

# Nursing Care System Development for Patients with Cleft Lip-Palate and Craniofacial Deformities at Srinagarind Hospital

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**Background:** A holistic nursing care system for patients with cleft lip-palate (CLP) and/or craniofacial deformities was arranged by the Nursing Department, Srinagarind Hospital, which provides tertiary nursing care. The nursing care system was developed as per system theory via participating management with action research following the Deming Cycle (PDCA) divided into 3 phases. Participants included 117 nurses from 8 divisions caring for patients with CLP and 128 parent caregivers. The research instruments included: 1) situation analysis, 2) meeting and planning and 3) self-administered questionnaire. Groups were divided according to the age, physical and mental aspects of the patients.

**Results:** 1) The nursing care system under study comprised psychosocial care, breastfeeding, counseling, providing assistance in various ways in order to respond to problems of patients/families by the multidisciplinary team. There was also follow-up to evaluate the results and in order to give patients/families longitudinal and continuing care. 2) Minor research of 4 nursing sections was initiated. 3) Nursing care standards, manuals, regulations and innovations for the organization of eight nursing sections were created and implemented.

**Conclusion:** The present study on developing a nursing care system for patients with CLP helped the team to (a) understand the overall nursing care system (b) to develop the organization of nurses by conducting research and (c) to create 12 works for developing care. The latter aimed to establish or create standards, nursing manuals, caring manuals, regulations, innovations, CDs, portfolios and informative cartoons to be applied systematically and shared across and between communities. The model for nursing care for patients with CLP in tertiary hospitals was clearly demonstrated.

**Keywords:** Nursing care system development, Cleft lip-palate and craniofacial deformities, Innovation, Srinagarind Hospital, Tawanchai Cleft Center

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The northeastern region has the highest rate of cleft lip-palate (CLP) deformities in Thailand (2.49 per 1,000 newborn babies)<sup>(1,2)</sup>. Most care continues to focus on corrective surgeries or in some cases only lip repair. These deformities affect the quality of life of patients and their families, particularly in the domains of physical and mental health and social interactions.

Being born with cleft lip/palate deformities affects one's sensibilities, the expectations of parents and relatives and most obviously the facial structure and the associated systems of breathing, smelling/tasting, eating and speaking. Caring for these deformities depends upon the time since birth to the age of 18 during which inter disciplinary teams of specialists will embark upon and complete many types of interventions including multiple surgeries. The goal is to ensure each organ and organ system affected by CLP functions normally or almost normally and that parents and relatives are also satisfied. Family also have to overcome emotional and psychosocial obstacles and

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they do so by being empowered with assistance/support, knowledge and suggestions from the healthcare team and related societies so that they can surmount the problems and difficulties their children will encounter throughout their first 18 years of natural development and treatment interventions<sup>(2,3)</sup>.

Currently, CLP-care engages specialists from various fields to continually look after patients from birth to young adulthood. This accurate and well-timed, care aims for beautiful faces, near normal voices, well-arranged teeth with normal occlusion, normal brain development and social adjustment. Parents, guardians or caregivers have knowledge and understand the goals of treatment. They know what it is to look after patients and the importance of checking with the team so that treatments are done according to age. The family confronts daily issues and manages crises as they arise. Importantly, the anxiety endured by the patient and his/her family are implicitly (and explicitly where appropriate) addressed by the team<sup>(3)</sup>.

Srinagarind Hospital, Faculty of Medicine, Khon Kaen University, has been giving surgical treatment to patients with cleft lip and palate since 1978. Since 1984 until now, the data shows that 2,153 patients were operated on and there were 3,545 operations, which is approximately 150 cases/year by average. The trend for patients getting surgical treatment has increased from 200 to 250 cases/year and there are also patients coming for other treatment. For example, there are 300-400 cases/year and more than 1,000 visits/year to come to be followed-up on development and nutrients, check up for ears and hearing and for speech therapy and 250 to 300 cases per year for getting care of the teeth in Cleft lip and palate clinic with open integrated service once a month.

Services for patients with CLP at the Faculty of Medicine and Srinagarind Hospital, Khon Kaen University, began in 1975. The systematic collection of the whole suite of operational statistics began in 1984. The data shows that 2,153 patients were operated on and there were 3,545 operations, which is approximately 150 cases/year by average. The trend for patients getting surgical treatment has increased from 200 to 250 cases/year and there are also patients coming for other treatment. For example, there are 300-400 cases/year and more than 1,000 visits/year to come to be followed-up on development and nutrients, check up for ears and hearing and for speech therapy and 250 to 300 cases per year for getting holistic care in the Cleft clinic once a month.

Many of these patients received funding from

the Red Cross Society. As a consequence, family caregivers are increasingly involved in ensuring long-term follow-up and want to be involved in the planning and decision-making<sup>(4,5)</sup>.

The nursing divisions in the multi-/inter-disciplinary team, providing services for patients with CLP and craniofacial deformities at Srinagarind Hospital, needed to have coordination of its services; that is, according to the longitudinal treatment of patients who meet different problems as they age/grow (*viz.*, pre-/post-operative physical, psychosocial, nutritional and developmental)<sup>(2,6)</sup>. Providing good nursing care service systems for patients with CLP means creating a “quality culture” and adopting a whole-group concept.

A quality work system can be achieved using the Deming Cycle as a model-Plan-Do-Check-Act (PDCA). This involves all nurses in systematic planning; clearly defining what, how, when she/he will do, for what he/she wants to create, including planning for short- and long-term outcomes. Implementation follows planning then verification of the results: what were the results, the problems and how to evaluate and improve the innovations. Operational strengths and weaknesses are analyzed and used to plan the next level of innovation; thus, the PDCA cycle comes full circle<sup>(7)</sup>.

## **Material and Method**

The Ethics Committee for Human Research, Khon Kaen University, reviewed and approved this study. It was action research among eight cooperating nursing sections from the Division of Nursing, Srinagarind Hospital, contributing to formulate an inclusive nursing model appropriate to hospitals at or above the tertiary care level. The research was divided into three phases and was conducted between May, 2010 and April, 2011:

### **Phase 1**

Situation Analysis: interview, group conversation, observation, nursing records of a 3 month review between May and July, 2010;

### **Phase 2**

Practice by Planning a Development Model: meeting, group planning, operating and improving, developing techniques, mechanisms for continuity and permanence:

- Meetings to explain the ways the research team operates;

- Eight research groups included: the delivery room, post-delivery patient building, surgery patient building 3C, patient building 3E, operating room, anesthetist, checking surgery room and the Tawanchai Cleft Center (Center for CLP Patient Care).

- Meetings to systematize care for patients with CLP; and,

- Implementation of the care functions within each operation.

- Evaluation of care functions within the first three months and every six months between August, 2010, and January, 2011.

### **Phase 3**

Evaluation and Conclusion: 3 months between February and April, 2011.

### **Population and Research Methodology**

The population in the present study was 117 care giving officials; a representative from each nursing section selected because they were considered key informants for the group discussions and interview and would be able to extend their learning with others. The representative of each section would have a meeting to explain the projects and the operation to develop the organization of nurses or service systems in each section. There were 128 patients/caregivers for patients with CLP at Srinagarind Hospital. The formula from Krejcie and Morgan<sup>(8)</sup> was used to determine the sample size.

### **Research Instrument**

- 1) Situation analysis
- 2) Meeting & planning
- 3) Questionnaire

The quantitative data were analyzed by percentage, average score and standard deviation (SD). The qualitative results, from open-ended questions, were analyzed using content analysis which included reading, comprehension, main point(s), interpretation and synthesis.

### **Results**

The nursing care system comprised psychosocial care, breastfeeding, help in other aspects in response to problems encountered by patients/their families due to needed or planned interventions by the interdisciplinary team. The results of the subsidiary studies of the organization of four nursing sections follow in Table 1.

The standard of nursing care, regulations and

innovations follow in Table 2.

### **Discussion**

Srinagarind Hospital with its nursing services and Tawanchai Cleft Center (Center for care of patients with CLP and craniofacial deformities), Faculty of Medicine, Khon Kaen University, is a world-renowned center for CLP research activities and academic services. Model management of services for these patients is therefore of primary importance. Development of nursing care systems is a well-known health management science. The authors team therefore had extrinsic and intrinsic interests in improving the nursing care service system for patients with CLP and craniofacial deformities at tertiary care hospitals. The ultimate goal is to create a Research Centre of Excellence.

The development of a nursing care system for patients with CLP and craniofacial deformities at Srinagarind Hospital was undertaken by eight related nursing care divisions within the hospital and resulted in a practical care system for the tertiary level hospitals and Centers of Excellence for CLP in the Northeast. Cooperation of the multi- and inter-disciplinary team enabled the creation of longitudinal treatment model: *i.e.*, from pregnancy to delivery, from infancy to school-age and through the teens to young adulthood. The nursing care system proactively promotes holistic care and support of CLP patients and their families as individuals, families and communities within the context of the local culture.

The nursing care system developed for patients with CLP and craniofacial deformities at Srinagarind Hospital succeeded in being inclusive as information and resources were drawn from empirical evidence within and across eight nursing care divisions within the hospital. The nursing care system thus devised integrated (a) the various division manuals in various ways (b) the standards for specialist nursing care and (c) the spectra of innovations in nursing care of the divisions. In addition to the cooperation among health professionals, caregivers were included and able to contribute to the process and outcomes. As a consequence, both patients and caregivers (a) acquired new knowledge (b) felt included and satisfied and (c) adopted a positive, constructive attitude towards the model of appropriate nursing care in the tertiary hospital context.

### **Conclusion**

The present study into developing the nursing care system for patients with CLP has helped the team

**Table 1.** Subsidiary studies of the organization of four nursing sections

Research	Result (s)
1. Development of nursing care system for patients with CLP & craniofacial deformities at Plastic Surgery Room & Tawanchai Cleft Center	<ul style="list-style-type: none"> <li>- Canvassed 22 officials for their opinion about the care of patients with CLP.</li> <li>- Responses used for focus discussion son ways to develop a nursing care system.</li> <li>- One-stop services provided for patients/their families for 6 months.               <ul style="list-style-type: none"> <li>- 106 caregivers evaluated from 128 samples (83%).</li> <li>- Caregivers had very high level of satisfaction for each item and overall (<math>\bar{x} = 3.56</math>, <math>SD = 0.13</math>).</li> <li>- Caregivers had a high level of knowledge (<math>\bar{x} = 3.7131</math>, <math>SD = 0.8141</math>).</li> </ul> </li> </ul>
2. Development of nursing care system for patients with CLP & craniofacial deformities at Srinagarind Hospital: pre-/ post-operatively	<ul style="list-style-type: none"> <li>- Used situation analysis, meetings and work development to evaluate innovation within the divisions               <ul style="list-style-type: none"> <li>- Resulted in                   <ul style="list-style-type: none"> <li>- New regulations &amp; nursing care manual by 12 nurses</li> <li>- Parents' manual</li> <li>- Informative video clip</li> <li>- Narrative cartoon by 30 care givers.</li> </ul> </li> </ul> </li> <li>- With the exception of the pictures &amp; cartoons, the items proved to be effective and appropriate.               <ul style="list-style-type: none"> <li>- Pictures in parent's manual and narrative cartoon were unclear, too small and/or unattractive.</li> </ul> </li> </ul>
3. Development of nursing care system for patients with CLP & craniofacial deformities in OR at Srinagarind Hospital	<ul style="list-style-type: none"> <li>- After situation analysis, OR personnel had their attitudes measured.               <ul style="list-style-type: none"> <li>- OR personnel had good attitudes towards services for patients with CLP.</li> <li>- They provided correct stepwise services to CLP patients.</li> </ul> </li> <li>- After results were made known, OR officials used suggestions to improve &amp; develop work.               <ul style="list-style-type: none"> <li>- Satisfaction of 30 caregivers was very high                   <ul style="list-style-type: none"> <li>- with OR services and personnel.</li> </ul> </li> </ul> </li> </ul>
4. Knowledge & satisfaction of caregivers CLP patients at Tawanchai Cleft Center	<ul style="list-style-type: none"> <li>- 41% of patients had left unilateral complete CLP</li> <li>- 68% of caregivers were the mother</li> <li>so 43% of caregivers had completed primary education               <ul style="list-style-type: none"> <li>- 40% worked in agriculture</li> </ul> </li> <li>- Average knowledge level among caregivers vis-a-vis specialized care of CLP patients a good level (<math>\bar{x} = 3.71</math>, <math>SD = 0.81</math>)</li> <li>- Average knowledge level about cause of CLP, treatment guidelines and treatment by a multidisciplinary team a moderate level (<math>\bar{x} = 3.28</math>, <math>SD = 0.85</math>)</li> <li>- Satisfaction of caregivers with service at In- and Out-patient Surgery Department very good for all items (<math>\bar{x} = 3.54</math>, <math>SD = 0.54</math>)</li> </ul>

(a) to understand the overall of nursing care system (b) to develop the organization of nursing sections through research (c) to create a total of 12 new works for improving the care of CLP patients (*i.e.*, standards, nursing manual, care manual, regulations, innovations, CDs, portfolios and informative cartoons). The nursing care system model has real potential for adoption and adaptation for other groups of patients.

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#### Potential conflict of interest

None.

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**Table 2.** Standard of nursing care, nursing manual & regulations, and innovations among the organizations of eight sections

Section	Aim	Innovation outcome
1. Delivery Room Ward	Develop manual of nursing care for babies with CLP	- Created manual - Contents validated by 5 experts in education & nursing care fields
2. Post-partum Ward	Develop & implement standards for helping mothers after delivering a baby with CLP or craniofacial deformities Create manual Promote breastfeeding	- Standards practical & adopted by mothers in post-partum ward  Nursing care manual created for babies with CLP and their mothers Manual created encouraging breast feeding for babies with CLP
3. 3E Ward	Set standards of nursing care for patients with CLP undergoing alveolar cleft bone graft	Standards set and adopted
4. Anesthesiology	Analyze situation & conduct meeting	Pre-anesthesia evaluation & preparation created leading to W.S.001 a document to be used in all systems at Srinagarind Hospital
5. Tawanchai Cleft Center	Develop manual for parents on interdisciplinary care of CLP patients Assemble manual on interdisciplinary care of CLP patients in tertiary level hospitals or centers with specialist care Collect information for parents with CLP children	Manual created  Manual distributed  Portfolio assembled
6. Out-Patient Surgical Department	Create manual for patients with CLP	Treatment & surgery guide produced
7. 3C Ward	Create care guide for CLP patients Develop common narrative Produce informational CD	Pre & post operation care guide created Story written about a boy named Tang-Mo who has CLP surgery CD created for pre-/post-operative care of CLP
8. Operating room	To develop work and set standards for OR care of CLP patients	Standards developed & adopted

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## การพัฒนาระบบการพยาบาลผู้ป่วยที่มีภาวะความพิการปากแหว่งเพดานโหว่ใบหน้าและศีรษะ โรงพยาบาลศรีนครินทร์

ศิริพร มงคลถาวรชัย, สุธีรา ประดับวงษ์, ดาราวรรณ อักษรวรรณ, สุมาลี พงศ์ภักทิพย์, เสาวลักษณ์ ธีรัตน์พงษ์,  
พรเพ็ญ ปทุมวิวัฒนา, อรทัย แสนบน, กาญจนา อุปปัญ, บวรศิลป์ เขาวนชื่น

**ภูมิหลัง:** การจัดระบบการพยาบาลผู้ป่วยที่มีภาวะความพิการปากแหว่งเพดานโหว่ ใบหน้าและศีรษะตามช่วงอายุ และตามปัญหาที่พบ ทั้งด้านร่างกายและจิตใจของฝ่ายการพยาบาล โรงพยาบาลศรีนครินทร์ ซึ่งให้การรักษายาบาล ในระดับเหนือตติยภูมิ โดยใช้ทฤษฎีเชิงระบบเข้ามาจัดการแบบมีส่วนร่วมในลักษณะ action research ของทีมพยาบาล ที่ร่วมดูแลแต่ละหน่วยงานในวงจรการพัฒนาคคุณภาพของ Deming Cycle คือ Plan-Do-Check-Act (PDCA) ซึ่งแบ่งออกเป็น 3 ระยะ ทั้งนี้เพื่อให้ได้รูปแบบ ระบบการบริการพยาบาลผู้ป่วยที่มีภาวะความพิการปากแหว่ง เพดานโหว่ ใบหน้าและศีรษะ โดยกลุ่มตัวอย่างที่ใช้คือ เจ้าหน้าที่พยาบาลที่ร่วมให้การดูแลผู้ป่วยปากแหว่ง เพดานโหว่ ทั้งหมด 8 หน่วยงาน จำนวน 117 คน ผู้ป่วยและญาติจำนวน 128 คน เครื่องมือที่ใช้คือ 1) การวิเคราะห์สถานการณ์ 2) การประชุมและวางแผนงานร่วมกัน 3) แบบสอบถาม

**ผลการศึกษา:** พบว่า 1) ระบบการพยาบาลประกอบด้วย การดูแลด้านจิตสังคม การให้นม การให้คำแนะนำ การให้ความช่วยเหลือในด้านต่างๆ เพื่อตอบสนองต่อปัญหาของผู้ป่วย/ครอบครัวตามแนวทางการรักษา ของทีมสหสาขาวิชาชีพ โดยมีการติดตามประเมินผลเพื่อให้ผู้ป่วย/ครอบครัวได้รับการดูแลแบบองค์รวมอย่างต่อเนื่อง 2) เกิดผลงานวิจัยย่อยของ 4 หน่วยงาน 3) เกิดมาตรฐานการพยาบาล คู่มือ แนวทางการปฏิบัติและนวัตกรรมของ 8 หน่วยงาน

**สรุป:** การศึกษาอย่างมีส่วนร่วมในการพัฒนาระบบการพยาบาลผู้ป่วยปากแหว่งเพดานโหว่ นี้ทำให้ทีมทราบถึง ระบบการพยาบาลแบบองค์รวม เกิดการพัฒนาหน่วยงานด้วยการวิจัยจำนวน 4 เรื่อง เกิดผลงานในการดูแล อย่างครบวงจรทั้งมาตรฐาน คู่มือการพยาบาล คู่มือการดูแล แนวทางปฏิบัติ นวัตกรรม ซีดี แผ่นภาพ การตื่นในการให้ข้อมูล จำนวนผลงานทั้งสิ้น 12 ผลงาน เพื่อรวบรวม ประกาศ และนำไปใช้อย่างเป็นระบบต่อไป ทำให้เห็นรูปแบบการพยาบาล ผู้ป่วยปากแหว่งเพดานโหว่ในโรงพยาบาลระดับเหนือตติยภูมิได้อย่างชัดเจน

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