

Study of Care for Patients with Cleft Lip/Palate (CLP) in Lao People's Democratic Republic

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Objective: The objectives of the study were to determine basic information, understand health-related problems and examine problem-solving strategies among patients with cleft lip/palate (CLP) residing in Lao People's Democratic Republic (PDR).

Material and Method: This was a cross-sectional, descriptive study. The research team interviewed 24 patients with CLP who underwent surgery at the Khammouan Hospital between October 16-20, 2010 and their caregivers. A questionnaire was developed by the research team to collect information on demographics, health-related problems and problem-solving strategies. Content validity was reviewed by five experts.

Results: Sixty-two percent (15/24) of the patients were boys with an average age of 6.3 years. Fifty percent of the patients had both a cleft lip and cleft palate. Heredity played a major role in causing the CLP among the majority of patients (58%). Most of caregivers resided in either Khammouan (33%) and Bolikhamxai Province (33%). With respect to the caregivers, their average age was 36 years, 50% were fathers and mothers, 87% had a family income lower than one million Kip/month (124 USD); all were satisfied with the treatment provided, 96% had sufficient knowledge for helping or publicizing the proper treatment to other patients and 87% knew of the healthcare resources for patients with CLP (i.e., Khammouan Hospital provides free-of-charge surgery). The caregivers also understood the need for regular, life-long follow-up care of cleft lip. However, 87% of the caregivers did not know the causes of CLP, 75% did not know that the patients with ridges cleft must have a ridges bone graft surgery, while 66% did not know about post operative care, wound care, audiometry and speech therapy.

Conclusion: Although timely receipt of primary cleft surgery is essential to the physical and psychosocial well-being of patients with CLP, those residing in Lao PDR did not receive surgery until the age of 6 years. The main reasons for this are the lack of awareness regarding diagnosis and treatment, limited availability of health services, and insufficient financial resources; therefore, both technical and financial support from external stakeholders is crucial. The establishment of a local medical infrastructure, training local surgeons and free access are also critical for the development of a sustainable and effective multidisciplinary management program for patients with CLP and their families.

Keywords: Care for patients, Cleft lip-palate, Lao PDR

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Cleft lip/palate (CLP) and craniofacial anomalies are congenital defects with numerous sequelae in the dental, speech, hearing, body-image and psychosocial realms. The condition also negatively

affects the entire family, especially parents and their disposition of financial resources. CLP even significantly affects national healthcare budgets in therapeutics. The number of Asian patients with CLP (especially in northeastern Thailand) is double that among Caucasians⁽¹⁾.

In 1998, Chuangsuwanich et al reported that 59% of the patients with CLP in Thailand reside in the geopolitical Northeast region⁽²⁾. For every 1,000 newborns, 2.49 have some form or degree of CLP⁽³⁾, which is the highest rate in the world⁽³⁾. The Central

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Intelligence Agency (CIA), has reported that Lao PDR has the highest rate of newborns with CLP in the world. For every 1,000 newborns, there are 36.47 with CLP⁽⁴⁾.

The Lao People's Democratic Republic (Lao PDR) is a developing country bordering Thailand with a language, lifestyle and culture similar to that of Northeast Thailand. Given the severity of the issue, the Thai Government and Khon Kaen University have implemented policies to help with the diagnosis of patients with CLP in the nations of the Mekong Sub Region, which includes the Lao PDR. Within the Lao PDR, there are many problems which decrease the efficiency of patients' accessing treatment; for example: poverty, unemployment, lack of technology and basic medical awareness at the community level⁽⁵⁾.

The diagnosis and treatment of newborns with CLP requires a multidisciplinary team, including plastic surgeons, pediatricians, obstetricians, gynecologists, otorhinolaryngologists, dentists, orthodontists, psychiatrists, nurses, social workers and public health officers. Treatment for patients with CLP includes multiple surgeries spanning from infancy to 15 years of age. A patient should have his/her first cleft lip surgery at 3-4 months and 10-18 months for cleft palate surgery⁽⁶⁾.

In some cases, after a patient has had surgery, he/she will still have hole or drain after surgery, so further surgeries will be required until the reconstructive surgeries are completed. Some cases will have a rolled up scar which results in the patient's having unclear pronunciation: these patients need to be evaluated by a speech therapist and radiologist, and have plastic surgery undergo until they will have the next surgery and/or until their pronunciation improves. Four- and five-year-old patients can undergo lip and nose plastic surgery. Eight- and 12-year-old patients can have alveolar cleft bone grafting. Patients over 15 years old can undergo jaw and facial bone surgery. After the surgery, if the patients, their parents and physicians are satisfied with the results, the treatments are concluded.

For the last 8 years, the Center for Cleft Lip-Cleft Palate and Craniofacial Deformities, Khon Kaen University, in association with the "Tawanchai Project", have cooperated with Handicap International Lao PDR; the Interplast team, Australia; a Belgium plastic surgeon; Smile Train; Aus AID⁽⁷⁾; Women International Group; Healing The Children Missouri Foundation; and Mahosot Hospital, Lao PDR, in the diagnosis of patients with CLP and craniofacial anomalies. However, it is most helpful/useful if assistance, introduction and/

or instruction can take place in the district where the patient lives. Therefore, multidisciplinary teams from the Faculties of Medicine and Dentistry, anesthetists from the Queen Sirikit National Institute of Child Health, Thailand and Canada, and surgeons from the USA, presented lectures in their subject areas, covering holistic care and treatment.

The authors were interested in studying about CLP among Laotian patients in Lao PDR because although several organizations have helped there for the last 8 years, there has not yet been any substantial review or research about the obstacles to getting treatment and outcomes. The authors hope that our research will help to promote sustainable and practicable CLP treatment in the Mekong Sub-Region.

Objective

1. To study the primary information regarding CLP treatment in Lao PDR; and,
2. To study the problems/obstacles faced by patients' needing CLP treatment in Lao PDR and possible solutions.

Material and Method

This was a cross-sectional, descriptive study. This description research was approved by the Ethics Committee for Human Research, Khon Kean University.

Data collection

Two types of questionnaires were used to assess five realms of knowledge: 1) Patient information and 2) General caregiver information as well as their knowledge regarding their understanding of CLP treatment and patient care. The knowledge questions had binary (Yes/No) answers.

The questionnaires were completed during 15-minute family interviews. The Thai interviewer used the Northeast Thai dialect (Isaan) which is similar to Laotian. Some Laotian families did not understand Isaan so an interpreter was used. The translator was a public health officer at Khammouan Hospital.

The collected data were analyzed using SPSS for Windows to evaluate the descriptive statistics, percentage and standard deviation⁽⁸⁾. The Laotian and Isaan were translated into Thai, then content analysis was reviewed to evaluate the qualitative feedback.

Results

Fifteen of the CLP patients were male. The average age of the patients was 6.3 years. Twelve of the patients had a dual type of deformation cleft lip and

Table 1. General CLP information by sex, age, type of deformation and cause (n = 24)

General Information	Amount (Person)	Percentage (%)
Sex (n)		
Male	15	62
Female	9	37
Age of CLP patient		
Lower than 1 year old	3	12
1-3 years old	6	25
3-5 years old	5	21
5-7 years old	2	8
Upper than 7 years old	8	33
Average age (x) = 6.3years old		
Type of deformation		
Cleft Lip	11	46
Cleft Lip and Cleft Palate	12	50
Cleft palate	0	0
Others	1	4
Family occurrence of CLP		
Parents/Relations have cleft lip or palate	14	58
None	10	42
Not known	0	0

cleft palate. Fourteen of the clefts were congenital (Table 1).

Eight of the caregivers lived in Khammouan and Bolikhamxai province. The average age was 35.9 years. Twelve caregivers were the father of the patient and 12 were mothers. Eleven caregivers were farmers and 21 had a family income lower than one million Kip (~124 USD) (Table 2).

The survey of caregivers' understanding vis-a-vis taking care of patients with CLP revealed that (a) 24 caregivers were satisfied with the treatment (b) 23 felt they had adequate knowledge about providing for or sharing about the proper treatment (c) 21 knew that Khammouan Hospital was a place for caring for patients with CLP and that it offered surgeries free of charge (d) 21 had not identified the cause of CLP (e) 18 had not understood that ridges cleft must have ridges bone graft surgery and (f) 16 did not understand post operatively wound care, particularly audiometric and speech practice (Table 3).

Discussion

Of the 24 patients with CLP, 12 had both a cleft lip and a cleft palate and 15 were male. This type of CLP and demographic prevalence is similar to Fogh-Anderson's study, published in 1942. Fogh-Anderson found that 50% of their patients had a combined cleft lip/palate and 60-80% of patients were male⁽⁹⁾. Fourteen

of our patients had a hereditary cause, which again is similar to another study, this one in 1989 by Ardinger et al.

The authors found patients as old as seven and more, who were just starting their CLP surgical treatment, which is much older than what is considered the appropriate standard. Vuthy (2011) conducted a study in Cambodia, a developing nation, and found that the maximum age for cleft lip surgery was 1 year and 8 months and the maximum age, for cleft palate surgery was 4 years and 6 months⁽¹⁰⁾.

Most of the caregivers came from 5 Kwang (or districts) close to Khammouan provincial capital. Most were agriculturists, uneducated or had not passed elementary school and the family income was lower than 1 million Kip (124 USD). Lao PDR has low education and income as it is a developing nation.

All 24 caregivers were the parents of the patients so the patients received good, loving, care. From the information provided by the caregivers, their understanding regarding the care of CLP indicated that, in the main, they did know about or understand about the disease (*i.e.*, its cause, the incidence, the conditions requiring bone graft surgery, post operative wound care and/or audiometric and speech therapy). This lack of awareness, however, is understandable in a developing country. The solution lies in implementing government policy and interventions that would

Table 2. General caregivers information by residence, age, relationship to patient, occupation, education and family income (n = 24)

General Information	Amount (Person)	Percentage (%)
Residence		
Khammouan	8	33
Bolikhamxai	8	33
Savannakhet	1	4
Oudomxai	1	4
Vientiane	1	4
Not stated	1	4
Age		
20-40 years old	19	79
41-60 years old	5	21
Average age (x) = 35.9 years old SD = 12.1		
Relationship to patient		
Father	12	50
Mother	12	50
Occupation		
Government officer	2	8
Agriculturist	11	46
Work as employee	1	4
Merchant	1	4
Housewife	3	12.5
Others	6	25
Education		
Uneducated	8	33
Elementary education	10	42
Secondary education/Vocational or High Vocational Certificate	6	25
Family income		
<1 million Kip (~124 USD)	21	87.5
>1 million Kip (~124 USD)	3	12.5

increase and promote individual CLP patient self-care (and family care) as well as multidisciplinary, long-term treatment of pediatric patients with CLP.

Conclusion

The most important aspect of assistance needed for taking care of patients with cleft lip and cleft palate in a developing country, notably Lao PDR, is public health officers' support, and the implementation and use of multidisciplinary care. Importantly, multidisciplinary care (including surgery) should be done locally whenever possible. Government and non-government agencies in Lao PDR need to support the Laotian public health officers to become self-reliant.

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Potential conflicts of interest

None.

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Table 3. Caregiver understanding of CLP patient care (n = 24)

Knowledge base	Yes	No
1. Cleft lip/cleft palate (CLP) disease	6 (25%)	18 (75%)
2. Incidence of CLP	3 (12.5%)	21 (87.5%)
3. Preoperative care for CLP	11 (46%)	13 (54%)
4. Postoperative care for CLP	8 (33%)	16 (67%)
5. Postoperative CLP wound care	8 (33%)	16 (67%)
6. Breastfeeding a CLP baby	14 (58%)	10 (42%)
7. Problems untreated CLP patients have with eating, speaking and hearing	17 (71%)	7 (29%)
8. Problems untreated CLP patients have with respiratory and middle ear infections	7 (29%)	17 (71%)
9. Khammouan Hospital provides useful information and helps CLP patients free of charge	21 (87.5%)	3 (12.5%)
10. CLP requires den to-orthodontic treatment	14 (58%)	10 (42%)
11. CLP requires audiometric and speech therapy	8 (33%)	16 (67%)
12. Patients with ridges cleft must have ridges bone graft surgery	6 (25%)	18 (75%)
13. CLP treatment begins in new born and continues until the patient and caregiver are satisfied with the outcome	9 (37.5%)	15 (62.5%)
14. Understand that the patient must receive treatment and follow up for many years, until the patient is fully grown	21 (87.5%)	3 (12.5%)
15. Understand the treatment process for patients with CLP	11 (46%)	13 (54%)
16. Able to apply the knowledge in real life	20 (83%)	4 (17%)
17. Could help or publicize about proper CLP treatment	23 (95.8%)	1 (4%)
18. Treatment satisfaction	24 (100%)	0 (0%)

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การศึกษาการดูแลผู้ป่วยปากแห้งเพดานโหว่ของประชาชนในสาธารณรัฐประชาธิปไตยประชาชนลาว

สุธิดา ประดับวงษ์, เสาวลักษณ์ ธีรตันพงษ์, ชนิษฐา วรธงชัย, คำแสน แก้วประดับสี, บวรศิลป์ เชาวน์ชื่น

วัตถุประสงค์: เพื่อศึกษาข้อมูลเบื้องต้น ปัญหา และแนวทางการแก้ไขปัญหาของการดูแลผู้ป่วยปากแห้งเพดานโหว่ในสาธารณรัฐประชาธิปไตยประชาชนลาว

วัสดุและวิธีการ: การศึกษาแบบภาคตัดขวาง (cross-section descriptive study) ครั้งนี้ได้ใช้แบบสอบถามในการสัมภาษณ์กลุ่มตัวอย่าง ผู้ป่วยปากแห้งเพดานโหว่ และผู้ดูแลที่เข้ารับบริการผ่าตัดช่วงจัดการประชุมเชิงปฏิบัติการระหว่างวันที่ 16-20 ตุลาคม พ.ศ. 2553 ณ โรงพยาบาลแขวงคำม่วน สาธารณรัฐประชาธิปไตยประชาชนลาว (สปป.ลาว) จำนวน 24 คน ในด้านข้อมูลทั่วไป และข้อมูลในด้านความรู้ความเข้าใจของผู้ดูแลในการดูแลผู้ป่วยปากแห้งเพดานโหว่ ผู้นิพนธ์ได้ออกแบบสอบถามโดยผ่านการประเมินจากผู้ทรงคุณวุฒิจำนวน 5 ท่าน

ผลการศึกษา: พบว่าด้านผู้ป่วยเป็นเพศชายมากที่สุด 63% อายุเฉลี่ย 6.3 ปี ประเภทความพิการมีทั้งปากแห้งเพดานโหว่มากที่สุด 50% และมีภาวะทางพันธุกรรมเกี่ยวข้องมากที่สุด 58% ด้านผู้ดูแลอาศัยอยู่ที่แขวงคำม่วนและบุรีคำไซมากที่สุดคิดเป็น 33% อายุเฉลี่ย 36 ปี ความสัมพันธ์กับผู้ป่วยเป็นบิดาและมารดามากที่สุด 50% รายได้ของครอบครัวต่อเดือนต่ำกว่า 1 ล้านกีบมากที่สุด 87% ผู้ดูแลมีความพึงพอใจในการเข้ารับการรักษาครั้งนี้ทุกคน มีความรู้ความเข้าใจในการช่วยเหลือ ประชาสัมพันธ์ ผู้ป่วยรายอื่น ๆ ให้เข้ามาได้รับการรักษาได้อย่างถูกต้อง 96% มีความเข้าใจว่ามีแหล่งให้ความช่วยเหลือในเรื่องต่างๆ แก่ผู้ป่วยปากแห้งเพดานโหว่ เช่น การผ่าตัดฟรี ณ โรงพยาบาลแขวงคำม่วน 87% และเข้าใจในความจำเป็นที่ต้องนำบุตรหลานมารับการรักษาตามช่วงอายุและตามนัดทุกครั้ง 87% แต่อย่างไรก็ตามมีผู้ดูแลที่ไม่มีความรู้ในเรื่องสาเหตุของการเกิดโรคปากแห้งเพดานโหว่มากที่สุด 87% ไม่เข้าใจในเรื่องของโรคปากแห้งเพดานโหว่และภาวะการแห้งถึงขั้นหนักที่จะต้องได้รับการผ่าตัดปลูกกระดูกที่ชั้นเหงือกร่วมด้วย 75% และไม่เข้าใจในการดูแลแผล และการดูแลหลังผ่าตัดปากแห้งเพดานโหว่ และการตรวจหูและฝึกพูดร่วมด้วย 66%

สรุป: การเข้ารับการรักษาตรวจรักษาและผ่าตัดแบบประจักษ์ของผู้ป่วยปากแห้งเพดานโหว่ใน สปป. ลาว พบว่าต่ำกว่าเกณฑ์ที่กำหนดอายุเฉลี่ย 6.3 ปี เหตุผลหลักคือการขาดความรู้ในเรื่องโรคและแนวทางการรักษา ข้อจำกัดในระบบการบริการสุขภาพของภาครัฐ และการขาดแหล่งสนับสนุนในด้านคำปรึกษาพยาบาล ขาดทุนทรัพย์ที่จะเดินทางไปรักษา การผ่าตัดต้องรอโอกาสจากองค์กรภายนอกที่จะเข้ามาช่วยเหลือ ดังนั้นการที่จะสนับสนุนให้การดูแลรักษาผู้ป่วยฯ ใน สปป. ลาว เกิดความยั่งยืนได้ ควรเป็นการช่วยจัดอบรมการดูแลแบบสหวิทยาการ พร้อมทั้งการฝึกหัดให้คัลยแพทย์ในแต่ละโรงพยาบาลที่มีศักยภาพสามารถผ่าตัดรักษาเองได้ ซึ่งจะส่งเสริมให้เกิดการดูแลแบบทีมสหสาขาวิชาชีพอันจะส่งผลดีต่อผู้ป่วย และครอบครัวใน สปป. ลาว ได้ต่อไป
