Clinical Outcomes of Primary Palatoplasty in Pre-School-Aged Cleft Palate Children in Srinagarind Hospital: Quality of Life

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Background: *Cleft lips and cleft palates are common congenital anomalies, which affects facial appearance, speech, hearing, teeth alignment and other structures. Craniofacial anomalies and speech disorders are crucial problems in the preschool-aged children (5-6 years old), when they start attending school and become more engaged in the community. This condition, which differentiates them from other students, can lead to teasing or mocking which can cause low-self esteem, an inferiority complex, and foster bad relationships with friends. Missing class in order to receive treatment and other additional care can affect a student's learning, development and overall-quality of life.*

Objective: *The purpose of this research was to study the quality of life in preschool-aged cleft palate children and satisfaction with their level of speech.*

Material and Method: *This was a retrospective, descriptive study. The data were collected by reviewing medical records of patients with cleft lip and cleft palate aged 5-6 years old who underwent operation and treatment with the Tawanchai Center at Srinagarind Hospital. There were 39 patients in this study. Data collection was conducted for 5 months (June to October 2013). The research instruments were: 1) General Demographic Questionnaire, 2) Quality of Life Questionnaire with 5 Domains, and 3) the Satisfaction of Speech Questionnaire. The descriptive statistics, percentages and the standard deviation were analyzed in the present study.*

Results: *The findings revealed family information pertaining to CLP treatment and the impact it has on consumption, speech training, hearing test, development, dental treatment, communication skills, participation, referral treatment as well as the quality of coordination for advanced treatment. The present study revealed that all of the aforementioned criteria were met at a high level. Moreover, the child's sickness had only a moderate impact on family life. In conclusion, the overall satisfaction was at a very high level.*

Conclusion: *It was concluded that the collaboration of the Tawanchai Cleft Center and the government, as well as with private and non-governmental organizations was exceptional, particularly in regard to providing proper and continuous treatment for patients with cleft lips and/or cleft palate. The findings reflect a good quality of life in the pre-schooled children with cleft lip and cleft palate that received treatment from the Tawanchai Cleft Center at Srinagarind Hospital. Furthermore, the study showed that the problems associated with the condition, only affected the family's lives at a minimal level.*

Keywords: *Quality of life, Cleft lip/cleft palate*

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Cleft lips and cleft palates are relatively common birth defects throughout the world. The incidence of patients with cleft lip cleft palate (CLP) in Thailand was 1.62/1,000 live births[1], although exclusively in Northeastern region of Thailand 2.49/1,000 of newborns[2]. A study performed in Europe showed the incidence of CLP was 1/500 newborns to 1/700 newborns[3]. Additionally, in the United States of America it is estimated that the incidence of CLP was 7.75/10,000 newborns and the rate of CLP in other countries was 7.94/10,000 newborns[4].

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Cleft lip and cleft palate is one of the regular congenital defects, which can cause multiple problems, including: feeding and nutritional problems, speech difficulties, hearing difficulties, facial appearance, and teeth alignment. Craniofacial deformities and speech disabilities are significant problems in the Pre-school aged cleft palate children (5-6 years old), when they start attending school and become more engaged in the community. The findings revealed that half of these children had a more difficult time with speech and articulation than other students[5]. This led to teasing and mocking which caused low self-esteem, hurt relationships with friends and learning disabilities. Additionally, missing class in order to receive surgery and other medical treatment including speech therapy affected these students opportunity to develop crucial social skills. Many of these factors therefore directly affected children and their families. Treatment of cleft lip and palate anomalies requires years of specialized care and is costly. Their families had to handle high levels of stress, the economic cost, and deal with a great deal of lost income as a result of missing work to take care for their children and insure that their children received a consistent and a long-term treatment throughout the child's development.

The best outcome studies (Dorf and Curtin, 1990) for cleft palate repair or palatoplasty was at 12 months and it is currently accepted before 18 months[6]. Other studies have found that a better improvement in speech can be obtained with palatoplasty before 14 months[7]. Furthermore, the study in North America revealed palatoplasty performed before 18 months (7-15 months) can help better balance between the facial bone development and speech development[8]. The timing of the individual procedures varies in different centers and with different specialists. Therefore, the Tawanchai Center for Cleft Lip-Cleft Palate and Craniofacial Deformities, Khon Kaen University has a treatment protocol in the management of cleft lip-cleft palate and craniofacial deformities, according to patient age, from pregnancy to 5 years old[9]. These protocols developed from North America guidelines to meet the same standards.

The individual steps of the treatment protocol of the multidisciplinary team are essential in planning and providing services to patients. The main targets are patient satisfaction and the ability to live normally in society. This retrospective study analyzed patients that were 5 years old who consistently received treatment at Tawanchai Center, Srinagarind Hospital. This age is considered as the period in which students adapt the most to the school and community. Thus, evaluating treatment outcomes at this age is very crucial because CLP children are different from other children because of their appearance and articulation, which can have an affect on quality of life when they attend school.

The Quality of life (QOL) is another aspect of evaluating outcomes of the treatment of patients with cleft lip and cleft palate. That is why the authors developed the Tawanchai Quality of Life Evaluation for patients with cleft lip and cleft palate[10]. It is believed that the Tawanchai Quality of Life Evaluation best measures the need and quality of life in this CLP group. As a consequence, this research adopted this evaluation as a guideline to evaluate the outcomes in pre-school-aged children (5-6 years old). The study illustrated that the patients had a low quality of life in the domains of economic, health and mental status[11].

Objective

The aim of this research was to study the quality of life in pre-school-aged cleft palate children and the satisfaction with their speech.

Material and Method

The present study was approved by the Human Research Ethics Committee, Khon Kaen University, with the approval number of HE561233. This was a descriptive retrospective study which analyzed medical records of 39 patients with cleft lip and cleft palate aged 5-6 years old who went through the operation and treatment at the Tawanchai Center, Srinagarind Hospital. Data collection was administered for 5 months (June to October 2013). The research tools were 1) General Demographic Questionnaire, 2) Quality of Life Questionnaire with 5 Domains, and 3) the Satisfaction of Speech Questionnaire. The research was conducted during a 3-month period from January to March 2014. The descriptive statistics, percentages and the standard deviation were with the SPSS version 11.5 for Window.

Results

The present study including 39 patients, 25 are unilateral cleft lip and cleft palate (64.1%), 23 males (59.0%), 37 patients received palatoplasty in the defined time period of 9-16 months (94.87%), 25 patients with aged 5 years old (64.1%), 8 patients live in Khon Kaen (20.51%). The data are presented in Table 1.

The Quality of Life was evaluated in 5 domains which adapted the rating scale from Chusri

Wongrattana's study[13].

Mean score	Level of opinion/need/satisfaction
4.50-5.00	Most highly satisfied
3.50-4.49	Highly satisfied
2.50-3.49	Moderately satisfied
1.50-2.49	Slightly satisfied
1.00-1.49	Very dissatisfied

Therefore, it was found that the family was highly satisfied in 8 items of Medical healthcare and the total mean score was high as well (mean = 3.96, SD = 0.947). Moreover, they were highly satisfied in 3 items of the medical service and the total mean score was high too (mean = 4.15, SD = 0.675). One of the families had a high need for information about health coverage and medical support. On the other hand, the family was only moderately satisfied with being economically self-sufficient and travelling expenses. The family's overall satisfaction had a high satisfaction level (mean = 3.57, SD = 0.811). On family impact, the family had a "slightly agree" on 2 items: they had to work more to cover CLP health expenses and the CLP child had more temper tantrums. Furthermore, the family had a "moderately agree" on 7 items and "highly agree" on 21 items. Additionally, the child's sickness had a moderate impact on the family (mean = 3.30, SD = 1.158). The data are presented in Table 2.

The satisfaction of speech evaluated from the questionnaire which adapted the rating scale from Chusri Wongrattana's study[12].

Mean score	Level of opinion/need/satisfaction
4.50-5.00	Very dissatisfied with speech
3.50-4.49	Slightly satisfied with speech
2.50-3.49	Moderately satisfied with speech
1.50-2.49	Highly satisfied with speech
1.00-1.49	Most highly satisfied with speech

The findings showed the overall satisfaction was "highly satisfied" in speech (mean = 1.97, SD = 0.791) as presented in Table 3.

Discussion

The results from the study revealed important statistics pertaining to thirty-nine pre-school-aged 5-6 years children with cleft lip and cleft palate. Males outnumbered females. The majority of patients

Table 1. General CLP information (n=39)

General Information	number	Percentage (%)
Medical Diagnosis		
Unilateral cleft lip cleft palate	25	64.1
Bilateral cleft lip cleft palate	14	35.9
Age of CLP patient		
5 years old	25	64.1
6 years old	14	35.9
Receiving Palatoplasty in the defined time period of 9-16 months	37	94.87
Receiving Palatoplasty in the defined time period of 49-64 months	2	5.13
Sex		
Male	23	59.0
Female	16	41.0
Residence		
Khon Kaen	8	20.51
Sakon Nakhon	5	12.82
Roi Et	5	12.82
Bueng Kan	4	10.26
Maha Sarakham	4	10.26
Loei	3	7.69
Nong Bua Lamphu	3	7.69
Nong Khai	2	5.13
Nakhon Phanom	2	5.13
Surin	2	5.13
Udon Thani	1	2.56
Total	39	100

Table 2. Quality of Life Items

Information	Mean ± SD (standard deviation)
Medical healthcare	
1. Need to know how to feed the infant	3.69±0.893
2. Need to know how to do speech training	4.15±0.875
3. Need to know how to stimulate the child development	4.28±0.759
4. Need to know how to do home dental healthcare	4.15±0.779
5. Need to know how to prevent ear infection	4.08±0.900
6. Need to know when to get a hearing test & audiometry	3.72±1.146
7. Need to know how to communicate to the child what is happening to him/her	3.85±1.089
8. Need to know what coping skills to teach when she/he is teased or bullied	3.77±1.135
Total of medical healthcare items	3.96±0.947
Medical service	
9. Need any officers to coordinate when you get the health service	4.08±0.664
10. Need to share decisions regarding treatment	4.21±0.732
11. Need to know any referral information from the local health service	4.15±0.630
Total of medical service items	4.15±0.675
Cost of medical care	
12. Need to know about the health coverage	4.15±0.812
13. Need to know how to get economic support	4.13±0.923
14. Your family is economically self-sufficient	2.69±0.766
15. Your family has a problem about travelling expenses	3.49±0.854
Total of cost of medical care items	3.62±0.839
Family's satisfaction	
16. You think that your child is satisfied in him/herself	3.49±0.721
17. You are worried about your child's health	3.90±0.912
18. You are satisfied with your child's appearance	3.72±0.857
19. Your child has behavioral problems during his/her sickness	3.18±0.756
Total of family's satisfaction items	3.57±0.811
Family impact	
1. Family has to work more to cover CLP health expenses	2.33±1.009
2. Family has to quit the job or work to care for the CLP child	2.82±1.167
3. Family has to borrow money because of the child's illness	3.18±1.048
4. Family has insufficient time to work because of spending so much time on CLP care	3.00±0.918
5. Family has no leisure activity because of CLP child's sickness	3.62±1.161
6. Family has little happiness because of the CLP child	3.69±1.239
7. Family has less time to care for the other children	3.64±1.135
8. Family lacks of energy because of the CLP child care	3.85±1.226
9. The relatives understand and provide a good supports	3.62±1.227
10. You are afraid to get pregnant again	2.87±1.657
11. You are worried about your CLP child's future	2.51±1.254
12. You feel pitiful your CLP child than the other child	2.38±1.350
13. You and your spouse try to solve the problem together	4.31±0.950
14. Family has been strengthened because of the CLP child's illness	4.00±0.973
15. Your CLP child is being disliked by his/her siblings	3.95±1.123
16. The CLP child has more temper tantrums	2.31±1.080
17. The CLP child's illness impact on your health problems	3.49±1.167
18. You have less time to care for yourself because of your child's illness	3.44±1.095
19. You have less time to rest because of your child's illness	3.36±1.181
20. The child's illness doesn't have impact on family's sexual enjoyment	3.67±1.199
Total of family impact items	3.30±1.158

Table 3. The speech evaluation results (n = 39)

The speech satisfaction	Standard deviation
1. Articulation	2.46±1.022
2. Hypernasality	2.23±0.667
3. Voice	1.82±0.885
4. Speech intelligibility	1.38±0.590
Total	1.97±0.791

encountered palatoplasty in the defined time period of 9-16 months. This finding demonstrated the effective treatment each family received by the multidisciplinary team, including providing information about any surgeries, so that the children could receive proper treatment[13].

The present study also revealed outcomes pertaining to the children's quality of life following treatment. Families often expressed the need for training in the areas of: consumption, speech training, ear and audio check-ups, dental care and communication skills with their children.

The result of the present study was highly relevant to the previous study on quality of life[12]. This showed the family's need for knowledge of proper treatment and consistent medical care. The present study suggest that coordination with the community in order insure that families are quickly referred to receive proper medical treatment is highly effective.

With regard to the cost of medical care, the families are moderately economically self-sufficient but having problems with travel expenses. According to the operation manual of the project "Beautiful Smile with Clear Voice"[14], patients and family should be easily able to reach a convenient service. The government provides help and medical service. Besides, the Red Cross supports transportation funding. Tawanchai Foundation for Cleft Lip-Cleft Palate and Craniofacial Deformities also provides medical help which is not covered in the medical treatment expense. Therefore, the economic suffering has been lowered to a moderate level. However, in order to strengthen the family's quality of life, it should have the Career Development Plan to add up the income for the family. It must be sustainable, concrete, and clear.

Regarding Family Impact, the study showed the family's satisfaction with lost income, time spent at work, and the family's debt were in the moderate level as well as anxiety about the child's future and fear of another child. It is clear that follow-up treatment received consistently for 5-6 years can help alleviate high stress levels. Moreover, receiving the frequent treatment information from the multidisciplinary team, having the Cleft Lip-Cleft palate health care, and Tawanchai Foundation, and meeting with other CLP families reflected strong support from the aforementioned organizations. Thus, the child's sickness had a moderate affect on the family.

Family satisfaction with speech was in the "highly" level. The families that regularly took their children to receive speech training expressed high degrees of satisfaction with the level of speech development. As a result, the children showed improvement in articulation, no hypernasality, speech intelligibility; speech was understandable. However, when these children attempted to integrate within society, they are often met with teasing by their peers and this social factor could change their behavior. Therefore, the preparation of children before entering society should be undertaken.

Conclusion

In conclusion, studying the patients with cleft lip cleft palate, who received treatment from the multidisciplinary team at the Tawanchai Cleft Center, revealed that these children received proper treatment and support from the government, private and Non-governmental organizations. While there are still problems associated with the condition, such as the effect on the domain of family life, the results show that this affect is only at a moderate level. These findings reflect an overall good quality of life for pre-school patients with cleft lip and cleft palate.

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Potential conflicts of interest

None.

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ผลลัพธ์ทางคลินิกของการผ่าตัดเสริมสร้างเพดานโหว่แบบปฐมภูมิในเด็กเพดานโหว่ช่วงก่อนวัยเรียนในโรงพยาบาลศรีนครินทร์: คุณภาพชีวิต

สุธีรา ประดับวงษ์, ศิริพร มงคลถาวรชัย, นัดดา แก้วคำแสน, เบญจมาศ พระธานี, นิรมล พัจนสุนทร, บวรศิลป์ เชาวน์ชื่น

ภูมิหลัง: ภาวะปากแหว่งเพดานโหว่เป็นความพิการแต่กำเนิดที่ก่อให้เกิดความผิดปกติด้านรูปร่างและเค้าโครงของใบหน้า การพูด การได้ยิน การขึ้นและเรียงตัวของฟัน ภาพลักษณ์และการพูดที่ผิดปกติเป็นปัญหาสำคัญในเด็กก่อนวัยเรียนช่วงอายุ 5-6 ปี ที่จะเริ่มเข้าสู่สังคมและโรงเรียน ความแตกต่างจากเด็กอื่นๆ ทำให้เกิดการล้อเลียนส่งผลให้ขาดความมั่นใจ มีปมด้อย ความสัมพันธ์กับเพื่อนไม่ดี การขาดเรียนเพื่อเข้ารับการผ่าตัดรักษาและการดูแลด้านอื่นๆ ส่งผลให้มีความบกพร่องทางการเรียน ด้านพัฒนาการ และด้านคุณภาพชีวิตโดยรวม

วัตถุประสงค์: เพื่อศึกษาคุณภาพชีวิต (Quality of life) เด็กปากแหว่งเพดานโหว่ในช่วงอายุก่อนวัยเรียนและความพึงพอใจต่อการพูด

วัสดุและวิธีการ: การศึกษาเชิงพรรณนาแบบย้อนหลัง (Retrospective study) ครั้งนี้ได้ศึกษาจากประวัติผู้ป่วยปากแหว่งเพดานโหว่ที่เข้ารับการรักษาและผ่าตัดกับศูนย์ตะวันฉาย โรงพยาบาลศรีนครินทร์อย่างต่อเนื่องในช่วงอายุ 5-6 ปีบริบูรณ์ จำนวน 39 ราย เก็บข้อมูลเป็นเวลา 5 เดือน (เดือนมิถุนายนถึงเดือนตุลาคม พ.ศ. 2556) โดยใช้เครื่องมือ 1) แบบบันทึกข้อมูลทั่วไป 2) แบบสอบถามคุณภาพชีวิต 5 ด้าน และ3) แบบสอบถามความพึงพอใจต่อการพูด วิเคราะห์ข้อมูลโดยใช้สถิติร้อยละ ส่วนเบี่ยงเบนมาตรฐาน

ผลการศึกษา: ด้านความต้องการข้อมูลการรักษาในเรื่อง การกิน การฝึกพูด การตรวจหู การดูแลพัฒนาการ ดูแลฟัน ทักษะการสื่อสารเพื่อแจ้งเรื่องโรคและการถูกเพื่อนล้อกับเด็ก การมีส่วนร่วมในการตัดสินใจ ข้อมูลการส่งต่อการรักษา และการประสานงานความช่วยเหลือในการรักษาพยาบาลอยู่ในระดับสูง ส่วนความเจ็บป่วยของบุตรมีผลกระทบต่อครอบครัวอยู่ในระดับปานกลางและมีความพึงพอใจต่อการพูดอยู่ในระดับสูง

สรุป: ความร่วมมือในการดูแลรักษาและผ่าตัดผู้ป่วยปากแหว่งเพดานโหว่ตามช่วงอายุอย่างต่อเนื่อง โดยทีมสหวิทยาการของศูนย์ตะวันฉาย โรงพยาบาลศรีนครินทร์ การสนับสนุนจากภาครัฐ ภาคเอกชน และองค์กรอิสระต่างๆ สะท้อนให้เห็นถึงคุณภาพชีวิตที่ดีของผู้ป่วยปากแหว่งเพดานโหว่ก่อนวัยเรียน ปัญหาที่มีผลกระทบต่อชีวิตและครอบครัวจึงอยู่ในระดับปานกลางเท่านั้น