Home and Environment Survey of Children with CLP in Khon Kaen Province

Daungkaew Rod-ong MSN*, Somchit Rongbudsri Med**,
Somchit Maneeganondh BNS*, Hattakorn Samretdee BSC**,
Suteera Pradubwong MSN*, Niramol Patjanasoontorn MD**

** Division of Nursing, Srinagarind Hospital, Faculty of Medicine, Khon Kaen University, Khon Kaen, Thailand*
*** Department of Psychiatry, Faculty of Medicine, Khon Kaen University, Khon Kaen, Thailand*

Background: *Cleft lips and palates (CLP) are congenital facial deformities that affect breathing, swallowing, speaking, cause unclear communication and academic problems. Most incidences are with the poor. For helping them in many aspects, a home visit project was conducted by Tawanchai Center to explore home and environment in a real situation.*
Objective: *Home visit the children with CLP in Khon Kaen province.*
Material and Method: *A descriptive study studied in Khon Kaen Province, 20 children with CLP, age between 0 to 12 year old, caregivers and their community representatives were interviewed. Data were analyzed by percentage.*
Results: *Results showed: 1) most children had schooling, 14/20 children were underweight, 2) 65 percent of caregivers were mothers, and working as famers or housewives, finished primary to secondary schools, 3) extended family type, most families had economic problems and over concern for children with CLP' health, 4) Community needed government agencies to provide training for educating and caring for children with CLP, 5) Children's homes: 4/20 children had a poor and unsafe home environment, in need of further reconstruction.*
Conclusion: *Some homes and environment for children with CLP needed to be reconstructed, as well as providing specified education and training for children with CLP for the community to understand them.*

Keywords: *Home survey, Environment, Cleft lips and palates*

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Cleft lips and palates (CLP) are congenital facial deformities that affect the patient's breathing, swallowing, speaking, and cause unclear communication and academic problems[1]. Families have feelings of regret and have to adjust themselves for their children' abnormalities. Health care teams corrected organ dysfunction and deficiencies, and provided psychological care to enhance their self-esteem and image[2]. Helping families to adjust socially and offer understanding with assessing health care service, are important[3]. The home visit project is conducted by Tawanchai Center to explore home and environment in a real situation for further planning in helping in all modalities.

Home visit patients with CLP in Khon Kaen Province.

Correspondence to:
Patjanasoontorn N, Department of Psychaity, Faculty of Medicine, Khon Kaen University, Khon Kaen 40002, Thailand.
Phone & Fax: +66-43-348384
E-mail: nirpat@kku.ac.th

Material and Method

A descriptive study studied in Khon Kaen Province, we interviewed 20 children with CLP, age between 0-12 years old and their caregivers and community representatives. They were patients registered at Tawanchai Center, Srinagarind Hospital, Khon Kaen Province. Twenty homes were visited, researchers interviewed patients and caregivers for general information, caregivers' attitudes toward their children's illness. The community representatives were interviewed with semi-structured questions. Researcher teams who had trained in home and environment rating, surveyed home and environmental. The data were present by percentage. Khon Kaen University Human Research Ethics Committee gave approval the research under number HE591110.

Results

The results showed that the children included in this study were 10 females and 10 males. The majority of subjects had unilateral CLP (n = 15, 75%) and were studying in primary school (n = 9, 45%). 12 children

(60%) had normal BMI and 14 children were underweight, whilst 4 patients were overweight (Table 1).

The majority of the caregivers who gave information were mothers (n = 13, 65%), their age ranged 20 to 30 years (30%), had completed primary and secondary schools (n = 14, 70%), most of them had good family relationship (n = 15, 75%). They were of an extended family (n = 17, 85%). Half of the participants had family financial problems with debt (n = 8, 40%). Half of them concerned about parenting (n = 10, 50%), and their child's educational problems and future career (n = 10, 50%). The caregivers must care for a child with CLP more than for the other children (n = 19, 95%) (Table 2). Additional comments including, good care should be continued, needed hospital travelling fund for work absence, needed support for some treatment expenses including, dental care and surgery, which were extra costs outside national coverage; needed scholarship to support their children's education.

In aspects of health problems of the children, dental caries were the most common reported problem (n = 13, 65%). With respect to providing developmental stimulation for their children at home, caregiver reported having toys for children in the house (n = 13, 65%), having books for children (n = 13, 65%), and reading storybooks to their children (n = 11, 55%). The caregiver attitude to their children with CLP asked why this has happened to them 50%, feel the children were poor and inferior 30% (Table 3).

The researcher teams report home environment: almost half of the families had fair environment (n = 9, 45%), whilst only 4 families had a poor and unsafe home environment in need of reconstruction.

The community representatives who joined the survey were females (n = 19, 95%), age ranged mostly between 41 and 50 years (n = 8, 40%), completed primary school (n = 12, 60%), were village health volunteers (n = 19, 95%), had been in the practice from 1 to 10 years (n = 8, 40%). They said there was no special treatment for children with CLP in their community. There was no special care for the CLP children. The volunteers needed to provide information and training from physician and nurses to help these children.

Based on semi-structured interviews, the concluding results were as follows

1) The children with CLP were treated like general children in community (n = 14), community advised surgery (n = 2), supported and advised about

Table 1. Demographic data of childrenwith cleft lips and palates

Characteristics		Number	%
Gender (n = 20)	Males	10	50
	Females	10	50
Age (years) (n = 20)	0-5	10	50
	6-12	10	50
Diagnosis	Unilateral CLP	15	75
	Bilateral CLP	5	25
Education	Had not attended school	6	30
	Child development center	1	5
	Kindergarten	4	20
	Primary school	9	45
Nutritional status			
Body weight	Underweight	7	35
	Normal	10	50
	Overweight	3	15
Height	Lower than average	5	25
	Normal	12	60
	Higher than average	3	15
BMI	Underweight	4	20
	Normal	12	60
	Overweight	4	20

BMI = Body mass index

Table 2. Demographic data of caregivers

Characteristics			Numbers	%
Interviewee (n = 20)	Fathers		1	5
	Mothers		13	65
	Grandparents		6	30
Gender (n = 20)	Males		3	15
	Females		17	85
Ages (years) (n = 20)	20-30		6	30
	31-40		5	25
	41-50		5	25
	51-60		1	5
	> 60		3	15
Educational level	Had not attended school		1	5
	Primary school		7	35
	Secondary school/vocational certificate		7	35
	Bachelor		3	15
	Above bachelor		2	1
Marital status	Married, living together		16	80
	Married, separated		1	5
	Devoiced		2	10
	Widow		1	5
Family relationship	Good		15	75
	Conflict		4	20
	NA		1	5
Family type	Nuclear family		3	15
	Extended family		17	85
Family members	Average 6 (range 2-12)			
Family income	Enough and had deposit		5	25
	Enough, had no deposit or debt		7	35
	Not enough, had debt		8	40
Occupation	Government employee		2	10
		Private employee	2	10
		Unskilled labor	3	15
		Trading/personal business	3	15
		Famers	5	25
		Unemployed/housewife	5	25
Physical illnesses	-Father	Had	6	30
		Did not have	13	65
		NA	1	5
	- Mother	Had	7	35
		Did not have	13	65
Mentally illnesses	- Father	Had	0	0
		Did not have	19	95
		NA	1	5
	- Mother	Had	4	20
		Did not have	16	80
Alcohol drinking	- Father	Yes	11	55
		No	8	40
		NA	1	5
	- Mother	Yes	4	20
		No	16	80

care (n = 2) and provided home visits more often.

2) Problems of children with CLP: no problem (n = 17), feeding and aspiration (n = 1), and children might feel inferior and did not want to socialize (n = 2).

Table 2. (Cont.) Demographic data of caregivers

Characteristics			Numbers	%
Smoking	- Father	Yes	9	45
		No	10	50
		NA	1	5
	- Mother	Yes	1	5
		No	19	95
Parenting	- By parents (grandparents helped sometimes)		15	75
	- By grandparents		5	25
Having genetics of the CLP	Yes		7	35
	NO		13	65
Access to Health Care Services				
Primary care unit/community hospital			14	70
University affiliated hospital/General hospital			6	30
Satisfactory with the health care services				
	Yes		16	80
	No		4	20
Family's concerns about their children as following aspects:				
Parenting	Yes		10	50
	No		10	50
Learning problems	Yes		10	50
	No		10	50
Friendship and community issues		Yes	5	25
		No	15	75
Future career		Yes	10	50
		No	10	50
Caring for CLP children different from other children (could select more than one answers)				
Like other children			3	15
Caring and feeling pity for more than other children			19	95
Being spoiled more than other children			11	55
Assisting in work less than other children			3	15
Has difficulty in caring for the children in(could select more than one answers)				
Finance			9	45
Nurture			5	25
Health			6	30
Learning			4	20
Neighbors			0	0
Hospital visit(geographically distance/often absent from work)			4	20
Providing support in health relate problems from				
Tawanchai Center			20	100
Other centers			0	0

3) Monitoring for body weight and height, vaccinations and other health promotion and prevention.

4) To train how to care and educate children with CLP (n = 8), financial support (n = 7), support through regular hospital visits (n = 3), a need for educational supply for the children (n = 2), supporting travelling expenses to the hospital (n = 2), support for

Table 3. Aspect of care, attitude and home environment situation

Problems in caring their children in aspect of		Numbers	%
Physical care			
Feeding/eating	Having difficulties	5	25
	Did not have any problem	15	75
Health problems			
Dental carries	Yes	13	65
	No	7	35
Skin problems and lice	Yes	6	30
	No	14	70
Chronic URI /ear infections	Yes	7	35
	No	13	65
Falls, fracture or accidents	Yes	4	20
	No	16	80
Bedwetting	Yes	9	45
	No	11	55
Emotional care (could select more than one answers)			
Crying, rampant want to get something right away		5	25
Scared strangers/did not talk to strangers		2	10
Naughty, resist, arguing		9	45
Social care (could select more than one answers)			
Took the children to school every day on school day		5	25
Took the children to temples, and the annual merit ceremony		18	90
In one month, children were mocked by friends		2	10
Having fun playing together	Yes	16	80
	No	4	20
In one month, children were punished by violent beatings			
	Yes	0	0
	No	20	100
Child developmental and stimulation			
Children had developed properly	Slower than average	2	10
	Normal by age	18	90
Having children's books in the house			
	No	7	35
	Yes	13	65
Having toys for the children in the house			
	No	3	15
	Yes	17	85
Having read a storybook with children			
	Never	9	45
	Yes	11	55
Attitudes about caring for the children with CLP (could select more than one answers)			
Feel burdened		4	20
Feel why this happened to his/her family		10	50
Feel that people did not accept this disorder		1	5
Feel that children were poor and inferior		6	30
Home environment comments by the visiting team			
Poor environment, unsafe, need to be continuing monitored and corrected		4	20
Fair environment		9	45
Good environment		7	35

CLP = cleft lips and palates

non-covered costs for tertiary care hospital (n = 1), and promote vocational training for future careers (n = 1).

5) They were treated as regular children (n = 16), needed socialization and adaptation (n = 1), not to

mimic the illness (n = 1), to counter not feelings of inferiority (n = 1).

6) Difficulties in caring for the children with CLP were explored and the volunteers reported having no problems (n = 16) whilst the others lack knowledge and confidence in giving advice and care for the children with CLP (n = 4).

Discussion

Cleft lips and palates are congenital deformities. The defects do not affect only the patients but families are affected by feelings of loss, regret, and concern, they need to overcome the problems. Half of the families need to know how to care for the children; they worry about the future of their children in schooling and career. In this study, parents report problems in dental caries, bed wetting, chronic ear infection, skin disease and feeding problems. They reported emotional problems including naughtiness, resistance, arguing, crying, tantrums. With regard to the attitude in having children with CLP, they nave questions as to why this has happened to their families, feeling pity that their children are inferior, and burdensomeness. The report suggested the need for multidisciplinary health teams to support children and families to deal with feelings of loss, regret, concern, and inferiority. For developmental problems of the children, 10% were slower than their age; need to focus in individually to correct the delay. In regard to parenting skills and child stimulation and use of books, toys and story reading, some families reported no books, no toys and no reading to their children. These families need support to correct this situation. Although receiving support from Tawanchai Center, the majority of the families are having problems with traveling costs to see doctors at the hospital as well as the additional treatment costs that they have to pay as well as previous studies[4,5]. This is consistent with household surveys across the country in the year 2015 by the National Bureau of Statistics which found that only 49.1% of the households had debt[6]. Those who are poor and with low income struggle more with CLP children. These economic problems require finding out how to increase their household income and pay less going to hospitals.

Thai health service system has 3 levels. Primary care, or health prevention in the community, with potential of personnel, is still limited in dealing with dynamic and complex health problems[7]. In this study, the village health volunteers were females, completed primary school but did not have guidelines in taking care of the persons with CLP. In addition, the community does not have any groups providing special care for this type of patients. The health volunteers, therefore, require training in educating and caring for the patients with CLP in order to have sufficient knowledge and confidence to guide the patient and their family.

For the home environment survey by the research team, the majority of the families had fair to good environment. This may be because they are in rural communities in which people help each other and are part of extended families where there are grandparents to assist in taking care of the children. The relationship in the family is also good. There were four families having poor home and environment situation that needed reconstruction and continuing monitoring, need to report to department of human development and social welfare in the area to evaluate their situation and offer help them.

The home visits helped to obtain data about the patient and family problems and real needs from each family which was similar to the study of Augsornwan and colleagues[8]. The study suggested that home visits are a good practice in collecting data and exploring problems and needs of the family since the children and their families would feel comfortable at home more than in the hospital setting. Therefore, the care team can talk and ask more questions. As a result, the children's family would be satisfied with the care team and confident in providing care for their children.

Conclusion

Cleft lips and palates are the most common congenital deformities that occur with the face and the patients need continuing long-term care. Although there is no problem accessing public health services, there is a problem with the cost of traveling to hospital visits and non- coverage of medical fees, because CLP's are common among the poor. The parents feel a burden and are overcome by their problems and need a supporting system. The village health volunteers also need knowledge to guide in helping families. From the survey, four families have poor environments and unsafe homes. Home visits and surveys are really important to identify problems and needed humanitarian services for these people not only in hospital setting.

What is already known on this topic?

Children with cleft lips and palates have physical and mental problems which require care from a multidisciplinary team.

What this study adds?

This study exposed that the real problems facing children with CLP and their families.

The families and communities do not have guidelines to provide specific care to children with CLP.

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Potential conflicts of interest

None.

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การสำรวจบ้านและสภาพแวดล้อมในเด็กปากแหว่งเพดานโหว่

ดวงแก้ว รอดอ่อง, สมจิตร์ หร่องบุตรศรี, สมจิตร์ มณีกานนท์, หัฏฐกร สำเร็จดี, สุธีรา ประดับวงษ์, นิรมล พัจนสุนทร

ภูมิหลัง: ภาวะปากแหว่งเพดานโหว่เป็นความพิการทางใบหน้าแต่กำเนิดที่มีผลกระทบต่อการหายใจ การกลืน การพูด การสื่อสาร และปัญหาการเรียนอุบัติการณ์ส่วนใหญ่มักพบในบุคคลที่มีฐานะยากจน การช่วยบุคคลเหล่านี้มีหลายด้านโครงการเยี่ยมบ้านของศูนย์ตะวันฉายจึงมีความจำเป็นในการเข้าไปค้นหาข้อมูลของบ้านและสภาพแวดล้อมที่เป็นอยู่จริง

วัตถุประสงค์: เพื่อเยี่ยมบ้านของเด็กที่มีภาวะปากแหว่งเพดานโหว่ในจังหวัดขอนแก่น

วัสดุและวิธีการ: เป็นการศึกษาเชิงบรรยายในเด็กที่มีภาวะปากแหว่งเพดานโหว่ 20 รายในจังหวัดขอนแก่น ช่วงอายุ 0 ถึง 12 ปี รวมทั้งผู้ดูแลและตัวแทนชุมชน โดยวิธีการสัมภาษณ์กึ่งโครงสร้าง วิเคราะห์โดยใช้สถิติร้อยละ

ผลการศึกษา: พบว่า 1) เด็กส่วนใหญ่ได้เข้าโรงเรียนตามกำหนด มีเด็กน้ำหนักต่ำกว่าเกณฑ์ จำนวน 14 รายใน 20 ราย 2) ผู้ดูแลร้อยละ 65 เป็นมารดา ซึ่งประกอบอาชีพทำนา และเป็นแม่บ้าน จบการศึกษาระดับประถมและมัธยมศึกษาเป็นส่วนใหญ่ 3) ลักษณะเป็นครอบครัวขยาย มีปัญหาด้านเศรษฐกิจ และมีความกังวลด้านความเจ็บป่วยของบุตร 4) ชุมชนต้องการการอบรมความรู้และวิธีดูแลเด็กกลุ่มนี้ 5) มีบ้าน 4 หลังคาเรือนที่มีสภาพแวดล้อมไม่ปลอดภัย จำเป็นต้องได้รับการช่วยเหลือซ่อมแซม

สรุป: มีบ้านที่จะต้องได้รับการช่วยเหลือซ่อมแซม ปรับปรุง เช่นเดียวกับชุมชนที่ต้องการความรู้ และการดูแลที่เฉพาะสำหรับเด็กกลุ่มนี้