers or local key persons in regional areas

5. Continuing mobile interdisciplinary management for children with cleft lip/palate at Mahasarakham Provincial Hospital once a month for 8-10 visits, for follow up of the interdisciplinary care ran by community health care providers or local key persons

6. Assessment of the community-based network system and interdisciplinary management for children with cleft lip/palate.

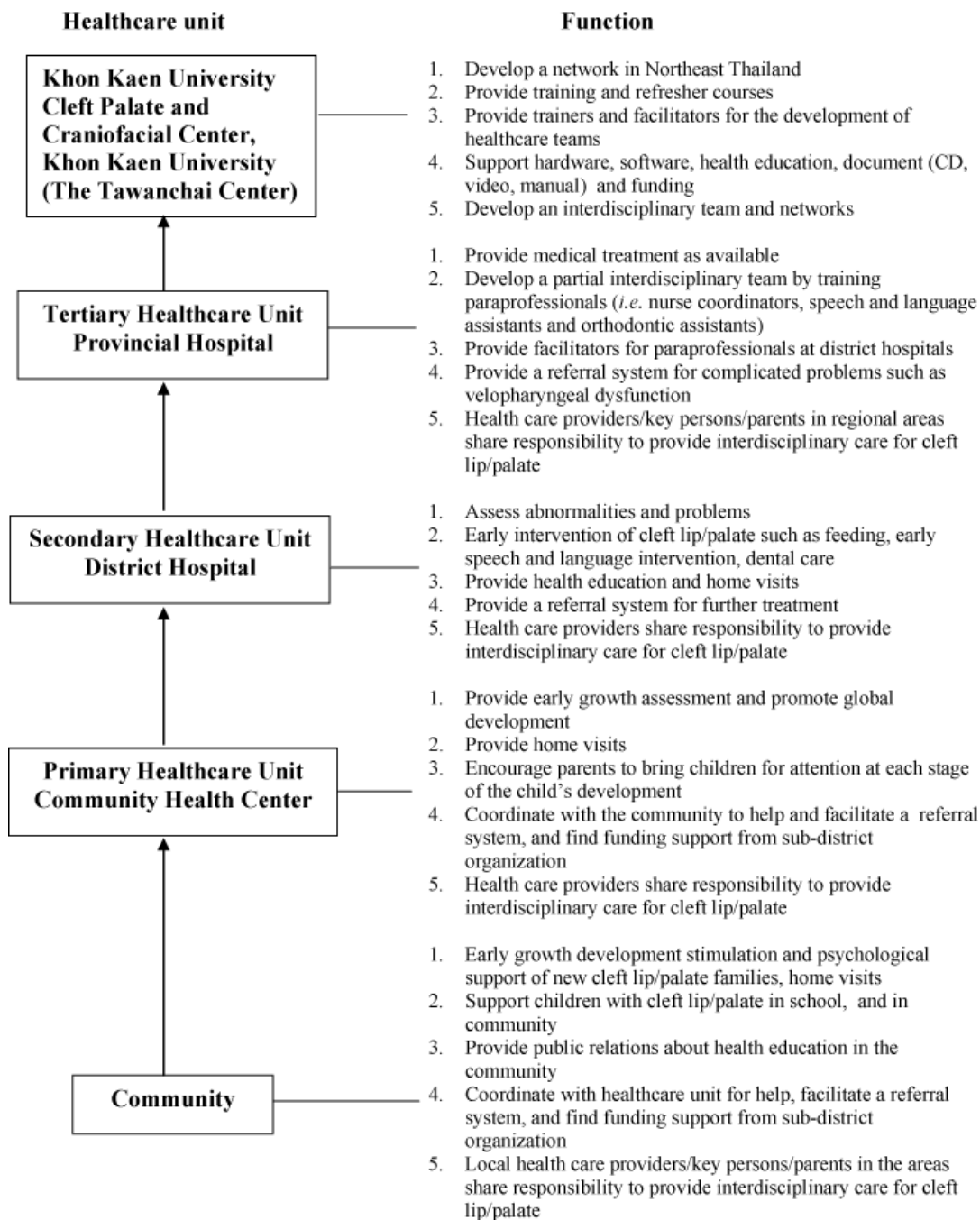
7. Report of results

## Discussion

A community-based network and interdisciplinary management for children with cleft-lip/palate were developed for the Thai context. Thailand has interdisciplinary professionals, however, there are not enough to provide service for the whole country. There are only 40 speech and language pathologists to serve the nation and most of them work in Bangkok, while 5 work in the North, 4 in the South and 1 in the Northeast (where the highest incidence of cleft birth occurs)<sup>(11)</sup>. It might be appropriate therefore to have interdisciplinary care for children with cleft-lip/palate at the community level. Some models for community-based service cannot meet the demand, hence a network system can be developed and applied to maximize the effectiveness of the few professionals<sup>(6)</sup>.

A proper community-based team model and networking system in Thailand needs a well-coordinated management center plus community-based teams. The community-based teams may consist of doctors or general practitioners, dentists, nurses, local health personnel, social workers, teachers, monks, and individuals with clefts and their family support group in the community. These teams help to provide appropriate primary cleft care services, health education, coordinate with social workers and coordinator for the home visiting program, help in registration and record of data of cleft patients in their community.

The key role of The Tawanchai Center is to take responsibility as the hub of the network by providing information and guidelines for the treatment planning and comprehensive service, centralized database and coordinating system, continuing education and training, promoting evidence-based best practices outcome evaluation and future research. There need to regular meetings and communication among the community-based teams and the community-based teams and the center. The establishment of “The



**Fig.1** Diagram of network system

Tawanchai Foundation for Cleft Lip/Palate and Craniofacial Deformities” should therefore provide much needed support for the implementation of the community-based model.

At the time of this study, The Tawanchai

Center had the following up-coming projects: 1) “Development of a Community-based Health Care and Health Promotion System for Individuals with Cleft Lip/Palate”; and, 2) “Community-Based Speech Therapy Model for Children with Cleft Lip/Palate” to reach

children and families in need in 2010. The objectives of these projects are to implement a community-based interdisciplinary health care model for individuals with cleft lip plate in Northeast Thailand. Both projects are predicated on the development of a training program for community trainers via sharing attitudes and awareness between institutions and communities as well as conducting more prescriptive and activity-based trainings<sup>(12,13)</sup>.

### Conclusion

A Community-Based Model of Network System for Children with Cleft Lip/Palate was developed by combining PHC, CBR and institutional cooperation (*i.e.*, sharing attitudes and awareness and conducting more prescriptive and activity-based trainings). The consensus from professionals and para-professionals is that an emphasis on the use CBR and PHC programs is needed as well as a focus on the poor areas of Northeast Thailand. This approach is being implemented in 2010.

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## รูปแบบชุมชนของระบบเครือข่ายและการดูแลรักษาเด็กปากแห้งเพดานโหว่แบบสหสาขาวิชาชีพ

เบญจมาศ พระธานี, บวรศิลป์ เขาวนขึ้น

**วัตถุประสงค์:** เพื่อนำเสนอระบบเครือข่ายในชุมชนและการดูแลรักษาเด็กปากแห้งเพดานโหว่แบบสหสาขาวิชาชีพที่สามารถนำไปประยุกต์ใช้สำหรับประเทศไทยและประเทศกำลังพัฒนาอื่นๆ

**วิธีการ:** ระบบเครือข่ายการดูแลผู้ป่วยปากแห้งเพดานโหว่ได้ถูกสร้างขึ้น โดยการประสานประสานการดูแลด้านสาธารณสุขมูลฐาน การฟื้นฟูสุขภาพในชุมชน และการบริการระดับวิชาชีพ (ศูนย์ตะวันออกชัย) เข้าด้วยกัน ได้จัดการประชุมเชิงปฏิบัติการ ใน 5 ครั้งคือ 1) การพัฒนาระบบและเครือข่ายในการดูแลปากแห้งเพดานโหว่ในภาวการณ์ปัจจุบัน 2) การศึกษาอุบัติการณ์ และสาเหตุของการเกิดการแห้งของปากเพดาน และความผิดปกติร่วมแบบสหสถาบันในภูมิภาคตะวันออกเฉียงเหนือ 3) การสร้างระบบเครือข่ายสำหรับการดูแลเด็กปากแห้งเพดานโหว่ในภาคตะวันออกเฉียงเหนือ 3.1) เครือข่ายของการพัฒนา ทักษะในการดูแลผู้ป่วยปากแห้งเพดานโหว่สำหรับพ่อแม่และครอบครัว 3.2) การพัฒนารูปแบบในการให้บริการ ด้านความผิดปกติของการพูดในเด็กปากแห้งเพดานโหว่ในประเทศที่กำลังพัฒนา และการพยาบาลแบบองค์รวมสำหรับเด็กปากแห้งเพดานโหว่ในประเทศที่กำลังพัฒนาและ 4) การพัฒนาระบบการดูแลเป็นทีมของสหสาขาวิชาชีพ และเครือข่ายการดูแลแบบองค์รวมเพื่อส่งเสริมคุณภาพชีวิต การฝึกพูดและภาษาสำหรับภาวะปากแห้งเพดานโหว่ในชุมชน

**ผลการศึกษา:** ได้รูปแบบชุมชนของระบบเครือข่ายและการดูแลรักษาเด็กปากแห้งเพดานโหว่แบบสหสาขาวิชาชีพ

**สรุป:** รูปแบบชุมชนของระบบเครือข่ายและการดูแลรักษาเด็กปากแห้งเพดานโหว่แบบสหสาขาวิชาชีพที่สร้างขึ้นสามารถประยุกต์ใช้ในประเทศไทย และประเทศที่กำลังพัฒนาซึ่งขาดการบริการแบบสหสาขาวิชาชีพได้ ทั้งนี้มีแผนในการนำไปใช้ในพื้นที่จริงในอนาคตอันใกล้

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