Evidence-Triggers for Care of Patients with Cleft Lip and Palate in Srinagarind Hospital: The Tawanchai Center and Out-Patients Surgical Room

Suteera Pradubwong MSN*, Pattama Surit DNSc**, Sumalee Pongpagatip MA*, Tharinee Pethcharat MSN*, Bowornsilp Chowchuen MD, MBA***

* Division of Nursing, Srinagarind Hospital, Faculty of Medicine, Khon Kaen University, Khon Kaen, Thailand
** Faculty of Nursing, Khon Kaen University, Khon Kaen, Thailand
*** Division of Plastic Surgery, Department of Surgery, Faculty of Medicine, Khon Kaen University, Khon Kaen, Thailand

Background: Cleft lip and palate (CLP) is a congenital anomaly of the lip and palate that is caused by several factors. It was found in approximately one per 500 to 550 live births depending on nationality and socioeconomic status. The Tawanchai Center and out-patients surgical room of Srinagarind Hospital are responsible for providing care to patients with CLP (starting from birth to adolescent) and their caregivers. From the observations and interviews with nurses working in these units, they reported that both patients and their caregivers confronted many problems which affected their physical and mental health. Based on the Soukup’s model (2000), the researchers used evidence triggers from clinical practice (practice triggers) and related literature (knowledge triggers) to investigate the problems.

Objective: The purpose of this study was to investigate the problems of care for patients with CLP in the Tawanchai Center and out-patient surgical room of Srinagarind Hospital.

Material and Method: The descriptive method was used in this study. For practice triggers, the researchers obtained the data from medical records of ten patients with CLP and from interviewing two patients with CLP, eight caregivers, two nurses, and two assistant workers. Instruments for the interview consisted of a demographic data form and a semi-structured questionnaire. For knowledge triggers, the researchers used a literature search. The data from both practice and knowledge triggers were collected between February and May 2016. The quantitative data were analyzed through frequency and percentage distributions and the qualitative data were analyzed through a content analysis.

Results: The problems of care gained from practice and knowledge triggers were consistent and were identified as holistic issues, including 1) insufficient feeding, 2) risks of respiratory tract infections and physical disorders, 3) psychological problems, such as anxiety, stress, and distress, 4) socioeconomic problems, such as stigmatization, isolation, and loss of income, 5) spiritual problems, such as low self-esteem and low quality of life, 6) school absence and learning limitation, 7) lack of available services, and 10) shortage of healthcare professionals, especially speech language pathologists (SLPs).

Conclusion: From evidence-triggers, the problems of care affect the patients and their caregivers holistically. Integrated long-term care by the multidisciplinary team is needed for children with CLP starting from birth to adolescent. Nurses should provide effective care to these patients and their caregivers by using a holistic approach and working collaboratively with other healthcare providers in the multidisciplinary team.

Keywords: Evidence-triggers, Cleft lip and palate, Problems of care

J Med Assoc Thai 2016; 99 (Suppl. 5): S43-S50
Full text. e-Journal: http://www.jmatonline.com

Cleft lip and palate (CLP) is a disorder of upper lip and palate caused by several factors, such as genetics, drugs, viruses, and toxins. It is more likely to develop during the first trimester of pregnancy, causing complications during labor, and affects various organs, such as face, oral cavity, teeth, and respiratory system. Moreover, it affects the child’s speech and language development, feeding, hearing, and eruption and alignment of the teeth. CLP was found in approximately one per 500 to 550 live births depending on nationality and socioeconomic status. In Thailand, the incidence of children with CLP is about...
In Srinagarind Hospital, the patients with CLP receive treatment from a multidisciplinary team which consists of plastic surgeons, pediatricians, gynecologists, otorhinolaryngologists, dentists, orthodontists, oral and maxillofacial surgeons, psychiatrists, nurses, social workers, and other health care providers. The treatment will start from birth to the age of 19 years which are described as follows:

During the age of three to six months: Cheiloplasty (the process of forming an artificial tip or part of a lip) will be performed.

During the age of 10 to 18 months: Palatoplasty (a surgical procedure used to correct or reconstruct the palate) will be performed. If a fistula or wound separation occurs, the patient needs a repairment. Speech and language assessment and therapy will be also started.

During the age of four to five years: The lip and nose will be reassessed before the patient starts school and enters society.

During the age of 8 to 12 years: Alveolar bone graft will be performed before the patient undergoes orthodontic treatments.

During the age of 15 years and older: In some serious cases, orthognathic surgery (a surgery to correct conditions of the jaw and face related to structure) will be performed.

The treatment will be end depending upon the satisfactions of patients, caregivers, and multidisciplinary teams, or they meet the satisfactory results.

The Tawanchai Center and out-patients surgical room of Srinagarind Hospital provide care for patients with CLP (from birth to adolescent) and their caregivers. Nurses working in these units are part of the multidisciplinary team and work collaboratively with other nurses in different units, such as an antenatal clinic, a postpartum room, a labor room, an operating room, a family planning unit, a surgical in-patient ward, and anesthesia unit. Moreover, nurses cooperate with staff working in other departments, such as a dental clinic and a speech and hearing clinic.

From the observations and interviews with nurses working at the Tawanchai Center and out-patient surgical room, and caregivers of patients with CLP, they reported that both patients and their parents confronted many problems which affected their physical and mental health.

Based on the Soukup’s model (2000), the researchers used evidence triggers from clinical practice (practice triggers) and related literature (knowledge triggers) to investigate the problems. The information gained from this study may help nurses better understand the problems and can use this information to develop proper interventions for patients with CLP and their families in the future.

**Objective**

To investigate the problems of care for patients with CLP in the Tawanchai Center and out-patient surgical room of Srinagarind Hospital.

**Material and Method**

The descriptive and qualitative methods were used. For practice triggers, the researchers obtained the data from medical records of ten patients with CLP and from interviewing two patients with CLP, eight caregivers, two nurses, and two assistant workers at the Tawanchai Center and out-patient surgical room. Instruments for the interview consisted of a demographic data form and a semi-structured questionnaire. Each interview took around 15 to 20 minutes. The interviewers asked the patients, caregivers, nurses, and assistant workers to identify common problems of care in patients with CLP. A field note and a tape recorder were used during the interview with the participant’s permission. For knowledge triggers, the researchers used a literature search. The keywords used for searching included “cleft lip and cleft palate”, “cleft lip and palate”, “cleft lip with and without cleft palate”, “patients with CLP”, “children with CLP”, “problems of care”, and “needs for care”. Academic databases for searching included PubMed, Medline Plus, CINAHL, and Cochrane Library. The data from both practice and knowledge triggers were collected for four months (February to May 2016). The quantitative data were analyzed through frequency and percentage distributions and the qualitative data were analyzed through a content analysis.

**Ethical consideration**

This study was approved by the Human Research Ethics Committee Khon Kaen University (HE581345).

**Results**

**Participants’ characteristics**

Patients were aged between 0 to 25 years old. Five of them were males (50%) and another five were females (50%). Eight patients (80%) had unilateral cleft lip and palate, and two patients (20%) had bilateral
cleft lip and palate. All of caregivers (100%) were mothers; aged between 25 and 45 years old, finished an elementary school, and had low incomes (average 3,000 baht or $100). Nurses and assistant workers had experiences in taking care of these patients more than one year. The highest level of education for nurses was a Master’s degree and for assistant workers was a Bachelor’s degree.

**Problems of care**

The information concerning problems of care was gained from 1) medical records, 2) interviewing patients with CLP, caregivers, nurses, and assistant workers, and 3) reviewing related literatures. The results are shown in Table 1-3.

**Discussion**

There is a consistency of the information gained from practice and knowledge triggers. From medical records, and the interviews of patients with CLP, caregivers, nurses, and assistant workers, the problems of care existed from childbirth to adulthood. The most common problem at the early stage of childhood is insufficient feeding due to the difficulties in sucking, swallowing, and choking. This can lead to malnourishment, weight loss, slow physical development, and aspiration. The findings in this study are consistent with previous studies which found that babies with CLP had feeding difficulty, swallowing problems, dental problems, and delayed development\(^{12,15,17}\). It was found that risks of a common cold, respiratory tract infections, otitis media, middle ear effusion, hearing impairment, and speech and language deficits were common among patients with CLP at the preschool age. These findings are consistent with previous studies\(^{10-12,14,15}\). Especially, speech and language deficits can persist to the stage of adulthood due to delayed speech therapy, lack of awareness and knowledge of speech and language impairment, low socioeconomic status, no speech services, and lack of SLPs\(^{10}\). Moreover, the patients with CLP may suffer from hearing impairment or hearing loss. The incidence of hearing loss is higher in patients with CLP than those without CLP\(^{11}\). When the patients enter school, the problems of articulation disorders, fistula of the palate, nostril asymmetry, abnormal tooth eruption, dental malalignment, and decayed teeth can occur and cause the patients to feel different from other children and to be absent from school because of many medical appointments. These problems impact the patients’ emotional, social, and spiritual aspects, such as anxiety, dissatisfaction with their image, loss of social interaction with friends, and isolation. Not only the patients but also their caregivers confront emotional and socioeconomic issues. The results are consistent with previous studies that found that children with CLP were at risk of psychosocial and spiritual burdens, such as depression, unhappiness, distress, low quality

<table>
<thead>
<tr>
<th>Problems of care</th>
<th>Age</th>
<th>Number of cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Feeding difficulty</td>
<td>4 months</td>
<td>2</td>
</tr>
<tr>
<td>- Nasoalveolar molding (NAM) before the surgery</td>
<td>4-5 years</td>
<td>2</td>
</tr>
<tr>
<td>- Articulation disorders</td>
<td>10 years</td>
<td>2</td>
</tr>
<tr>
<td>- Hearing impairment, otitis media, and middle ear effusion</td>
<td>12-13 years</td>
<td>2</td>
</tr>
<tr>
<td>- Speech and language deficits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- School absence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Image dissatisfaction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Articulation disorders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Fistula of the palate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Articulation disorders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Hearing impairment, otitis media, and middle ear effusion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Image dissatisfaction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Frequency of a common cold</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Dropping out from follow-up schedules and having insufficient treatments</td>
<td>25 years</td>
<td>2</td>
</tr>
<tr>
<td>- Image dissatisfaction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Economic problem</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Speech and language deficits</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Problems of care

For patients with CLP
- Newborn to 5 years of age
  - Difficulties in sucking, swallowing, choking, and feeding
  - Displacement of nasoalveolar molding
  - Articulation disorders
  - Decayed teeth
  - Speech and language deficits
  - Risk of a common cold, respiratory tract infection, otitis media, and hearing loss
  - Frequency of medical appointments and evaluations
- 6 years of age to adolescence
  - School absence due to the frequency of hospital visits
  - Speech and language deficits
  - Nostril asymmetry
  - Abnormal tooth eruption and dental malalignment
  - Emotional and mental problems: worry about their image and socialized anxiety
- Adulthood
  - Image dissatisfaction
  - Speech and language deficits
  - Malocclusion of mandibles
  - Job refusal
  - Economic problems

For caregivers
- Lack of knowledge and confidence in raising the child with CLP
- Anxiety concerning the surgery and articulation disorders
- Worry about the child’s future
- Economic problems due to low family incomes and prolong payment for medical expenses and transportation to the hospital

Table 2. Problems of care gained from interviewing patients with CLP (n = 2), caregivers (n = 8), nurses and assistant workers (n = 4)

Conclusion

From evidence-triggers, the problems of care affect the patients and their caregivers holistically. Integrated long-term care by the multidisciplinary team is needed for children with CLP starting from birth to adulthood. Moreover, nurses who play a significant role in the multidisciplinary team should provide effective care to these patients and their caregivers by using a holistic approach. Moreover, education, counseling, and support can help nurses strengthen the patients’ and their caregivers’ abilities to care for themselves and reduce their feelings of anxiety and isolation. Nurses should also identify their role and work collaboratively with other healthcare providers in the multidisciplinary team.

What is already known on this topic?

CLP affects patients’ and their caregivers...
1) Mossey PA, Little L, Munger RG, Dixon, MJ, Shaw, WC. Cleft lip and palate. Lancet 2009; 374: 1773-85(8). CLP is generally divided into two groups: cleft lip with or without cleft palate, which affect the lip and oral cavity differently. The incidence of CLP was 1.7 per 1,000 live births, with ethnic and geographic deviations. This abnormality affects the child speaking, hearing, image, and psychosocial aspect. An integrated long-term treatment by the multidisciplinary team is needed for children with CLP starting from birth to adulthood.

2) Pradubwong S, Pongpagatip S, Vorrathongchai K, Chowchuen B. The development of the nursing care system for patients with cleft lip-palate and craniofacial deformities at Tawanchai Cleft Center, Srinagarind Hospital, Khon Kaen, Thailand 2012; 95 (Suppl. 11): S55-S66(9). Prior to this study, most treatments for children with CLP focused on the operations for repairing the abnormalities rather than addressed other aspects, such as quality of life of patients and their families. As the condition required a long period of treatment, there were some patients dropping out and having insufficient treatments. Moreover, misunderstanding towards the roles among multidisciplinary team may cause the patients and their families not to be able to access the integrated services. Therefore, the researchers developed the nursing care system for patients with CLP and craniofacial deformities under the guidance of care from a multidisciplinary team and holistic care approach. The nursing care system consisted of psychosocial care, breastfeeding, counseling, and other assistance as required. The result from interviewing 106 caregivers revealed that they were highly satisfied with nursing services.

3) Prathanee B. Development of speech services for people with cleft palate in Thailand: Lack of professionals. Journal of Medical Association of Thailand 2012; 95 (Suppl. 11): S80-S87 (10). Speech and language deficits are commonly found in children with CLP. Unfortunately, many patients received delayed speech therapy or didn’t receive it at all due to lack of awareness and knowledge of speech and language impairment, low socioeconomic status of the families, no speech services, and lack of speech and language pathologists (SLPs). As these problems were major concerns for SLPs, the researcher developed two modalities: bottom-up and top-down models, consisting of community-based services, networking for speech therapy, Cleft Audit Protocol for Speech Augmentation (CAPS-A), and speech assessment. With these models, children with CLP could have their speech and language problems corrected.

4) Thanawirattananit P, Prathance B, Hanawirattananit S. Audiological status in patients with cleft lip and palate at Srinagarind Hospital. Journal of Medical Association of Thailand 2012; 95 (Suppl. 11): S93-S99(11). Hearing impairment is one of the significant problems in children with CLP. They suffered from at least one episode of otitis media and middle ear effusion which may lead to hearing loss. It was found that the incidence of hearing loss in children with CLP was higher than those without CLP. The incidence of hearing loss ranged between 30% and 93%. In this study, the results showed that 186 patients (79.49%) were confronted with hearing loss. Among these numbers, 165 (88.71%) had bilateral hearing loss and 16 (8.6%) had unilateral hearing loss.


6) Patjanasoontorn N, Pradubwong S, Rongbutstri S, Mongkhonthawornchai S, Chowchuen B. Tawanchai Cleft Center quality of life outcomes: One of study of patients with cleft lip and palate in Asia Pacific Region. Journal of Medical Association of Thailand 2012; 95 (Suppl. 11): S141-S147(13). Caregivers indicated the need for knowledge about dental care, speech development and therapy. They also wanted to know the available local health services. For raising the child with CLP at five-years of age, the knowledge and information of child development, health promotion, the health service system, and sharing decision-making with the child’s treatment were requested by the parents.


Children with CLP were at risk of psychosocial burdens due to a number of medical appointments and evaluations, repeated surgeries, feeding difficulty, stigmatization, and speech and language limitation. Patients with CLP had greater behavior problems, more symptoms of depression, and were less happy than those without CLP. They also had more psychological distress and lower quality of life than normal children. CLP can cause many problems to the patients, such as feeding difficulty, speech limitation, hearing loss, different facial appearance from other children, and malalignment of the teeth. At preschool age (5-6 years old), teasing and mocking from other people may cause low self-esteem, hurt relationship with friends, and learning limitation. The patients may miss class very often because of surgeries and medical treatments which can be an obstacle to their social development. The families may confront stress, medical and transportation costs, and lost income.

Facial deformity affected patients with CLP and their families especially on appearance even after surgical correction. Patients with CLP had lower self-esteem and poorer quality of life than those without CLP.

Vocational and social issues affect rehabilitation and development of patients with cleft lip and cleft palate. However, psychological problems like lowered self-esteem and difficulties in social interaction have also been noted in them. Not many pediatric reconstructive surgery teams have a psychiatrist on their panel. It is likely that psychological problems are higher in incidence than literature actually suggests. Hence it is very essential that such cases are identified by the surgical team to maximize positive outcome of surgery and rehabilitation. This study discusses psychological issues revolving around cleft lip and cleft palate along with lacunae in many psychological research studies.

Psychological problems like low self-esteem and difficulties in social interaction have been noted in patients with CLP. However, not many psychiatrists are in a healthcare team. Therefore, it is more likely that psychological problems are higher in incidence than literature actually suggests.

<table>
<thead>
<tr>
<th>Articles</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>7) Pisek A, Pitiphat W, Chowchuen B, Pradubwong S. Oral health status and oral impacts on quality of life in early adolescent cleft patients. Journal of Medical Association of Thailand 2014; 97 (Suppl.10): S7-S16[14].</td>
<td>Children with CLP were at risk of psychosocial burdens due to a number of medical appointments and evaluations, repeated surgeries, feeding difficulty, stigmatization, and speech and language limitation. Patients with CLP had greater behavior problems, more symptoms of depression, and were less happy than those without CLP. They also had more psychological distress and lower quality of life than normal children.</td>
</tr>
<tr>
<td>8) Pradubwong S, Mongkhonthawornchai S, Keawkhamsean N, Prathanee B, Patjanasoontorn N, Chowchuen B. Clinical outcome of primary palatoplasty in pre-school-aged cleft palate children in Srinagarind Hospital: Quality of life. Journal of Medical Association of Thailand 2014; 97 (Suppl.10): S25-S31[15].</td>
<td>CLP can cause many problems to the patients, such as feeding difficulty, speech limitation, hearing loss, different facial appearance from other children, and malalignment of the teeth. At preschool age (5-6 years old), teasing and mocking from other people may cause low self-esteem, hurt relation ships with friends, and learning limitation. The patients may miss class very often because of surgeries and medical treatments which can be an obstacle to their social development. The families may confront stress, medical and transportation costs, and lost income.</td>
</tr>
<tr>
<td>10) Sousa AD, Devare S, Ghanshani J. Vocational and social issues affect rehabilitation and development of patients with cleft lip and cleft palate. Indian Assoc Pediatr Surg 2009; 14 (2): 55-58[17].</td>
<td>Psychological problems like low self-esteem and difficulties in social interaction have been noted in patients with CLP. However, not many psychiatrists are in a healthcare team. Therefore, it is more likely that psychological problems are higher in incidence than literature actually suggests.</td>
</tr>
</tbody>
</table>
workers for participating and Mr. Martin Leach for assistance with the English-Language presentation.

Potential conflicts of interest
None.

References
การกำหนดสิทธิทางคลินิกเพื่อการดูแลผู้ป่วยโรคบางแห่ง เทคโนโลยี โรงพยาบาลศรีนครินทร์: สุนัขและแมว และต่อความต้องการ

ศูนย์ ประดิษฐ์, ปิยมา ศูรี, ศุภณัฐ พลภัศภิชาทิพย์, อาวิน เทวกุล, บวรกิติ์ เจริญชัย

อุปหนัก: การประมาณการสิทธิทางคลินิกเป็นกิจกรรมที่เกิดจากยาและศูนย์สุขภาพคลินิก ศูนย์การวิจัยและพัฒนาระดับปฐมทัศน์ โรงพยาบาลศรีนครินทร์ ให้การดูแลผู้ป่วยโรคบางแห่งของคนไข้ (ตั้งแต่แรกเกิดจนถึงผู้สูงอายุ) รวมทั้งจุดเริ่มจากการสังเกตและชี้แจงสภาพที่รวมได้ พบว่าผู้ป่วยและผู้ดูแลผู้ป่วยขาดการทราบภาวะสุขภาพที่ต้องการการกระทำและวิจารณ์ผู้ป่วยโดยได้รับการอบรมแนวทางของ Soukup (2000) โดยกำหนดสิทธิทางคลินิกจากมุมมองที่ได้จากการปฏิบัติงาน (practice triggers) และตัวกระตุ้นที่ได้จากความรู้ (knowledge triggers) เพื่อเสริมประสิทธิภาพการดูแลผู้ป่วย

วัตถุประสงค์: เป้าหมายในการศึกษาค้นคว้าเพื่อตรวจสอบปัจจัยในการดูแลผู้ป่วยโรคบางแห่งของคนไข้ในโรงพยาบาลศรีนครินทร์

วิธีและวิธีการ: การวิจัยเป็นงานนวัตกรรมและคุณภาพ (descriptive and qualitative research) ที่เน้นการกำหนดสิทธิทางคลินิก ผู้ที่ได้รับการดูแลผู้ป่วย หากมีดัชนี 10 ราย และสิทธิ์ของผู้ป่วย 2 ราย ผู้ดูแล 8 ราย พบว่า 2 ราย และสิทธิ์ของผู้ป่วย 2 ราย เตรียมการก่อนเกี่ยวกับการเปรียบเทียบระหว่างการมีสิทธิ์หรือไม่มีสิทธิ์ พบความแตกต่างในผลการเมื่อมีสิทธิ์ เห็นว่าการมีสิทธิ์และความเป็นอยู่ที่ดีขึ้น ต่อไป

ผลการศึกษา: การศึกษาพบผู้ป่วยและผู้ดูแลผู้ป่วยโดยมีการปฏิบัติงานที่เป็นมาตรฐานและวิจารณ์ สามารถสนับสนุนความต้องการคุณภาพ โดยคำว่า 1) การให้ความรู้และสาระการไม่เกี่ยวกับการสิทธิ์ทางคลินิก 2) ความต้องการในการดูแลผู้ป่วยด้วยความช่วยเหลือและคุณภาพ 3) ผู้ที่มีความต้องการ เช่น ต้องการรักษา เทียบเท่า, 4) ผู้ที่มีความต้องการ เช่น ต้องการรักษา เทียบเท่า 5) ผู้ที่มีความต้องการ เช่น ต้องการรักษา เทียบเท่า 6) ผู้ที่มีความต้องการรักษา เทียบเท่า, 7) ผู้ที่มีความต้องการรักษา เทียบเท่า, 8) ผู้ที่มีความต้องการรักษา เทียบเท่า, 9) ผู้ที่มีความต้องการรักษา เทียบเท่า, 10) ผู้ที่มีความต้องการรักษา เทียบเท่า

สรุป: การศึกษาพบผู้ป่วยที่มีสิทธิ์ทางคลินิกนั้นมีการดูแลผู้ป่วยในระดับสูงกว่าและคุณภาพดีกว่า ส่วนการประเมินการดูแลผู้ป่วยของสิทธิ์ทางคลินิกต้องมีการแบ่งหน้าที่ ที่ต้องมีการควบคุมการดูแลผู้ป่วยและคุณภาพดีกว่า

S50 J Med Assoc Thai Vol. 99 Suppl. 5 2016