Tawanchai Cleft Center Quality of Life Outcomes: One of Studies of Patients with Cleft Lip and palate in Thailand and the Asia Pacific Region

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Background: *The needs and quality of life (QOL) of children with cleft lip and palate (CLP) after being processed through the healthcare system are important in order to understand how to improve the standards of care. The Tawanchai Cleft Center of Thailand in collaboration with Cleft Lip and Palate Care Center of the Asia Pacific Region, conducted a number of studies on various aspects of treatment outcomes as an indication of its performance. This paper presents the outcome effects on QOL.*
Objective: *To determine (a) the QOL of children with CLP in Northeast Thailand registered and followed-up at the Tawanchai Centre, (b) their ongoing care needs and (c) the mental health of their parents when the children reach 5 years of age.*
Material and Method: *Using the Need, Satisfaction, QOL and GHQ-12 questionnaires, the authors evaluated 36 five-year-old children with CLP, living in Northeast Thailand, registered at birth for treatment at the Tawanchai Cleft Center.*
Results: *The aspects most needing attention were: dental, speech therapy and local healthcare service. The QOL was low in the economic, child relationships and psychological domains. The parents need more training on how to raise children with CLP most appropriately. According to the GHQ-12, none of the families identified any mental problems.*
Conclusion: *Children with CLP at five years of age under the care of the Tawanchai Cleft Center by their own self-assessment have satisfactory outcomes in most domains. Notwithstanding, there is need to improve parent training and access to dental care, speech therapy and local healthcare services.*

Keywords: *Cleft lip and palate, Children, Quality of life, Needs assessment, Mental health*

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The Tawanchai Cleft Lip and Palate Care Center at Khon Kaen University Thailand was established in 1999. Its mission is to receive referrals from across Northeast Thailand, which has a population of ~22 million. In 1998, Chuangwanich reported that the number of persons afflicted with CLP in the Northeast constituted ~59% of cases for the whole nation. The incidence of CLP was 2.49 per 1,000 newborns. The Tawanchai center is responsible for the management of newborns with CLP, so guidelines for multidisciplinary care were developed in order to achieve standard outcomes. The 5-year-old outcomes included: surgical, dental, speech, nursing care, psychosocial and QOL. The Center developed the Thai Cleft Quality of Life Questionnaire (Thaicleft QOL) that has good reliability (0.861)[1]. The questionnaire has 20 questions including the needs of care for children, including: service needs, economic needs, satisfaction with treatment, parental perceptions and psychosocial stressors.

Children registered with the Tawanchai Cleft Centre since birth will have been treated according to the Centre's new longitudinal guidelines (a) the family will have been supported and trained by nurses (b) the newborn will have undergone physical exams by a pediatrician and plastic surgeon to determine the defects in order to plan the series of necessary reconstructive surgeries (c) nurses will have helped the mother to feed the newborn and assist with mother-infant bonding and (d) the parents will have been taught how to cope with the social stigmatism.

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The Thai government also supports the healthcare of children with CLP by giving them universal health coverage and an additional budget for travel expenses related to the years of follow-up surgeries. The 36 children with CLP will receive their first reconstructive surgeries before they are 5 years old. They will also have received their first dental care, speech rehabilitation and development assessment.

In order to improve the standard of care in its guidelines, the Tawanchai Cleft Centre needs to assess the longitudinal treatment outcomes up to 5 years of age, in the domains of psychosocial, economic and mental health of the patient and his/her family.

Objective

To determine the QOL of children with CLP registered with, and followed-up at, the Tawanchai CLP Center in Northeast Thailand after 5 years of treatment (*i.e.*, their care needs, the mental health of their parents).

Material and Method

This cross-sectional study was performed using various questionnaires to collect data on the children with CLP and their families, after 5 years of treatment at the Tawanchai Cleft Center. The parent's completed a questionnaire on (i) general demographics, (ii) healthcare needs, (iii) Thai cleft QOL and (iv) mental well-being using the General health questionnaire (GHQ-12). The data were collected in 2011 when the children came for follow-up as per the Centre's guidelines for care for five-year-olds. There were 36 children in this group.

The general information questions queried: age, sex, type of CLP, education level, family income, prenatal health, history of drug use and any genetic history of the birth defect.

The questionnaire about family needs included: (a) need of a nursing and medical education management plan, (b) expenses and (c) satisfaction with the quality of care. The questionnaire employs a Likert-type rating score from 1 to 5 (1 = least and 5 = strongly agree).

The 20-question Thai Cleft QOL also uses a rating score (*i.e.*, from 1 to 5). For example, "You have to work more to earn enough to pay for the cost of caring for the CLP", "You lost income because of having to care for the CLP child" and "You feel hopeless".

The Thai version of the General Health Questionnaire (GHQ-12) has 12 questions[2] and uses a rating score (*i.e.*, from 1-4). Each question has a cut-off point for 'normal' or 'abnormal' (*i.e.*, may have a problem). If more than two questions are abnormal, the patient and/or parent may have a recalcitrant psychosocial problem.

The descriptive statistics (percentages, means and standard deviation (SD) were assessed using Microsoft Excel to calculate.

Results

The present study included 36 children with CLP who have reached the 5-year treatment mark (18 males; 18 females). Left unilateral cleft lip and palate, right unilateral cleft lip and palate and bilateral cleft lip and palate represented 58.3%, 22.2% and 19.4% of the cases, respectively. One-fifth (19.4%) had a genetic history of CLP.

Mothers were the primary respondents (72.2%). The most common career of the parent was farmer (52.8%). The most commonly achieved level of education was elementary (47.2%) followed by secondary or vocational school or vocational certification l (41.7%). Most (77.8%) of the families had an income below the poverty line (*i.e.*, < 4,000 US$/year), which is less than the GDP per capita of Thailand or the purchasing power parity (ppp) (9,500 US$/year in 2011)[3].

The health provider most commonly used was the government sponsored Universal Coverage (88.8%); for which treatment is 'free' and the traveling expenses are paid (10-15 US$ per hospital visit).

Tables 2-4 present the results of (i) needs satisfaction, (ii) QOL and (iii) mental health. Caregivers indicated a need to know more about dental care, speech development and therapy and locally available health services. At five-years of age, parents raising a CLP child need to know about and consider child development, health promotion, the health service system and sharing decision-making with the CLP treatment team. Parents needed to know where to get economic support and when to do testing for hearing. Areas of less concern but still important were: coping with teasing (bullying), health coverage and communication to/with the child. Feeding was of least concern perhaps because it had been dealt with during the infant period.

For satisfaction with treatment, parents were moderately satisfied with the appearance of their CLP child.

On the QOL questionnaires (Table 3), the rating scale ranges from 1 to 5: 1 = do not agree, 2 = slightly agree, 3 = agree, 4 = slightly agree and 5 = strongly agree. Questions 1-4 cover the economic

Table 1. General characteristics of children with cleft lip and palate at 5 years of age (N=36)

Variable	Number	Percentage
Sex		
Boys	18	50.0
Girls	18	50.0
Total	36	100.0
Age		
5 years old	36	100.0
Type of Deformity		
BCLP	7	19.4
UCLP (Lt)	21	58.3
UCLP (Rt)	8	22.2
History of CLP in families		
Yes	7	19.4
No	29	80.6
Residence province		
Maha Sarakham	11	30.5
Khon Kaen	5	13.8
Nakhon Phanom	1	2.8
Si Sa Ket	1	2.8
Udon Thani	2	5.6
Roi Et	2	5.6
Sakon Nakhon	3	8.3
Loei	2	5.6
Chaiyaphum	4	11.1
Nong Bua Lumphu	3	8.3
Bueng Kan	2	5.6
Total	36	100.0
Relationship of person answering questionnaires		
Father	1	2.8
Mother	26	72.2
Grandmother	6	16.6
Not specified	3	8.3
Total	36	100.0
Occupation		
Government worker	2	5.6
Farmer	19	52.8
Merchant	4	11.1
Employer	1	2.8
Housewife	4	11.1
Laborer	3	8.3
Other	3	8.3
Age of respondent		
20 – 40 years old	24	66.67
41 up	12	33.33
Education of respondent		
Uneducated	-	-
Elementary	17	47.2
Secondary/ Vocational	15	41.7
Bachelor degree	4	11.1
Post-graduate	-	-
Family income (US$)/year		
< 4,000	28	77.8
> 4,000	8	22.2
Health provider		
Universal coverage	32	88.8
Civil servant plan	4	11.2
Self-paid	-	-

Table 2. Needs questionnaires of families with CLP children at the Tawanchai Cleft Center (n = 36) (rating scale 1-5, 1: not agree, 2: less likely agree, 3 agree, 4: much agrees, 5: strongly agree)

Needs	$\bar{x}$	SD
1. To know how to feed the infant	2.86	1.27
2. To know how to do speech training	3.72	0.97
3. To stimulate child development	3.36	1.17
4. To know how to do home dental care	4.25	0.84
5. To know how to prevent ear infection	3.36	1.39
6. To know when to get a hearing test & audiometry	3.30	1.43
7. To know how to communicate to the child what is happening to him/her	3.05	1.31
8. To know what coping skills to teach when he/she is teased or bullied	3.25	1.08
9. Where to get health services	3.36	1.31
10. Need to share decisions regarding treatment	3.36	1.33
11. Need a referral from their local health service	3.39	1.34
12. To know about their health coverage	3.19	1.37
13. How to get economic support	3.33	1.09
Satisfaction		
14. Your family is economically self-sufficient	3.00	0.68
15. You cannot afford travelling expenses	2.83	1.05
16. Your child is satisfied in him/herself	3.28	0.66
17. Your are worried about your child's health	3.11	1.14
18. You are satisfied with your child's appearance	3.42	0.69
19. Your child has behavioral problems	2.55	1.13

Table 3. Thai cleft QOL n = 36 (Likert score 1-5)

Items	$\bar{x}$	SD
1 You have to work more to cover CLP health expenses*	3.44	0.84
2. You quit your job or work to care for the CLP child*	3.05	1.04
3. You have to borrow money	2.44	1.13
4. You haven't enough time to work because you spend so much time on CLP care	2.92	0.99
5. Your family has no leisure activity because you have to so much CLP child care	2.39	1.08
6. Your family has little happiness because of the CLP child	2.47	1.03
7. You have less time to care for your other children	2.44	1.05
8. You lack energy because of the CLP child care	2.64	1.22
9. Your family is supportive (+)	3.80	0.82
10. You are afraid to get pregnant again	2.83	1.16
11. You worry about your CLP child's future*	3.86	1.17
12. You pity the CLP child*	3.75	1.15
13. Your family is resolved to find solutions to problems (+)	3.75	0.99
14. Your family has been strengthened (+)	3.83	0.84
15. The CLP child is disliked by his/her other siblings	2.30	1.17
16. The CLP child has more temper tantrums*	3.30	1.45
17. The CLP child's illness has given you health problems	2.36	1.12
18. You have less time to care for yourself	2.28	1.08
19. You have less time to rest	2.25	1.025
20. You have decreased sexual enjoyment	2.05	0.98

(+) = positive questions, * = agreement

domain; questions 5-7 family function; questions 8-14 the psychological domain; questions 15-16 the social relation domain, and questions 17-20 the physical domain. In the economic domain, agreement was for 2

Table 4. General health questionnaire (Thai GHQ-12) n = 36 (Likert score from 1-4, if positive 2 or more items possible have mental health problems)

Items	(x)	SD	normal
1. You can concentrate on your work	2.86	0.42	>2
2. You cannot sleep well	1.67	0.72	<3
3. You feel useful and helpful to others	3.14	0.42	>2
4. You can make decisions	3.14	0.42	>2
5. You feel tension	1.83	0.91	<3
6. You feel overwhelmed by difficulties	1.67	0.72	>3
7. You feel enjoyment on a regular basis	2.92	0.28	>2
8. You can face problems	3.00	0.24	>2
9. You feel unhappy and sad	1.47	0.51	<3
10. You have lost self-confidence	1.50	0.51	<3
11. You feel worthless	1.39	0.49	<3
12. In general, you feel adequate	2.94	0.23	>2

of 4 items (*viz*., have to work more, and loss job or leave). There was no agreement on any item in the family function domain. In the psychological domain, parents agreed on 2 of 7 items (*viz.*, worry about child's future and being pitied more than usual). The items marked with '+' mean that there were no problems. In the relationship domain, parents agreed on 1 of 2 items (*viz*., more temper tantrums). In the physical domain, the parents/caregivers did not agree with any of the items.

The result of the GHQ-12 for mental health indicated that all of the parents/caregivers had normal scores for all items.

Discussion

Among the 36 children with CLP in the present study, '*being male with left cleft lip*' was the most common association. This result is similar to research done in Lao PDR[4]. The families in our study (a) were most commonly farmers, (b) had a low income, (c) had an education less than a Bachelor degree and (d) were covered under the Universal Coverage Healthcare System.

The most commonly subscribed healthcare coverage in Thailand is the Universal Coverage (UC) System: it has no deductible so is ostensibly free of charge. It includes all standard care including surgery, dental, speech therapy and development assessment. Despite its being comprehensive, families covered by UC still have some traveling costs to pay and/or suffer loss of income when they come to hospital, and that affects their quality of life. In the 'needs' questionnaire of children at five years of age, dental care, speech therapy, and information transfer to local health services were the top concerns; so personnel at the primary or local health service level need extensive training regarding the guidelines for CLP treatment.

At this age, the child is young and their expressed psychological understanding about their appearance is limited. As a consequence, the QOL questionnaire detected only 2 of 4 known economic issues. The CLP did, however, make parents and children react more emotionally, feel more self-pity and be more indulgent. Such results parallel findings in a parent report by Speltz et al[5].

These results raised concerns among healthcare personnel advocating for more holistic counseling of parents in order to enable them to raise their CLP child with better self-esteem. The parents need to convey more confidence so the children in turn can mirror vis-a-vis their own condition: if the parents affirm them they can have internal strength to buttress them against taunts and self-doubting. Intervention in cognitive behavior therapy for school-age children and adolescents re better coping with teasing about their appearance and speech problems can also help to reduce their anxiety and internalizing and ruminating[6].

The GHQ-12 (Table 4) revealed that parents in the current study were not experiencing mental problems, at least no item was rated beyond the normal range. This seems to be consistent with the QOL that we measured even though the result appears contrary to the admitted stresses experienced by the parents. Overall, the QOL and GHQ-12 for families of children with cleft lip and palate in the current study showed

good results with respect to support services received which agrees with a similar study on families of children with an intellectual disability[7].

Conclusion

The Tawanchai Cleft Center implemented a multidisciplinary team approach for children with CLP. When care begins at birth, as per our guidelines, at five years of age the progress in the psychosocial and QOL domains can be measured. The results show that only a few problems persist as early and follow-up interventions are ensuring that all aspects of care are being met in an integrative, humanized approach. Importantly, parents express confidence and trust in the team so that their mental wellness has been protected.

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Potential conflicts of interest

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ผลลัพธ์คุณภาพชีวิตโดยศูนย์ตะวันฉาย: การศึกษาผู้ป่วยปากแหว่งเพดานโหว่ในประเทศไทยแถบเอเชียแปซิฟิก

นิรมล พัจนสุนทร, สุธีรา ประดับวงษ์, สมจิตร์ หร่องบุตรศรี, ศิริพร มงคลถาวรชัย, บวรศิลป์ เชาวน์ชื่น

ภูมิหลัง: *ความต้องการและคุณภาพชีวิตของเด็กปากแหว่งเพดานโหว่ หลังจากได้รับการดูแลรักษาเป็นสิ่งสำคัญที่ต้องพัฒนามาตรฐานการดูแล ศูนย์ตะวันฉายได้ศึกษาด้านผลลัพธ์การรักษาในหลายแง่มุมที่เกี่ยวข้องซึ่งเรื่องนี้จะเป็นหนึ่งในการประเมินด้านผลลัพธ์ของการรักษาด้วย*

วัตถุประสงค์: *เพื่อศึกษาคุณภาพชีวิตของเด็กปากแหว่งเพดานโหว่ ความต้องการและสุขภาพจิตของผู้ปกครองเด็กปากแหว่งเพดานโหว่ที่มีภูมิลำเนาในภาคตะวันออกเฉียงเหนือที่เข้ารับรักษาในโครงการตะวันฉาย*

วัสดุและวิธีการ: *เก็บข้อมูลในเด็กปากแหว่งเพดานโหว่ที่มีอายุ 5 ปี ที่อาศัยในภาคตะวันออกเฉียงเหนือที่เข้ารับการรักษาในศูนย์ตะวันฉายอย่างต่อเนื่อง เครื่องมือที่ใช้ในการเก็บข้อมูลประกอบด้วย แบบสอบถามความต้องการความพึงพอใจแบบวัดคุณภาพชีวิตและแบบประเมินสุขภาพทั่วไป GHQ 12*

ผลการศึกษา: *ความต้องการในการดูแลพบว่าการดูแลเรื่องฟัน การฝึกพูดและการดูแลสุขภาพจากสถานบริการใกล้บ้านเป็นความต้องการสูงสุด ในด้านคุณภาพชีวิตพบว่ากลุ่มตัวอย่างมีคุณภาพชีวิตต่ำในด้านเศรษฐกิจด้านสุขภาพกายและจิตใจของเด็ก ผู้ปกครองต้องการแนวทางการดูแลเด็กสำหรับการประเมินสุขภาพทั่วไปพบว่าไม่มีความผิดปกติทางสุขภาพจิต*

สรุป: *การติดตามเด็กที่เข้ารับการรักษาอย่างต่อเนื่องกับศูนย์ตะวันฉายในช่วงอายุ 5 ปี มีผลลัพธ์การรักษาที่น่าพึงพอใจ*