

Quality of Life in Patients with Cleft Lip and Palate after Operation

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Background: Cleft lip and cleft palate are the most common craniofacial anomalies. Srinagarind Hospital has 150-200 cases each year. The operating process of care, requires continuity of care involving a multidisciplinary team. When the patients go to hospital for an operation they experience pain, limited activity and also food is very different from normal life. When attending school they suffer speech articulation problems and feel shy and isolated, which has a detrimental affect on their life style and quality of life.

Objective: The main purpose of the study is to the present study quality of life in patients with cleft lip and palate after operation.

Material and Method: The present study is descriptive research using qualitative and quantitative approaches. The studied population were patients age 8-18 years old who were admitted at 3C Ward and Outpatient Department, Srinagarind Hospital. 33 patients were interviewed for the quantitative approach. Guideline for in-depth interview with 15 patients were used for the qualitative approach. Quantitative data were analyzed and presented in frequency, percentage and standard deviation. The qualitative data were analyzed through content analysis.

Results: Patients consider their QOL is high level, but in detail they still worry about self concept psychological well-being. From indept interview patients would like to get further treatment to minimize their scar as soon as possible.

Conclusion: Patients consider their quality of life as high level, but they would like to get further treatment.

Keywords: Cleft lip and cleft palate, Quality of life, Operation

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Cleft lip and cleft palate are the most common craniofacial anomalies, affecting approximately 2.49 of every 1,000 children born in North East of Thailand⁽¹⁾. Srinagarind Hospital has 100-150 cases of cleft lip each year⁽²⁾. Unexpected birth of infants with cleft lip and cleft palate has psychological effects for parents and some parents feel nervous with their child and lead to matrimonial problems^(3,4). The process for cleft lip and palate care, requires continuity of care involving a multidisciplinary team⁽¹⁾.

Patients with cleft lip and palate often have problems with feeding, swallowing difficulties and delayed development. When they go to hospital to

receive surgery, pain, limited activity and food are very different from normal life. When they go to school children will separate them from other friends. They have speech articulation problem, shyness, teasing, social isolation and loneliness^(5,6). When becoming teenager they have low self esteem and self image. Previous research shows that the patients were not satisfied their appearance. 35% of the adults with repaired cleft lip and palate desired further treatment⁽⁷⁾ and also found that society was not ready to accept people with differences in appearance⁽⁷⁾. Facial esthetics is an important aspect of quality of life in adults with repaired cleft lip and palate⁽⁸⁾. The general quality of life was satisfactory in patients with cleft lip and palate, but life meaning, family life and private economy were lower than in the control group. Females within the cleft group had lower levels of quality of life in global life, disturbed life and family life as well as their socioability and well-being scales⁽⁹⁾. The nurses

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role begins at patients birth and continues until the conclusion of treatment so they will have good knowledge of patients opinion about quality of life after operation or treatment and can provide nursing or coordinate with team and networking to take care of patients and family in community. Previous research showed that patients and family were not satisfied with their treatment, so the researcher would like to know how is the quality of life of the patients after operation in Srinagarind Hospital to provide nursing care and communicate with team to improve their quality of life.

Research question

How does the quality of life in patients with cleft lip and palate after operation?

Purpose of the study

1. To study the quality of life in patient with cleft lip and palate after operation.
2. To study the patients needs to improve their quality of life.

Quality of life

The quality of life is a multi-level and amorphous concept and can vary in priority among people in different age groups. Quality of life has been defined in societal, objective and individual, subjective terms. It includes income, employment, housing, education, other living and environmental circumstances. The individual perceptions of quality of life are experiences and values and related well-being, happiness and life satisfaction⁽¹⁰⁾. There are many models of quality of life such as human needs of Maslow's that are deficiency needs, security, growth needs and self-actualization and models based on psychological well-being, happiness, morale and life satisfaction^(11,12). To be a child with cleft lip and palate, being effect on a person's life including psychological status^(7-9,13). No previous study about the quality of life in patients with cleft lip and palate in Thailand.

Quality of life Measurement

The present study used WHOQOL and Zhan model to measure the quality of life.

WHOQOL⁽¹⁴⁾

Overall quality of life and general health divide in to 6 domain thus.

1. Physical health assessment including energy and fatigue, pain and discomfort, sleep and rest.
2. Psychological: Body image and appearance,

negative feelings, positive feelings, self-esteem, thinking, learning, memory and concentration

3. Level of Independence: Mobility, activities of daily living, dependence on medicinal substances and medical aids work capacity.

4. Social relationships: Personal relationships, social support, sexual activity.

5. Environment: Financial resources, freedom, physical safety and security, health and social care: accessibility and quality home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation, leisure, physical environment and transport.

6. Spirituality, religion and personal beliefs.

Zhan Model⁽¹⁵⁾

Zhan develop a model of QOL base on definition of QOL as "the degree to which a persons life experiences are satisfying" described QOL as a multidimensional concept that cannot be completely measured by either a subjective or an objective approach. She identified dimensions of quality of life as life satisfaction, self concept, health and functioning and socioeconomic factors. The quality of life also influenced by personal background, health, social situation, culture, environment and age.

Research Methodology

The present study use descriptive research using qualitative and quantitative approaches. It was approved by The Ethics Committee for Human Research, Khon Kaen University.

Sample population

The studied population were patients of in and outpatients in Srinagarind Hospital, Faculty of Medicine, Khon Kaen University. Patients with cleft lip and palate repair were purposively selected for the study according to the following criteria:

Inclusion criteria

- Patients with cleft lip or palate.
- Patients with cleft lip and palate.
- Age of 8-18 years old.
- Use to have operation.
- Full consciousness, can communicate with researcher.

Exclusion criteria

Patients with cleft lip and palate with another anomalies.

Outcome variables

Quality of life in patients with cleft lip and palate and patients need.

Data collection

Patients with cleft lip or cleft lip and palate who were admitted in 3C ward, Srinagarind Hospital or in Outpatient Department before they leave hospital will receive adequate verbal and written information regarding the present study and information about the purpose, process, disadvantages and advantages in the present study. After they agree to participate in the study, they were interviewed by nurse. Data collection was obtained from June 2006 to December 2007, 33 patients were interviewed for the quantitative approach. Assign randomization. Guideline for in-depth interview with 15 patients were used for the qualitative approach.

Data analysis

There are two main part of analysis, describing characteristics of the patients and analysis for answering the research question. Quantitative data was analyzed and presented in frequency, percentage and standard deviation. The qualitative data was analyzed through content analysis.

Measurement of the outcome

1. Demographic data questionnaires selected for study were age, sex, diagnosis, type of surgery, education, parents age, marital status and income. The data were collected at out patients unit and surgical ward.

2. Quality of life questionnaire. It is 5 level rating scale. Researcher modified questionnaire from WHO questionnaire base on Zhan quality of Life model. Thus Life satisfaction in various domain. Self concept psychological well-being. Health functioning physical well- being and Socioeconomic factors social well-being. Cronbach's Alpha Coefficient of the questionnaire obtained was 0.82. The authos divide quality of life into 5 level. Mean 1.0-1.49 very low, Mean 1.50-2.49 low, Mean 2.50-3.49 fair, Mean 3.50-4.49 high, Mean 4.50-5.00 very high.

3. In-depth interview.

Results

Demographic data

The patients sex 52% are male they are 8-17 years old, average 12.93 years old, 15% are Cleft lip, 40% are Cleft palate and 45% are Cleft lip and cleft palate. They are multiple admittance (2-6 time) average

3.3 time. The parents education are primary school. The family income is about 5,260 Baht/month.

Level of quality of life

Patients consider their quality of life in 4 dimension as high level ,but the detail in each dimension is vary as shown in table.

From in-depth interview the authors found

Table 1. Life satisfaction in various domain

Topic	Mean	SD
Satisfied with yourself	3.8	0.83
Satisfied with your personal relationship	4.6	0.68
Satisfied with the treatment	4.3	0.97
Satisfied with access to health service	4.3	0.68
Enjoy your life	4.5	0.61
Total	4.0	0.87

Table 2. Self concept psychological well-being

Topic	Mean	SD
Accepted in body appearance	3.8	0.78
Shy, hide the scar	2.7	1.22
Feel worry if people attention	2.9	1.39
Satisfied in body image	3.7	1.07
Total	3.6	1.20

Table 3. Health functioning physical well-being

Topic	Mean	SD
How safe you feel in daily life	4.38	0.69
Play or activity same as friends	4.38	0.77
Get bored keep going to hospital	3.50	1.04
Feel better after treatment	4.44	0.61
Satisfied with your health	2.94	1.21
Total	3.90	1.0

Table 4. Socio-economic factors social well-being

Topic	Mean	SD
Enough money to meet your needs	3.16	0.92
Satisfied with your capacity for study	2.55	1.38
Satisfied with the support from friends	4.00	0.90
Satisfied with your living place	3.90	0.80
Satisfied with transportation	3.60	0.97
Total	3.60	1.10

some of word

“I feel better after operation, but not enough because still have scar”.

“I felt shy but now feel better, after finish with the nose I will be very happy”.

“After I got treatment from 2004, I feel I am same as other people and its a new life”.

“If didn't have cleft, I think I will get more opportunity to study”.

“Before I can't speak well, friends like to tease me, teacher can't understand me, after operation everything better”.

“Don't want to attract people attention. Some people like to see and ask “what's wrong”. I need this scar disappear or small as possible”

“Mother spent a lot for transportation and other thing to be here”.

Patients needs

From in-depth interview the authors found that patients need health care professionals to have more knowledge and ability to advice them about care, how to take care themselves at home need to have better referral system. They like to have a book or leaflet about Cleft to read and some of them want health care professional come to visit at home after they come back from hospital, some quotes.

“We need nurse come to visit sometime at home to make us sure about taking care our child”.

“If have a book or leaflet or video then we can learn and know about the disease, how to get treatment how to take care of my self or parents can know how to take care their children”.

“Sometime hard to get better treatment for hospital that we need, because the local hospital don't want to refer to the hospital the authors need”.

“We ask local health professional here ,but seem they can not explain us clearly”.

Limitation

From the present study the sample population is difference in age (8-17 years old), diagnosis (cleft lip and cleft palate) that can make the results in some detail very high standard deviation.

Conclusion and discussion

Patients consider their quality of life as high level, but they would like to get further treatment.

Almost all of them still worry about the scar, because scar at nose and lip is obvious. It is attract people attention, also friends like to tease them. Patients

feel ashamed, especially school age patients, so they need the scar disappear or small as possible. Patients need health care professional in community who has better ability to take care of them.

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Potential conflicts of interest

None.

References

1. Chowchuen B. Interdisciplinary care of cleft lip cleft palate and craniofacial anomalies. Khon Kaen, Thailand: Siriphan Offset Publisher; 2004.
2. Medical record. Khon Kaen, Thailand: Srinagarind Hospital Khon Kaen University; 2005.
3. Augsornwan D, Namedang S, Pongpagatip S. Information needs of parents of children with craniofacial anomalies undergoing operation. Journal of Nurses Association of Thailand, North-Eastern Division 2005; 23: 46-54.
4. Johansson B, Ringsberg KC. Parents' experiences of having a child with cleft lip and palate. J Adv Nurs 2004; 47: 165-73.
5. Hunt O, Burden D, Hepper P, Stevenson M, Johnston C. Self-reports of psychosocial functioning among children and young adults with cleft lip and palate. Cleft Palate Craniofac J 2006; 43: 598-605.
6. Snyder H, Pope AW. Psychosocial adjustment in children and adolescents with a craniofacial anomaly: diagnosis-specific patterns. Cleft Palate Craniofac J 2010; 47: 264-72.
7. Ramstad T, Ottem E, Shaw WC. Psychosocial adjustment in Norwegian adults who had undergone standardised treatment of complete cleft lip and palate. II. Self-reported problems and concerns with appearance. Scand J Plast Reconstr Surg Hand Surg 1995; 29: 329-36.
8. Sinko K, Jagsch R, Prechtel V, Watzinger F, Hollmann K, Baumann A. Evaluation of esthetic, functional, and quality-of-life outcome in adult cleft lip and palate patients. Cleft Palate Craniofac J 2005; 42: 355-61.
9. Marcusson A, Akerlind I, Paulin G. Quality of life

- in adults with repaired complete cleft lip and palate. Cleft Palate Craniofac J 2001; 38: 379-85.
10. Bowling A. Quality of life assessment. In: Ayers S, Baum A, McManus C, Newman S, editors. Cambridge handbook of psychology, health and medicine. 2nd ed. New York: Cambridge University Press; 2007: 319-21.
 11. Fallowfield L. What is quality of life? London: Hayward Medical Communications, 2009.
 12. Andrews FM, editor. Research on the quality of life. Ann Arbor, MI: The Institute for Social Research, University of Michigan; 1986.
 13. Noor SN, Musa S. Assessment of patients' level of satisfaction with cleft treatment using the Cleft Evaluation Profile. Cleft Palate Craniofac J 2007; 44: 292-303.
 14. World Health Organization. WHOQOL measuring quality of life. Geneva: WHO; 1997.
 15. Zhan L. Quality of life: conceptual and measurement issues. J Adv Nurs 1992; 17: 795-800.

คุณภาพชีวิตผู้ป่วยปากแหว่งเพดานโหว่หลังผ่าตัด

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ภูมิหลัง: ปากแหว่งเพดานโหว่เป็นความพิการแต่กำเนิดที่พบมากที่สุดและผู้ป่วยที่มีความพิการของศีรษะ และใบหน้า แต่กำเนิด โรงพยาบาลศรีนครินทร์มีผู้ป่วยเข้ารับการรักษา 150-200 รายต่อปี กระบวนการรักษาดูแลผู้ป่วยปากแหว่งเพดานโหว่ เป็นการรักษาที่ใช้ระยะเวลาที่ยาวนานต่อเนื่อง และเกี่ยวข้องกับสัมพันธ์กันหลายสาขาวิชาชีพ เมื่อต้องผ่าตัด การผ่าตัดก่อให้เกิดความเจ็บปวด ทุกข์ทรมาน การถูกจำกัดอาหารและกิจกรรมต่างจากปกติ เมื่อเด็กเข้าสู่วัยเรียน มีปัญหาด้านภาพลักษณ์ การพูดไม่ชัด ทำให้เด็กมีความอาย ผลการเรียนรู้ตกต่ำ มีปัญหาในการเข้าสังคม มีผลต่อการดำเนินชีวิต และคุณภาพชีวิตของผู้ป่วย

วัตถุประสงค์: เพื่อศึกษาคุณภาพชีวิตของผู้ป่วยปากแหว่งเพดานโหว่หลังผ่าตัด

วัสดุและวิธีการ: เป็นการศึกษาเชิงบรรยาย ใช้วิธีการเก็บข้อมูลเชิงปริมาณและเชิงคุณภาพ กลุ่มตัวอย่างเป็นผู้ป่วยอายุ 8-18 ปี ที่มารับการรักษาที่หอผู้ป่วย 3ค และแผนกการพยาบาลผู้ป่วยนอก โรงพยาบาลศรีนครินทร์ จำนวน 33 ราย เก็บข้อมูลโดยการสัมภาษณ์โดยใช้แบบสอบถามจำนวน 33 ราย และการสัมภาษณ์เชิงลึกจำนวน 15 ราย วิเคราะห์ ข้อมูลเชิงปริมาณโดยการแสดงค่าความถี่ ร้อยละและส่วนเบี่ยงเบนมาตรฐาน ข้อมูลเชิงคุณภาพวิเคราะห์เชิงเนื้อหา

ผลการศึกษา: พบว่าระดับคุณภาพชีวิตผู้ป่วยหลังผ่าตัดอยู่ในระดับสูง แต่เมื่อดูรายละเอียดรายข้อพบว่าผู้ป่วยยังมีความกังวลในเรื่องอัตมโนทัศน์และภาพลักษณ์ จากการสัมภาษณ์เชิงลึก ผู้ป่วยยังต้องการรับการผ่าตัดเพิ่มเติม รักษาแผลเป็นที่มืออยู่ให้ลดลงมากที่สุดเท่าที่จะทำได้

สรุป: ผู้ป่วยตระหนักว่าระดับคุณภาพชีวิตของตนเองอยู่ในระดับสูงแต่มีความต้องการรับการรักษาเพิ่มเติมต่อไป
