

Development of Information System for Patients with Cleft Lip and Palate undergoing Operation

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Background: Srinagarind Hospital has 150-200 patients with cleft lip and palate each year. When patients are admitted to hospital for surgery patients and family feel they are in a crisis of life, they feel fear, anxiety and need to know about how to take care of wound, they worry if patient will feel pain, how to feed patients and many things about patients. Information is very important for patients/family to prevent complications and help their decision process, decrease parents stress and encourage better co-operation.

Objective: To develop information system for patients with cleft lip-palate undergoing operation.

Material and Method: This is an action research divided into 3 phases. Phase 1 Situation review: in this phase we interview, nursing care observation, and review nursing documents about the information giving. Phase 2 Develop information system: focus groups, for discussion about what nurses can do to develop the system to give information to patients/parents. Phase 3 evaluation: by interviewing 61 parents using the structure questionnaire.

Results: 100 percent of patients/parents received information but some items were not received. Patients/parents satisfaction was 94.9 percent, no complications.

Conclusion: The information system development provides optimal care for patients and family with cleft lip and palate, but needs to improve some techniques or tools to give more information and evaluate further the nursing outcome after.

Keywords: Nursing care system, Information, Cleft lip and palate

J Med Assoc Thai 2015; 98 (Suppl. 7): S151-S157

Full text. e-Journal: <http://www.jmatonline.com>

Cleft lip and palate are the most common craniofacial anomalies. Srinagarind Hospital has 150-200 cases each year⁽¹⁾. These patients needs continuity of care involving a multidisciplinary team and need surgery as soon as possible, some patients having operation about 10 times. It is quite a long time for them from 3 months old until teenager. When patients/family go to hospital for surgery patients and family feel they are in crisis of life, experience fear, anxiety and need to know how to take care of wound, worry if patients feel pain, how to feed patients, what kind of food they can have. Also what activity they can or cannot do after operation and many things about patients⁽²⁾. The information is very important for patients/family to prepare them to face this situation. Previous research

has shown that parents of patients with cleft lip and palate receive information about 94 percent, but caregiver cannot take care of patients wound correctly. Parents satisfaction 92 percent, lost follow-up 5 percent and wound infection 2.44 percent^(3,4). The nurses role begins from patients birth until the end of treatment and work continuously and closely with the patients so they require knowledge, experience and ability to give information including taking excellent care of their patients and families to prevent illness, duplicate rehabilitation and promote quality of life⁽⁵⁾. It can prevent complications and help their decision process, decrease parents stress and encourage better co-operation.

Cleft lip and cleft palate

Cleft lip and cleft palate is the most common congenital craniofacial anomaly. In Thailand affecting approximately 2.49 in every 1,000 births⁽⁶⁾. Cleft lip and cleft palate occurs early in pregnancy. The tissue that forms the lip ordinarily fuses by 5 to 6 weeks, and the

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palate closes between 7 and 9 weeks of gestation. The type of clefting varies with the embryonic stage when its development occurred. There are several types of cleft lip, ranging from a small groove on the border of the upper lip to a larger deformity that extends into the floor of the nostril and part of the maxilla (upper jaw bone)⁽⁷⁾.

Patients with cleft lip and palate have problems with feeding, swallowing difficulties and delayed development. When going to school, children will separate from other friends. They have speech articulation problems, suffer from shyness, social isolation and loneliness⁽⁸⁾. When becoming teenagers they have low self esteem and self image⁽⁹⁾. When they go to hospital to receive surgery, the pain, limited activity and food are very different from normal life.

Lip repair and palatoplasty is the most common method to correct the problem. The goal of this surgery is to fix the separation of the lip, palate. Sometimes, a second operation is needed⁽¹⁰⁾.

Feeding

Usually infants get milk from breast feeding or bottle feeding by sucking, to provide nourishment for growth and development. It is very important for infants to obtain adequate nutrition. The physical act of sucking involves using the jaw, tongue, gum, palate and lips⁽¹¹⁾. There are 3 reflexes for feeding, rooting, sucking, and swallowing reflex. Effective feeding supports weight gain of infant to get ready for operation. Sucking is a very important issue as it is not only a source of food but it is comforting for infants⁽¹²⁾. The feeding process provides bonding between mother and child as well as oral motor skill development⁽¹¹⁾. After palatoplasty physicians do not allow breastfeeding or bottle feedings, only spoon/syringe/medical dropper placed on for 2 weeks after operation to avoid tension at the sutured area during sucking⁽¹³⁻¹⁵⁾. So patients often cry because of not being used to syringe/spoon feeding, can take less milk and not feel comfortable as breast/bottle feeding, as well as sucking being a response to patients need⁽¹⁶⁾.

Nursing care

Nursing care is the process where nurses use their nursing ability to adjust the balance between self care ability and self care demand. Starting by researching the problem or needs then developing patient or clients ability for self care. Nursing care is a dynamic depending on patients needs⁽⁵⁾. Nursing care has to integrate 4 dimensions of service thus treatment,

health promotion, prevention of illness and rehabilitation as well as concern about holistic care⁽⁷⁾. Nurses provide nursing care to all people to solve health problems.

Giving information is a nursing role to help patients understand about disease, treatment and care. Patients want to receive information, but they often feel inadequately informed about their health and treatment⁽¹⁷⁾. To give information effectively, nurses need a range of skills and knowledge of the topics. Information can help patients/family better able to manage their health and treatment, better psychological outcomes such as less anxiety and depression and reduce condition and hospital admissions⁽¹⁸⁾. Sometimes patients may not understand the information because it is too complex or they cannot read, they are not good condition such as give information while have pain or too much information. Patients may not understand the relevance of the information to their situation. Patients may understand the information, but may not believe the information and not act on it.

There are four important considerations when providing information: who is receiving and giving the information? Where is the information being given? How should the information be provided? What format should be used? It is important to consider who is receiving it and how this might affect the process. Consideration needs to be given to the individuals age, sex, educational or cultural background, and knowledge or experience^(19,20). Even if people have no previous experience of a health problem, they may have knowledge and beliefs that are accurate or inaccurate. Giving information to some patient groups can be especially challenging. These groups include: low literacy, children and adolescents and different language. Poor literacy can be a barrier to improving individuals' health-related knowledge and to their engaging in self-care⁽²¹⁾.

The information giving to the patients

The information given to the patient include information before and after operation^(2,13).

Information before operation:

General information: usually nurses provide information about hospital rules, nursing activity, patients daily activity and physical hygiene such as shower. Explain parents condition after operation.

Specific information: 2 important specific information.

Feeding: after operation for lip repair patients

can get milk by sucking from bottle or breast feeding, but after palatoplasty patients can not suck. Parents have to feed them by spoon, syringe and nurses will provide a soft rubber tube attached on the end of the syringe.

Position: children should be put in upright position and burping after feeding.

Operative information: patients prepared by mouth care, nose care, NPO 6-8 hours and patients will have an intravenous catheter to provide fluids.

Information after operation

After surgery patients will have pain and cry, the wound will have stitches with swelling, bruising, blood around the stitches and in the mouth⁽¹⁴⁾. The postoperative management of patients after surgery focuses on protection of the operative site. Many children like to sleep in special bed, parents need to prevent their wound contacting the sheets. Physician will not allow Patients with palatoplasty sucking. After feeding the child's mouth should be cleaned by feeding them drinking water. The wound should be dressed by applying NSS with a cotton bud to clean the suture line and then put antibiotic ointment. Pain should be controlled with pain killer, holding and rocking is good for patients also. Stitches will dissolve in approximately seven days.

Airways: patients should be put in upright position on left or right side. Bleeding should be observed from the wound.

Cleft palate: patients will have stitches on the palate which will dissolve after several days. In some cases, packing will be placed on the palate. There may be some bloody drainage coming from the nose and mouth in the first day. There will be some swelling at the surgery site for about a week, pain felt for 2-3 days can be relieved by pain killer. Some patients will have nasal congestion, nasal snorting, mouth breathing. Drinking water after meal will cleanse the incision site and then continue to rinse this area gently with water several times a day, if necessary.

Diet after surgery: for lip repair patients can have breastfeeding, bottle-feedings, or cup feedings after surgery. Then can have a soft diet in second day after surgery. Palatoplasty patients should not use breastfeeding, bottle feeding, straw or pacifier, because it can damage the surgical site.

Activity after surgery: patients can walk or play after surgery, but should not run or engage in rough play (i.e., wrestling, climbing) or play with "mouth toys" for one to two weeks after surgery.

Discharge planning: Parents are taught feeding techniques, how to observe aspiration, take care of the incision and assess the incision for sign of infection. We tell the parents to keep the children's hands away from their face and confirm with them the pain killer dosage, time, and route. Patients will have appointment date for follow-up with surgeon and the cleft team before leaving hospital.

Objective

To develop information system for patients with cleft lip-palate undergoing operation.

Material and Method

Patients with cleft lip or cleft lip and palate who were admitted in 3C ward, Srinagarind Hospital received adequate verbal and written information regarding the study and information about the purpose, process, disadvantages and advantages in the study. After they agreed to participate in the study, they received same standard of nursing care as all patients. This is an action research divided into 3 phases.

Phase 1

Situation review: In this phase we interviewed nurses, nursing care observation and nursing documents review.

Nursing interview

We review the information that nurses provided to the patients by interviewing 12 nurses use semi-structure questionnaire. The questions were what, when, and how nurses were giving information to the patients/family, if have any problem about giving information and how can solve the problems.

Nursing care observation

We observe nursing care from the day patients were admitted until the discharge.

Nursing documents review

We review nursing documents from nursing assessment, nursing care plan, nurses note and other record about the information that nurses give to patients. How and when nurse do that activities by researcher.

The result of the situation review found all nurses said they give all the information patients need, we also found nurses did different thing in each shift, some of them give information but did not record, some shift did not give some information because they think

patients/family already got information from the shift before, so when patients were discharged some information patients/family said they didn't receive and some information was not understood. This study period was from September-December 2011.

Phase 2

Develop the information system: After situation review we have 2 focus groups, 6 nurses in each group to discuss about what nurses can do to develop the information system for the patients/family and if anything more nurses can do. This phase we have concise and appropriate guide lines, nursing manual, hand book, VCD for parents/family and story telling about cleft lip and cleft palate and agree to create leaflet, teaching protocol, and teaching record.

Leaflet

With color picture to make clear for parents to read and see.

Teaching protocol

To guide each shift each day what information nurses should give to the patients/family. The topic for teaching was as follows:

First day

Patients were admitted and given general information including information on disease and treatment, NPO time, hygiene care, appropriate position, pain assessment and management, feeding and diet, wound care/mouth care and provided with VCD and Leaflet.

Operative day

Repeat details about food and feeding, wound care training.

Post operative day 1-2

Repeat all information.

Discharge day

Teach parents/family about abnormal sign and symptom, Appointment date.

Teaching record

For nurses to tick what information they gave to patients/family from the day they were admitted until discharge. This form had the content about wound care feeding, mouth care and other (Table 1). Nurses will tick the form after they give patients/family

information then sign their name, so nurses on each shift know what information has already been given and follow the teaching protocol. When patients were discharged nurses can confirm the information patients/family received and if understood before they leave the hospital (Table 1). The study period was from January-April 2012.

Phase 3

Evaluation: After implementation we evaluate the information system by interviewing 61 parents of patients with cleft lip and cleft palate using the structure questionnaire. The data collection was obtained from May-December 2012.

Ethical consideration

This study is a part of nursing care system development for patients with cleft lip-palate and craniofacial deformity in Srinagarind Hospital. It was approved by Khon Kaen University Ethics Committees for Human Research.

Results

Demographic data: 10 registered nurses aged 24-35 years old, average 25.7 years old having experience about cleft lip and cleft palate care for 3-13 years, average 5.7 years. They graduated bachelor degree of nursing. Parents/caregiver of patients of cleft lip and cleft palate were aged 14-48 years old, average 45 years old, 70 percent were grandmother, 92 percent graduated primary school.

Receiving information: we found that 100 percent of patients/parents received information but some items were not received. Some items were receive but not understood (Table 2).

Patient/parents satisfaction

94.9%, no complications parents can take care of their children with no wound infection in this period of time and no patients lost follow-up.

Discussion

The study shows parents/care giver received information about wound dressing, pain management, but did not understand. They did not receive information about medicine. The VCD about cleft lip and palate to provide parents/caregiver the content already covered about medication. The results indicate sometimes parents/caregiver did not understand or were not concerned about information from VCD, or maybe it was too difficult for some of them, maybe

Table 1. Teaching record

| Topic | admitted | | | Operation day | | | P/O D1 | | | P/O D2 | | | D/C |
|-----------------------------------|----------|---|---|---------------|---|---|--------|---|---|--------|---|---|-----|
| | M | E | N | M | E | N | M | E | N | M | E | N | |
| 1) Disease and treatment | | | | | | | | | | | | | |
| 2) General information | | | | | | | | | | | | | |
| 3) Provided VCD about CLCP | | | | | | | | | | | | | |
| 4) NPO time | | | | | | | | | | | | | |
| 5) Hygiene care | | | | | | | | | | | | | |
| 6) Appropriate position | | | | | | | | | | | | | |
| 7) Pain assessment and management | | | | | | | | | | | | | |
| 8) Feeding and diet | | | | | | | | | | | | | |
| 9) Wound care/mouth care | | | | | | | | | | | | | |
| 10) Warning sign | | | | | | | | | | | | | |
| 11) Provided Leaf let | | | | | | | | | | | | | |
| 12) Repeat about food and feeding | | | | | | | | | | | | | |
| 13) Wound care training | | | | | | | | | | | | | |
| 14) Repeat all information giving | | | | | | | | | | | | | |
| 15) Abnormal sign and symptom | | | | | | | | | | | | | |
| 16) Appointment date | | | | | | | | | | | | | |

M = morning shift; E = evening shift; N = night shift

Table 2. Receiving information

| Information | Not receive | | Receive | | | |
|---------------------------|-------------|-----|------------|------|----------------|-----|
| | | | Understand | | Not understand | |
| | Case | % | Case | % | Case | % |
| Disease and treatment | 0 | 0 | 61 | 100 | 0 | 0 |
| Feeding | 0 | 0 | 61 | 100 | 0 | 0 |
| Wound dressing | 0 | 0 | 55 | 90.2 | 6 | 9.8 |
| Mouth care | 0 | 0 | 61 | 100 | 0 | 0 |
| Pain management | 0 | 0 | 57 | 93.4 | 4 | 6.6 |
| Medicine | 1 | 1.6 | 60 | 98.4 | 0 | 0 |
| Abnormal sign and symptom | 0 | 0 | 61 | 100 | 0 | 0 |
| Appointment date and time | 0 | 0 | 61 | 100 | 0 | 0 |

because of many caregiver only finished primary school, and they are grandmother so sometime not understand because of anxiety and education⁽¹⁸⁾. The considerations to giving information are when providing information, who is receiving and giving the information, where is the information being given, how should the information be provided and what format should be used^(20,21).

Conclusion

Information is very important for patients and

family to prepare them to face their situation and prevent complication. The information system development provides optimal care for patients and family with cleft lip and palate, but needs to improve some techniques or tools to give more information on some items and evaluate further the nursing outcome afterwards.

What is already known on this topic ?

From previous studies giving all the information patients and family want can reduce stress. Giving information by VCD is good for patients and

family. The verbal, non verbal information, instruction leaflet, font size, the color of information sheet also giving time for patients to confirm the information is very important considerations for giving patient information.

What this study adds ?

Using teaching protocol and teaching record together to guide nurses to provide the information for the patients/ family to make sure all information can be given to the patients at the right time and right way.

Acknowledgement

The authors wish to thank Nursing Division, Srinagarind Hospital, Faculty of Medicine Khon Kaen University. Khon Kaen University Cleft lip-Palate and Craniofacial Deformities, Khon Kaen University in Association with “Tawanchai Project” for supporting this project.

Potential conflicts of interest

None.

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การพัฒนาระบบการให้ข้อมูลผู้ป่วยปากแห้งเพดานโหว่ที่เข้ารับการรักษาผ่าตัด

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ภูมิหลัง: ผู้ป่วยปากแห้งเพดานโหว่ที่เข้ารับการรักษาในโรงพยาบาลศรีนครินทร์มีประมาณ 150-200 ราย ต่อปี เมื่อผู้ป่วยต้องเข้ารับการรักษาในโรงพยาบาลเพื่อผ่าตัด ผู้ป่วยและครอบครัวมีความรู้สึกกลัว กังวล มีความต้องการรู้ เกี่ยวกับการดูแลบาดแผล กังวลว่าผู้ป่วยจะปวด การให้อาหารจะให้อย่างไรและอีกมากมายซึ่งถือเป็นภาวะวิกฤตของครอบครัว ข้อมูลเป็นสิ่งสำคัญสำหรับผู้ป่วยและครอบครัวในการป้องกันภาวะแทรกซ้อนและช่วยในกระบวนการตัดสินใจลดความเครียด และทำให้เกิดความร่วมมือในการรักษาพยาบาล

วัตถุประสงค์: เพื่อพัฒนาระบบการให้ข้อมูล ผู้ป่วยปากแห้งเพดานโหว่ที่เข้ารับการรักษาผ่าตัด

วัสดุและวิธีการ: เป็นการศึกษาเชิงปฏิบัติการ แบ่งการศึกษาเป็น 3 ระยะ คือ ระยะที่ 1 ศึกษาสถานการณ์ปัจจุบัน โดยการสัมภาษณ์ การสังเกตการณ์ ปฏิบัติการพยาบาล และการศึกษา จากเอกสารการพยาบาลในประเด็นข้อมูลที่พยาบาลให้แก่ผู้ป่วย ระยะที่ 2 การพัฒนาระบบการให้ข้อมูลโดยการทำ focus group ในการแสดงความคิดเห็นในการพัฒนาระบบการให้ข้อมูลผู้ป่วย ระยะที่ 3 ประเมินผลโดยใช้การสอบถามผู้ปกครองผู้ป่วย

ผลการศึกษา: ผู้ปกครองทุกรายได้รับข้อมูลแต่ในรายละเอียดมีบางประเด็นที่ไม่ได้รับ ผู้ป่วยไม่เกิดภาวะแทรกซ้อนจากการปฏิบัติตัวไม่ถูกต้อง ผู้ปกครองมีความพึงพอใจต่อการได้รับข้อมูลร้อยละ 95

สรุป: การพัฒนาระบบการให้ข้อมูลให้ประโยชน์ในการให้การดูแลผู้ป่วยปากแห้งเพดานโหว่และครอบครัวแต่ต้องการการพัฒนาเทคนิคหรือวิธีการในการให้บางข้อมูล และประเมินผลสัมฤทธิ์การพยาบาลในลำดับต่อไป
