

Needs and Quality of Life for Children with Cleft Lip/Palate and Their Families in the North Thailand

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Background: Cleft lip and cleft palate (CLP) is one of the major public health problems in Thailand. Caregivers or families are strongly responsible to take a good care of children with CLP. Caregivers or families' needs and quality of life (QoL) are needed for treatment planning.

Objective: To determine the needs and QoL of caregivers or families of the children with CLP and relationships between the physical health, psychological health, social relationship, satisfaction with environment and overall QoL.

Material and Method: Twenty-five caregivers or families of the children with CLP who had joined the Family Camp provided by the Northern Woman's Development Foundation in Chiang Rai Province. The THAICLEFT Need Questionnaire for children with cleft lip/palate and families and the WHOQOL-BIEF THAI Version questionnaire were used. Caregivers' needs and QoL were analyzed using mean with standard deviation and correlations.

Results: The majority of the respondents were females (88.0%), employee (36.0%), and had completed primary school (44%). The caregiver reported their needs on medical care (3.31), medical service (3.76), cost of medical care (3.52), and families' satisfaction of 3.19. The overall QoL was in a good level of 48.0% and a fair level of 52.0%. Furthermore, the participants' psychological health, social relationship, and satisfaction with environment were in good to fair level of 64.0%, 76.0% and 62.0%, respectively. The participants reported having physical health in a fair level (56.0%). There was a statistically significant correlation between the four major QoL domains and overall QoL ($p < 0.01$).

Conclusion: Medical service was the most information need for the caregivers or families. The overall QoL was in fair level which was lower than QoL of general population. There is a need to improve the QoL of the physical health and satisfaction with environment. In order to enhance the QoL of the children with CLP and their caregivers, the findings of the present study should be taken into account whilst developing a treatment plan for the children with CLP.

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

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Children with cleft lip and palate (CLP) suffer from both physical and psychological conditions, along with other social problems, including speech and language delay, hearing loss, dysphonia, unintelligibility, velopharyngeal insufficiency after surgery. Previous studies found that the high prevalence of speech and language abnormalities, including delayed speech and language development (16 to 19%), articulation defects (23 to 90%)⁽¹⁻⁵⁾, resonance disorders (27 to 43%)^(2,3,6), and voice disorders (0.6 to 50%)^(2,6-13). In addition, residual abnormal configuration after repair, results in low

physical attractiveness. Furthermore, the speech and language defects in the children with CLP are common problems that affect psychosocial disadvantages, then their quality of life (QoL). Family functioning due to abnormalities of speech always appears when children communicate to people and call negative attention from society.

The cleft that involves the lip and nose imposes evident facial differences; therefore, as a consequence, clefts related facial differences could be expected to have a profound impact on social interactions and quality of life (QoL) of patients⁽¹⁴⁾. Previous studies indicated that children with clefts had lower quality of life than normal peers⁽¹⁴⁻¹⁹⁾.

Pre-school normal children have critical time. This period generally has a rapid development of cognitive skills, socioemotional competence, and

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interactive behavior⁽²⁰⁾, resulting in increased self-perception and personality formation. Children with clefts, however, face teasing from peers⁽²¹⁾ and have less interaction both speech and physical signs of interest^(22,23). They, therefore, have negative self-perception⁽²⁴⁻²⁶⁾. School age is also critical time for acceptance by peers. Therefore, to measure the QoL of children with clefts adequately, a scientifically sound and clinically meaningful patient-reported outcomes⁽¹⁴⁾ as well as family outcomes needs to be examined. The objective of this study was, therefore, to investigate QoL of the families and children with clefts during school age.

Material and Method

A cross-sectional descriptive study was conducted.

Participants: Twenty-five caregivers (parents, relatives or main caretakers) of the children with cleft lip and palate, who had joined in the Family Camp, which was conducted by the Northern Woman's Development Foundation at The Youth Men's Christian Association (YMCA), Chiang Rai Province, Thailand during 24 to 26 April 2015. Multidisciplinary approaches, including speech therapy, orthodontic care, physical development, ENT and hearing investigation were provided to the children with CLP in the Family Camp. Of note, the children with CLP and their caregivers regularly attended the Family Camp once a year. Due to limitations of speech services in the North, Thailand, particularly in Chiang Rai, local speech and language pathologists possibly could provide speech assessments and corrections every 3 to 6 months supporting by the Northern Woman's Development Foundation's arrangements or appointment of speech clinics in the nearest centers.

The THAICLEFT Need Questionnaire for children with CLP and families^(18,19) was used for an assessment of the needs of children with cleft's families. The questionnaire composed of general demographics and needs, covered 19 questions (items) and 5 domains. The item scores were rated using 5-point Likert scales (1 = no agreement; 2 = less agreement; 3 = moderate agreement; 4 = much agreement; 5 = strong agreement). The needs were explored in four main domains, including Medical healthcare (question 1 to 8), Medical service (question 9 to 11), Cost of medical care (question 12 to 15), and Family's satisfaction (question 16 to 19). The present study also additionally assessed the Family impact of caregivers.

The WHOQOL-BRIEF-THAI version

questionnaire was used to evaluate QoL. This questionnaire explored the participants' feeling about their quality of life, health, or other areas of their life. The participants were interviewed and the questionnaires were filled in by the researchers. The WHOQOL-BRIEF-THAI version questionnaire consisted of four major parts and 26 items, including, Physical health (7 items of the questions No. 2, 3, 4, 10, 11, 12 and 24), Psychological health (6 items of the question No. 5, 6, 7, 8, 9 and 23), Social relationship (3 items of the question No. 13, 14 and 25) and Satisfaction with Environment (8 items of the question No. 15 to 22) and 2-item overall QoL (question No. 1 and 26). Therefore, the QoL scores would range from 1 to 5 on the Likert scales and the overall QoL possible would range in the sum scores of 25 to 112. The QoL score was the categorized into three levels: poor QoL (sum score ranged from 25 to 54), fair QoL (sum score ranged from 55 to 83) and good QoL (sum score ranged from 84 to 112).

Numbers and percentage were used to describe the characteristics of the participants. Mean and standard deviation were employed to describe the QoL and Need scores. Comparisons with standard interpretation based on previous studies were used to present the levels of QoL. Spearman's rank correlation was used for determine to relationship among domains.

Results

Overall, 25 families had joined the Family Camp. Majority of the participants or caregivers were females (88.0%) with the age ranged from 18 to 55 years. In all, 56.0% were employee and 44.0% had completed primary school, whilst 12.0% had completed a bachelor degree. The participants had Family income per month of 8,160 Baht and medical cost was 992.25 Baht per visit (Table 1).

Needs of the caregivers of children with CLP were presented in Table 2. Considering the participants' needs on each of the four main domain, the result found that for the medical care domain, the participants' most common needs were to know how to do home dental healthcare (mean = 4.28) and how to stimulate the child development (3.84). For the Medical service domain, the most common need was referral information from the local health service (mean = 3.92), whilst the need in regard to the cost of medical care was on how to obtain financial supports (mean = 3.79). For the Family's satisfaction domain, the participants reported their child was satisfied with him/herself after treatment (mean = 3.64). For the Family impact, this present study found

Table 1. The participants' characteristics

Variables	Number	Percentage
Gender		
Males	3	12.0
Females	22	88.0
Age (years)		
<18	2	8.0
18 to 25	9	36.0
26 to 35	8	32.0
36 to 45	3	12.0
46 to 55	3	12.0
Occupation		
Employee	14	56.0
Agriculture	9	36.0
Merchant	2	8.0
Education		
Illiterate	5	20.0
Primary school	11	44.0
Secondary school	3	12.0
Certificate	3	12.0
Bachelor degree	3	12.0
Income/month (Thai baht)		
Mean (SD)	8,160.00 (11,393.27)	
Median (min: max)	5,000.00 (1,500: 15,000)	
Medical cost per visit	992.25 baht	

that the cleft families had been strengthened because of the CLP child's illness (mean = 4.00). This is possibly because they had given more attention on how to care for their cleft child and how to support their child living with the real society. In addition, the participants and their spouses had tried together to solve the problems and supported each other (mean = 3.76). Moreover, the family impact also was affected by the understanding of relatives and their good support (mean = 3.68) (Table 2). This present study also found that the families of the children with CLP needed more mental support. In addition, love, warmth and sympathy occurred during the treatment periods, and the majority of participants tried to set their goals to give a good treatment for their child.

The overall QoL was shown in fair and good levels of the overall QoL of CLP parents, 52.0% and 48.0%, respectively, with the mean score of 94.64 (SD = 11.49). The physical health domain was shown on fair (56.0%) and good levels (44.0%) with the mean score of 26.56 (SD = 3.93). The psychological health domain was shown in good and fair levels of 64.0% and 28.0%, respectively, with the mean score of 22.00 (SD = 3.68). The social relationship domain was also in a good (76%) and fair level (16.0%) with the mean score of 10.52 (SD

= 2.10). The satisfaction with environment domain was shown in good and fair levels of 52.0% and 44.0%, with the mean score of 10.52 (SD = 2.10) (Table 4).

The correlation between four major QoL domains were found statistical significance ($p < 0.01$, two-tail test). The correlation level ranged from 0.45 to 0.68. The overall QoL of parents also confirm strongly correlation among the four major domains. The correlations ranged from 0.65 to 0.85 with statistical significance ($p < 0.01$) (Table 5).

Discussion

Majority of the caregivers who involved in this present study were females and aged 18 to 55 years (Table 1). This implied that the main role in taking care for the children with CLP were performed by the middle age females who were of working age and therefore needed to leave their work to be the caregivers. Most of the participants in this present study had an average low income per month of 8,160 Baht. To obtain the treatment services, the patient and their family would have an expense for transportation and food (365.60+148.40 = 514 Baht) and loss of income (478.50 Baht) per each visit with, therefore, a total expense of 992.25 Baht. These might affect family's QoL and satisfaction.

Regarding to caregivers' needs, they needed to know about home dental healthcare the most, followed by referral information from the local health services, sharing decisions regarding treatment, stimulation of child development, prevention of ear infection, respectively. Most of caregivers had an overall need in a moderate level whilst a high level of needs were reported in information of health, medical services and cost of medical care. These were evidence-based data to revise a protocol in order to provide more information for them. Moreover, we can conclude that most of the caregivers need support that can assist them to maintain care at home such as dental care, how to prevent ear infection and how to feed their child.

This present study is consistent with previous studies^(18,19,27), which found that most QoL questions of Likert scale ratings consisted of negative (only 3 negative questions of the questions number 2, 9 and 11) and positive questions (23 questions)⁽²⁸⁾. The results revealed that the caregivers had QoL of the physical domain in a fair level and had a good QoL of psychological health, social relationship, and satisfaction with environment. This study also confirmed the good correlations within four major QoL domains and overall QoL with statistical significance ($p < 0.01$). This present study found that children with

Table 2. Needs of the caregivers of children with CLP

Items	Mean	SD
Medical healthcare		
Need to know how to do home dental healthcare	4.28	0.74
Need to know how to stimulate the child development	3.84	1.21
Need to know how to prevent ear infection	3.72	1.17
Need to know how to do speech training	3.64	1.25
Need to know how to feed the infant	3.00	1.35
Need to know coping skills in order to teach the child when she/he is teased or bullied	2.84	1.11
Need to know how to communicate to the child what is happening to him/her	2.72	1.31
Need to know when to get a hearing test & audiometry	2.56	1.47
Total of medical healthcare items	3.31	0.81
Medical service		
Need to know any referral information from the local health services	3.92	1.12
Need to share decisions regarding treatment	3.84	1.03
Need any officers to coordinate when obtaining the health services	3.52	1.23
Total of medical service items	3.76	0.98
Cost of medical care		
Need to know how to obtain financial support	3.79	1.14
Your family is economically self-sufficient	3.52	0.92
Need to know about the health coverage	3.33	1.27
Your family has a problem about travelling expenses	3.28	1.24
Total of cost of medical care items	3.52	0.75
Family's satisfaction		
You think that your child is satisfied with him/herself	3.64	0.81
You are satisfied with your child's appearance	3.52	0.87
You are worried about your child's health	3.12	1.33
Your child has behavioral problems during his/her sickness	2.48	0.96
Total of family's satisfaction items	3.19	0.63
Family impact		
Family has been strengthened because of the CLP child's illness	4.00	0.65
You and your spouse try to solve the problem together	3.76	1.01
The relatives understand and provide a good supports	3.68	1.07
You feel pitiful your CLP child than the other child	3.36	1.22
You are worried about your CLP child's future	3.04	1.24
Family has to work more to cover CLP health expenses	3.04	1.14
The CLP child has more temper tantrums	3.04	1.06
Family has to quit the job or work to care for the CLP child	2.88	1.13
Family has insufficient time to work because of spending so much time on CLP care	2.68	0.85
Family has to borrow money because of the child's illness	2.52	1.16
You are afraid to get pregnant again	2.52	1.45
Family has no leisure activity because of CLP child's sickness	2.38	1.21
You have less time to care for yourself because of your child's illness	2.36	1.22
You have less time to rest because of your child's illness	2.24	1.16
The CLP child's illness impact on your health problems	2.20	1.22
The child's illness doesn't have impact on family's sexual desire	2.12	1.27
Family lacks of energy because of the CLP child care	1.92	1.12
Family has little happiness because of the CLP child	1.88	0.83
Family has less time to care for the other children	1.88	0.97
Your CLP child is being disliked by his/her siblings	1.56	0.92
Total Family impact	2.41	0.56

Table 3. The QoL items score

QoL items	Mean	SD
How satisfied are you with your personal relationships?	4.08	0.75
How available to you is the information that you need in your day-to-day life?	4.04	0.88
How much do you need any medical treatment to function in your daily life?	4.00	0.81
How satisfied are you with your access to health services?	4.00	0.91
How satisfied are you with your transport?	3.96	1.17
Are you able to accept your bodily appearance?	3.88	0.97
How much do you enjoy life?	3.80	1.15
To what extent do you feel your life to be meaningful?	3.80	1.04
How well are you able to get around?	3.80	0.76
To what extent do you have the opportunity for leisure activities?	3.76	0.66
How satisfied are you with your sleep?	3.76	0.83
How satisfied are you with the conditions of your living place?	3.68	1.02
How satisfied are you with the support you get from your friends?	3.68	1.10
How satisfied are you with your sex life?	3.64	1.15
How healthy is your physical environment?	3.60	0.91
How satisfied are you with your ability to perform your daily living activities?	3.56	1.22
How satisfied are you with yourself?	3.56	0.86
How safe do you feel in your daily life?	3.52	0.77
How satisfied are you with your health?	3.44	0.86
How well are you able to concentrate?	3.28	0.61
How would you rate your quality of life?	3.24	0.92
To what extent do you feel that physical pain prevents you from doing what you need to do?	2.60	0.87
How satisfied are you with your capacity for work?	2.92	0.86
How often do you have negative feelings such as blue mood, despair, anxiety, depression?	2.69	1.42
Do you have enough money to meet your needs?	2.52	1.22
Do you have enough energy for everyday life?	2.20	1.01

Table 4. The participants' Quality of Life based on four main domains

Domain	No. of items	Possible range	QoL score (Mean ± SD)	QoL Level n (%)		
				Poor	Fair	Good
Physical health	7	7 to 35	26.56 (3.93)	0	14 (56.0)	11 (44.0)
Psychological health	6	6 to 30	22.00 (3.68)	2 (8.0)	7 (28.0)	16 (64.0)
Social relationship	3	3 to 15	10.52 (2.10)	2 (8.0)	4 (16.0)	19 (76.0)
Satisfaction with environment	8	8 to 40	10.52 (2.10)	1 (4.0)	11 (44.0)	13 (52.0)
Overall QoL	26	25 to 112	94.64 (11.49)	0	13 (52.0)	12 (48.0)

CLP had physical health and satisfaction with environment which was less than normal population, whilst general populations were normally at the good level, approximately of 60.0%⁽²⁹⁾ in all four major domains. These results indicated that the number of children with CLP had a lower overall QoL (48.0%) than normal general population (60.0%). As a result, the QoL of families were needed to improve. When we looked for the relationship between the occupations of

caregivers, most of them were employees with low income (Table 1). These factors might influence their physical health. The important information in developing a protocol or activities should raise the QoL level for the children with CLP.

For further planning, the physical health and satisfaction with environment domains should be a focus of the plan such as improving the health services for active care, home health care and home visits in

Table 5. Relationship among the four main domains and overall QoL

	Overall QoL	1) Physical health	2) Psychological health	3) Social relationship	4) Satisfaction with Environment
Overall QoL	1.00				
1) Physical health	0.77	1.00			
2) Psychological health	0.85	0.56	1.00		
3) Social relationship	0.66	0.48	0.68	1.00	
4) Satisfaction with Environment	0.79	0.45	0.53	0.55	1.00

$p < 0.01$ for all domains

order to reduce families' expenses to hospital and to create an environment to support the families and ultimately aiming to improve the QoL of the children with CLP.

Conclusion

The caregivers or family of children with CLP need more information about medical care and an improvement in their QoL. Therefore, the plan should focus on providing information of medical care and establishing QoL, particularly, physical function and the environment function.

What is already known on this topic?

Children with CLP had both physical and psychosocial problems from residual stigmas, including speech disorders or speech and language defects after surgical repair, which might result in lower QoL and special need requirements.

What this study adds?

Medical service information is the greatest need for caregivers and family. The overall QoL is in a fair level, which was lower than the QoL of general population. Physical and environmental functions were most needed by the caregivers and family, which needs must be added in the further approaches.

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Potential conflicts of interest

None.

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ความต้องการและคุณภาพชีวิตของครอบครัวเด็กปากแหว่งเพดานโหว่ในภาคเหนือของประเทศไทย

พุดินันท์ สุทธิ, รัชณี มิตถิตติ, ภัทรมน วิจักขณาลัญญ์, เบญจมาศ พระธานี

ภูมิหลัง: ภาวะปากแหว่งเพดานโหว่ยังคงเป็นปัญหาสุขภาพหลักอย่างหนึ่งของประเทศไทย ผู้เลี้ยงดูหลักหรือครอบครัวต้องมีความพึงพอใจสูงในการเลี้ยงดูให้เด็กที่มีภาวะปากแหว่งเพดานโหว่มีสุขภาพที่ดี ความต้องการและคุณภาพชีวิตของผู้เลี้ยงดูหลักหรือครอบครัวเป็นสิ่งจำเป็นที่ต้องทราบเพื่อใช้ในการวางแผนให้การรักษา

วัตถุประสงค์: เพื่อศึกษาความต้องการและคุณภาพชีวิตและหาความสัมพันธ์ระหว่างสุขภาพทางร่างกาย จิตใจ สังคม ความพึงพอใจต่อสิ่งแวดล้อมและคุณภาพชีวิตโดยรวมของผู้เลี้ยงดูหลักหรือครอบครัวของเด็กที่มีภาวะปากแหว่งเพดานโหว่

วัสดุและวิธีการ: ผู้เลี้ยงดูหลัก 25 คน/ครอบครัวของเด็กที่มีภาวะปากแหว่งเพดานโหว่ที่มาเข้าค่ายครอบครัวที่จัดโดยมูลนิธิพัฒนาสตรีภาคเหนือในจังหวัดเชียงราย แบบสอบถามความต้องการของครอบครัวของเด็กที่มีภาวะปากแหว่งเพดานโหว่ภาษาไทย (The THAICLEFT Need Questionnaire) และแบบสอบถามคุณภาพชีวิตขององค์การอนามัยโลกฉบับย่อ (The WHOQOL-BIEF THAI Version) ถูกใช้เป็นเครื่องมือในการสอบถามความต้องการและคุณภาพชีวิตของครอบครัวของเด็กที่มีภาวะปากแหว่งเพดานโหว่ ความต้องการและคุณภาพชีวิตถูกนำเสนอเป็นค่าคะแนนเฉลี่ย ค่าเบี่ยงเบนมาตรฐานและการวิเคราะห์ความสัมพันธ์ระหว่างคุณภาพชีวิตในแต่ละด้าน

ผลการศึกษา: ผู้เข้าร่วมการศึกษาร้อยละส่วนใหญ่เป็นผู้หญิง (88%) มีอาชีพรับจ้าง (36.0%) จบการศึกษาระดับ ประถมศึกษา (44%) ผู้เลี้ยงดูหลักมีคะแนนเฉลี่ยในความต้องการด้านต่างๆ ดังนี้ ความต้องการข้อมูลด้านการแพทย์ 3.31 ความต้องการข้อมูลด้านการรักษาพยาบาล 3.76, ความต้องการข้อมูลด้านค่าใช้จ่ายในการรักษาพยาบาล 3.52 ความพึงพอใจของครอบครัว 3.19 คุณภาพชีวิตโดยรวมของผู้เลี้ยงดูหลักครอบครัวอยู่ในระดับดี 48.0% และระดับพอใช้ 52.0% คุณภาพชีวิตด้านจิตใจ ด้านความสัมพันธ์กับสังคม และความพึงพอใจกับสิ่งแวดล้อมมีความสัมพันธ์ดี 64.0%, 76.0% and 62.0% ตามลำดับ ความสัมพันธ์ด้านสุขภาพอยู่ในระดับพอใช้ 56.0% การวิเคราะห์ทางสถิติ พบว่ามีความสัมพันธ์ในระดับดีระหว่างคุณภาพชีวิตหลัก 4 ด้านและคุณภาพชีวิตโดยรวม (p-value <0.01)

สรุป: ความต้องการข้อมูลด้านการรักษาพยาบาลเป็นความต้องการที่ผู้เลี้ยงดูหลักหรือครอบครัวต้องการมากที่สุด คุณภาพชีวิตโดยรวมของเด็กที่มีภาวะปากแหว่งเพดานโหว่อยู่ในระดับพอใช้และต่ำกว่าเกณฑ์ คุณภาพชีวิตทั้ง 4 ด้านนั้น พบว่าคุณภาพชีวิตด้านสุขภาพและความพึงพอใจกับสิ่งแวดล้อมเป็นด้านที่ต้องการช่วยเหลือ เพื่อเป็นการช่วยเหลือในการยกระดับคุณภาพชีวิตนั้นเจ้าหน้าที่สาธารณสุขและหน่วยงานที่เกี่ยวข้องควรมีข้อมูลที่ได้ไปวางแผนเพื่อปรับปรุงคุณภาพชีวิตของครอบครัวของเด็กปากแหว่งเพดานโหว่ต่อไป
