Original Article

Impact of the Children with Cleft Lip and Palate on Their Families in the North of Thailand

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Background: Cleft lip and cleft palate [CLP] remain a major public health problem around the world, as well as in Thailand. Families are strongly responsible to take good care of the children with CLP. The impact of the children with CLP affected on their families' quality of life should be explored.

Objective: To investigate the impact of children on a CLP family.

Materials and Methods: Nineteen families of the children with CLP who joined the Family Camp that was provided by the Northern Woman's Development Foundation in Chiang Rai Province, Thailand, were selected. The Impact of Family Scale [IOFs], comprising 33 items in five domains was employed in this present study. The structure questionnaire was composed of demographic data and the IOFs which were translated into Thai and thereafter reliability was compared with previous studies. The impact of family scale was presented as mean with standard deviation.

Results: Most participants were females (84.22%), and their most common reported occupation was employee (57.90%), of the participants' their highest education was primary school level (57.92%), and their medical expenses were approximately 902.90 baht per visit. The overall impact of family score was 2.72. In all, coping problems had the highest impact score of 3.70, followed by financial impact of 3.03, social impact of 2.86, and personal impact of 2.72. On the other hand, siblings showed the lowest impact score of 1.65.

Conclusion: There was high negative impact of children on CLP families. The impact modalities were financial, social, personal, coping and sibling impacts, respectively. Knowing the full impact the children with CLP on families [IOFs] would benefit related organizations in enhancing social and family preparation for proper management which ultimately aims to increase their quality of life. Consultation with medical services and expenses, financial and social support are needed.

Keywords: Impact of family scale [IOFs], Cleft lip and cleft palate [CLP], Family impact, North of Thailand

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Cleft lip and cleft palate [CLP] are birth defects that occur when a baby's lip or mouth do not form properly before birth. Moreover, these birth defects are called "orofacial clefts" or "oral clefts" [OFCs]. The CLP affecting 1 to 2 per 1,000 newborns, together they are among the more common birth defects, and the most commonly affect the face(1). A child born with CLP or other craniofacial anomalies always has multiple and complex problems, including early feeding, nutritional concerns, middle ear diseases, hearing deficiencies, deviations in speech and resonance, dentofacial and orthodontic abnormalities, and psychosocial adjustment problems(2). Previous studies confirmed the delay in speech and language development of 16 to 19%, articulation defects of 23 to 90%(3-7), resonance disorders of 27 to 43%(3,4), and voice disorders voice disorders of 0.6 to 50%(4,5,7). On the other hand, families who have children with CLP are also impacted with respect to economic, health and

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social aspects of life.

Impact of CLP on the family has not been a focus of study. Although treatments of CLP require multiple surgical and other interventional procedures from birth into adulthood and frequent clinic attendances to deal with problems related to impaired facial growth, speech impairment, hearing difficulties, and dental care. As such, CLP can bring a range of additional life stressors, which may require substantial changes in family structure and function, affecting emotional, social, and financial resources and the well-being of the family unit and individual members(8,9). More recent research has suggested that children with CLP had little impact on parents' quality of life but high impact with social and economic aspects(10). Nevertheless, effective parental adaptation is critical in helping the child with CLP adjust to his or her condition. Key factors include a caring and consistent parent figure, socioeconomic advantages, a positive extended family network, and family management characteristics such as good communication, effective coping, and family cohesion(11). A previous study found children with CLP parents had positive outcomes such as increased sensitivity toward others, ability to help each other, acceptance of life's challenges, enhanced communication skills, greater flexibility, ability to move on in the face of challenges, and closer relationships(11). Recent studies showed that family resources have significant positive adaptation to a major health problem by coping and adjustment(12-14).

There appears much scope for applying the resiliency model to further our understanding of the family impact of CLP and the psychosocial factors involved in parental outcomes, both positive and negative. The aim of this study was to examine the family impact of CLP and levels of adjustment and psychological distress and to investigate whether other aspects of the family have been impacted, or other reported medical problems have influenced such outcomes.

Materials and Methods

Study sample

Nineteen families of the children with CLP, who joined the Family Camp, which was conducted by the Northern Woman's Development Foundation at the Youth Men's Christian Association [YMCA], during 24 to 26 April 2015 in Chiang Rai Province, Thailand. Multidisciplinary approaches, including speech therapy, orthodontic care, physical development, and the care for ENT and hearing problems were provided for the children with CLP in the Family Camp. The children with CLP and their caregivers attended the Family Camp once a year. Regarding the limitations of speech services in the North of Thailand, particularly in Chiang Rai, local speech and language pathologists [SLP] provided speech assessments and corrections every 3 to 6 months by the Northern Woman's Development Foundation's arrangement. This present study was approved by the Khon Kaen University Ethics Committee for Human Research (Project No.: HE 581088).

Instruments

The instrument "Impact on Family Scale [IOFs]" was employed to evaluate the impact of children with CLP on the family's life. The instrument was developed in the Anglo-American literature as a self-report instrument to measure the effects of chronic conditions and disabilities in childhood on the family(15). In several studies of various diseases, the potential of this instrument has been documented(16-18). The IOFs was applied and translated into Thai (Thai culture, life style and norm in Thai society) to evaluate the impact of children with CLP on their families' life. It consisted of 33 items, dividing into five subscales: financial impact (4 items), social impact (15 items), personal impact (5 items), impact on coping (3 items) and impact on siblings (6 items). The parents were asked to rate on a four-level scale (strongly disagreed = 1, disagreed = 2, agreed = 3, and strongly agreed = 4). The IOFs had both with sibling (33 items) and without sibling (27 items). Overall, nineteen families, of which seven families were without sibling, were explored for their concerns in regard to their future life of having another child.

Statistical analyses

Number and percentage were used to describe the characteristics of the sample. Mean and standard deviation were employed to describe the IOFs. Comparisons with standard interpretation of IOFs based on previous studies were presented with the levels of reliability (Cronbach's Alpha Reliability).

Results

A total of nineteen families who joined the Family Camp were included in this present study. The majority of participants or caregivers were females (84.22%) with ages ranging from 18 to 55 years. In all, 57.90% were employees, 57.92% had the highest level of education from primary school, whilst 10.52% completed a bachelor degree. The participants' family income per month was approximately 8,012 baht and a cost of medical visit was 902.90 baht per hospital visit (Table 1).

The original IOFs consisted of 33 items with English language. The instrument was translated into several languages, thus expanding its application in different cultures and countries[19,20]. The reliability and validity of the translation into German has been confirmed[21]. In this present study, the 33 items with 5 impact domains of IOFs were applied. Hence, the IOFs were translated to Thai based on Thai context and culture. This was the first time of using this instrument in Thailand and the reliability was analyzed. The results found that the reliability in five impact domains indicated good reliability (ranged from 0.78 to 0.89) and the overall IOFs were 0.82 (Table 2).

Table 1. Characteristics of the participating children with CLP or their caregivers (n = 19)

Variables	Number	Percentage
Gender		
Males	3	15.78
Females	16	84.22
Age (years)		
18 to 25	5	26.31
26 to 35	8	42.13
36 to 45	3	15.78
46 to 55	3	15.78
Occupation		
Employee	11	57.90
Agriculture	7	36.84
Merchant	1	5.26
Education		
Primary school	11	57.92
Secondary school	3	15.78
Certificate	3	15.78
Bachelor degree	2	10.52
Income/month (Thai baht)		
Mean (SD)	8,012 (10,023.24)	-
Median (min: max)	5,000.00 (1,500:15,000)	-
Cost of each medical visit	902.90 baht	-

Result of the IOFs revealed that the mean scores for impact on coping were highest, whilst the impact on sibling was the lowest (Figure 1).

Discussion

This present study provided initial data on the impact of children with CLP on their families (Table 3). The financial impact ranged from 2.65 to 3.47. This suggested moderate to high impact, especially for those who have to reduce their time at work in order to care for their children, which, as a result, had an overall financial impact of 3.03. This supported findings of Kramer et al[9] and Surit et al[22] that the financial impact was an important key in the family with CLP children and the economic status was the main aspect affecting quality of life in Thai urban area. Social impact was scored as 2.86, especially infrequent visits to family and friends (3.62), less special family activities and

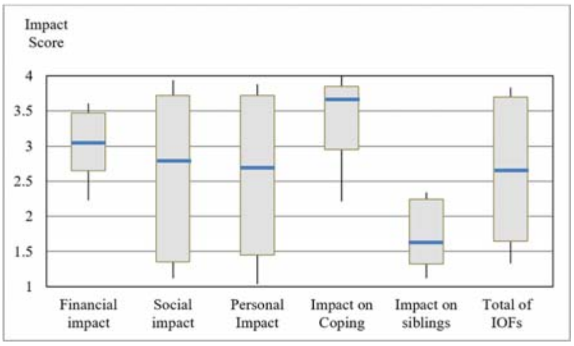

Figure 1. Impact on Family scales in the families having a child with CLP.

Table 2. Distribution of five domains of the impact of family score (IOFs) (n = 19)

Domain	No. of items	Possible range	IOFs (Mean ± SD)	Cronbach's alpha reliability
Financial impact	4	4 to 16	12.12 (13.12)	0.78
Social impact	15	15 to 60	42.90 (33.46)	0.89
Personal impact	5	5 to 20	13.60 (13.25)	0.81
Impact on coping	3	3 to 12	11.10 (12.33)	0.76
Total of IOFs without siblings	27	27 to 108	79.65 (73.67)	0.84
Impact on siblings	6	6 to 24	9.90 (10.29)	0.81
Total of IOFs with siblings	33	33 to 132	89.76 (85.53)	0.82

Table 3. The Impact of family score (IOFs)

The Impact of Family Scale (IOFs)	Mean	SD
Financial impact		
1) An additional income is required to cover the medical expenses	3.25	3.31
2) I have to reduce my time at work in order to care for my sick child	3.47	3.30
3) The illness causes financial troubles in the family	2.74	2.26
4) Medical management results in reduced time at work	2.65	2.13
Total financial impact	3.03	2.67
Social impact		
5) Because of the illness of our child we see our family and our friends more infrequently	3.62	3.01
6) Special family activities are often spoiled because of my child's illness	3.47	3.01
7) It is very difficult to find a person willing to care for the sick child	3.12	2.98
8) We sometimes have to change our plans to go out at the last minute because of the illness of our child	2.91	2.77
9) Because of the illness of our child we cannot travel long distances	3.47	3.02
10) Because of the illness of our child we have no fun going out	3.51	3.11
11) Taking care of my ill child is so time consuming that I do not have adequate time for other family members	2.91	2.34
12) The illness of our child means that I am often overtired and exhausted	3.04	2.20
13) Neighbours treat us in a different way because of the disease of our child	1.65	2.03
14) I live day by day and do not plan my future	1.92	2.37
15) My life is sometimes like a rollercoaster: I feel totally destroyed when the condition of my child is bad and very joyful when the condition of my child is good	3.16	3.01
16) It is a burden for me to go to the hospital	1.35	2.02
17) I had to stop working because of my child's illness	2.08	2.56
18) My relatives arealways very understanding and helpful	3.32	3.09
19) Managing the illness of my child helps me to manage myself	3.41	2.43
Total of social impact	2.86	2.04
Personal impact		
20) Because of the illness I cannot imagine having further children	3.57	3.13
21) Nobody understands the enormous pressures I have to cope with	3.72	3.03
22) Relatives think they know better than me what is best for my child, and interfere in the care of my child	1.45	2.09
23) I am worried about the future of my child (when he/she is a grown-up and I would have died)	2.82	2.72
24) Sometimes I wonder if I should treat my child in a different way from a normal child	2.02	2.04
Total of personal impact	2.72	2.55
Impact on coping		
25) My partner and I analyze the problems together	3.85	2.89
26) Due to our special experiences we become stronger as a family	3.72	3.12
27) We try to treat our child as if they were a normal child	3.53	3.03
Total of impact on coping	3.70	3.23
Total of IOFs without siblings (27 items)	2.95	2.21
Impact on siblings		
28) Neighbours treat us in a different way because of the disease of our child	1.83	2.02
29) My other children seem to be sick more frequently than other children at their ages	1.32	2.12
30) My other children are afraid of the illness of my sick child	1.51	2.04
31) Due to the special needs of the sick child often quarrels occur with other children	1.32	2.11
32) Because of the illness of our child I care for the welfare of the other children very much	1.72	2.34
33) It is difficult to pay adequate attention to the other children because my sick child takes up so much of my time and energy	2.24	2.80
Total of Impact on Siblings	1.65	2.49
Total of IOFs with siblings (33 items)	2.72	2.07

limited long-distant travel because of their children's illness (3.47). Surprisingly, the families always looked forward to hospital appointments, and were grateful for their neighbors' good relations, support and understanding for their conditions. The moderate of personal impact was addressed in this present study (2.72). Participants reported being reluctant to having another child due to this illness (3.57) in addition to having enormous pressures to cope with (3.72).

All responding families confirmed the high positive coping impact (3.70), for example; they tried to analyze the problems together (3.85), became stronger as a family due to their special experiences (3.72) and try to treat their child as if they were a normal child (3.53), the previous study also confirmed that families with cleft experienced an increased impact on coping with statistical significance ($p<0.001$)(9).

The reliability in this present study was consistent with previous studies(19-21). The total impact on family scale was rather high (2.72). Many previous studies have addressed the Quality of Life [QoL] of the patients with CLP and their families(8,23,24). It seems very likely that QoL is an ultimate goal for CLP child and their families. Therefore, concepts of interdisciplinary care in modern cleft centers should address both the child and the family(25). Detailed knowledge of impacts affecting the families having children with CLP might support affected families, specifically in coping with the particular situations and in providing adequate care for the patient and support for their QoL.

This present study demonstrated the primary report of IOFs in Thai society. The IOFs for Thai version needs to be further developed and tested for their validity, reliability and cross culture in order to be used as a standard tool in the near future.

Conclusion

The common impacts of children with CLP on their families were financial, social, personal, coping and sibling impacts, respectively. Related organizations and society should take note of the IOFs and take them into account in increasing the patient's QoL. Consultation with medical services regarding expenses, financial and social support is needed.

What is already known on this topic?

Children with CLP had both physical and psychosocial problems from residual stigmas after repair. The QoL of the children with CLP and their families were analyzed in previous studies. IOFs in Thai context have not been used to investigate the impacts of children with CLP on their family.

What this study adds?

The IOFs is initiated in this present study. The common impact of the children with CLP on their families includes financial, social, personal, coping and sibling impacts, respectively.

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Potential conflicts of interest

The authors declare no conflicts of interest.

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ผลกระทบต่อครอบครัวที่มีบุตรปากแหว่งเพดานโหว่ในภาคเหนือของประเทศไทย

พฤฒินันท์ สุฤทธิ์, รัชนี มิตกิตติ, ภัทรมน วิจักขณาลัญฉ์, เบญจมาศ พระธานี

ภูมิหลัง: ภาวะปากแหว่งเพดานโหว่ยังคงเป็นปัญหาสุขภาพที่พบทั่วโลกรวมถึงประเทศไทย ครอบครัวถือว่าเป็นสถาบันหลักที่สำคัญในการดูแลผู้ป่วย การศึกษาผลกระทบที่เกิดขึ้นกับครอบครัวมีความจำเป็นต่อการวางแผนและเพิ่มคุณภาพชีวิตที่ดี

วัตถุประสงค์: เพื่อศึกษาผลกระทบที่เกิดขึ้นกับครอบครัวที่มีบุตรปากแหว่งเพดานโหว่

วัสดุและวิธีการ: กลุ่มที่ศึกษาคือครอบครัวผู้ที่มีภาวะปากแหว่งเพดานโหว่จำนวน 19 ครอบครัวที่มาเข้าค่ายครอบครัวที่จัดโดยมูลนิธิพัฒนาสตรีภาคเหนือ ในจังหวัดเชียงราย โดยใช้แบบวัดผลการทบต่อครอบครัวหรือ impact of family scale (IOFs) ที่ประกอบด้วย 33 ข้อคำถาม 5 ด้าน เครื่องมือหลักในการศึกษาครั้งนี้ คือ แบบสอบถามที่ประกอบด้วยสองส่วน คือ ข้อมูลทั่วไปและแบบวัดผลกระทบต่อครอบครัวที่แปลเป็นภาษาไทย โดยใช้ทดสอบค่าความเที่ยงของเครื่องมือเทียบกับการศึกษาที่ผ่านมา โดยค่าผลกระทบต่อครอบครัวจะนำเสนอโดยค่าเฉลี่ยและค่าส่วนเบี่ยงเบนมาตรฐาน

ผลการศึกษา: ครอบครัวส่วนใหญ่ที่ตอบแบบสอบถามเป็นผู้หญิง (84.22%) มีอาชีพหลัก คือ รับจ้าง จบการศึกษาในระดับประถมศึกษา (57.92%) ค่าใช้จ่ายในการไปรักษาพยาบาลในแต่ละครั้งประมาณ 902.90 บาท ผลกระทบต่อครอบครัวโดยภาพรวมค่อนข้างสูง โดยมีค่าเฉลี่ยอยู่ที่ 2.72 เมื่อพิจารณาองค์ประกอบของผลกระทบต่อครอบครัวพบว่าผลกระทบต่อการเผชิญความเครียดมีค่าเฉลี่ยสูงสุด คือ 3.70 รองลงมาคือ ผลกระทบด้านเศรษฐกิจ มีค่าเฉลี่ย 3.03 ผลกระบททางด้านสังคม มีค่าเฉลี่ย 2.86 และผลกระทบส่วนบุคคล มีค่าเฉลี่ย 2.72 ส่วน ผลกระทบต่อพี่น้องในครอบครัวมีค่าน้อยที่สุด โดยมีค่าเฉลี่ย 1.65

สรุป: ผลกระทบต่อครอบครัวของเด็กปากแหว่งเพดานโหว่อยู่ในระดับสูง ผลกระทบโดยมีองค์ประกอบที่สำคัญด้านต่างๆ เรียงจากมากไปน้อย คือ การเผชิญความเครียด เศรษฐกิจ สังคม ส่วนบุคคลและพี่น้องในครอบครัวตามลำดับ การให้ข้อมูลเกี่ยวกับผลกระทบที่เกิดกับครอบครัวของเด็กปากแหว่งเพดานโหว่แต่เนิ่นๆ แก่องค์กรที่เกี่ยวข้องเพื่อจะสนับสนุนการเตรียมความพร้อมของสังคมและครอบครัว ซึ่งจะเป็นการเพิ่มคุณภาพชีวิตของครอบครัวให้ดีขึ้นได้ การให้คำปรึกษาทางด้านการรับบริการทางการแพทย์รวมถึงค่ารักษา การสนับสนุนทางสังคมและค่าใช้จ่ายเป็นสิ่งที่จำเป็น