Challenges and Long-Term Management of Patients with Craniofacial Clefts in Thailand

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Objective: *To report challenges and long-term management of patients with craniofacial clefts, treated at Srinagarind Hospital, Khon Kaen, Thailand.*
Material and Method: *Patients who were treated at Srinagarind Hospital, between 1993 and 2001. A review of data was performed including general information, classifications, photographs, radiographic findings, dental records, reconstructive surgeries, and long-term management.*
Results: *A total of 20 patients were recruited; six males and 14 females, grouped into six median, two paramedian and 12 oblique clefts. Age of the first treatment ranged from one to 39 years, age of the last follow-up ranged from 11 to 48 years and the range of follow-ups was 11 to 24 years. The reconstructive procedures included a variety of techniques of plastic surgery for soft tissue repairs and bone grafting for facial reconstructions. Four patients with median clefts and paramedian clefts died. One patient lost to follow-up. Fifteen patients were followed-up and the results were satisfying.*
Conclusion: *Diagnosis, evaluation, and treatment of clefts and craniofacial deformities are complex. The proper management is challenging because of socioeconomic, cause difficulties in follow-ups according to the planned protocol. Other associated anomalies are important. Protocols with well-co-ordination of an interdisciplinary team in Craniofacial Center and continuing evaluation at appropriate schedule and age group until completion of facial growth are critical factors. Establishment of a foundation and comprehensive care model with families, local health professionals and school will benefit the most to this group of patients.*

Keywords: *Craniofacial clefts, Challenges, Long-term management, Thailand*

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Craniofacial clefts are abnormal disfigurements of cranium and face with deficiencies, excesses, or normal amount of tissue occurring along a linear region[1]. The incidence is rare, estimated widely from 0.75 to 5.4[2] and mostly in developing countries. There are challenges for classification, evaluation, multidisciplinary management, surgical reconstruction, long-term management and measuring the outcomes of these birth defects. The reconstructive procedures of craniofacial clefts are extremely difficult in terms of achieving long-term goals in completion of rehabilitation, in dimension of esthetics, functional, spiritual and developmental aspects. The results have to be evaluated at the time of complete facial growth in adolescent age or when satisfied by patients and their family. Many of the literatures reported the results of solitary cases[3-5], however, there is little information of the report for clinical series and long-term management of patients.

The purpose of this study was to report the challenges and long-term management of patients with craniofacial clefts treated at Srinagarind Hospital, Khon Kaen University, Thailand. The results from this study would be useful for future management of these patients.

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Material and Method

The study included all patients with craniofacial clefts who were initially treated at Srinagarind Hospital between 1993 and 2001 based on clinical presentation and radiological reports. They were

classified according to the Tessier's classification[6] as median clefts (cleft No. 0/14), paramedian clefts (cleft No. 1/13 and 2/12) and oblique clefts (cleft No. 3/11, 4/10 and 5/9). The cleft No. 0/14 were divided into a tissue deficiency type or holoprosencephaly and a tissue excess type or frontonasal dysplasia[7,8]. The following information was reviewed including general information, cleft classification, photographs, radiographic findings, dental records, reconstructive surgeries, and long-term management.

The study protocol was approved by the Ethics Committee of Khon Kaen University, according to the Helsinki Declaration. Written informed consent was obtained from each patient.

Protocol for treatment

Photographs, dental records and, if possible, a 3D Computer Tomography (CT) scan and Magnetic Resonance Imaging (MRI) were used to classify deformities, and evaluate the soft tissue and bony deformities, as well as other associated anomalies. The primary or secondary reconstructions were performed according to urgency of the deformities and appropriate age of the patients. The interdisciplinary team, including plastic surgeons, neurosurgeons, orthodontists, speech pathologists, radiologists, socials workers, psychiatrists and nurse co-ordinators provided their opinions on treatment plans. The needs and expectations of patients and their family were used for decision making on treatment.

Results

Twenty patients were recruited: six males and 14 females. Age ranged from one to 39 years. They were grouped into six median, two paramedian and 12 oblique clefts. Table 1 shows the details of these patients.

Eighteen patients received soft tissue repairs, including a variety of plastic surgical techniques and one tissue expansion. Five patients received bone grafting for facial and orbit reconstruction. Four patients died, including two patients of median cleft with holoprosencephaly and severe associated anomalies, one patient with median cleft with frontonasal dysplasia, and one patient with paramedian cleft, because of associated intracranial anomalies and sepsis. A cause of death in one patient was not identified. One patient lost to follow-up. Even though additional surgeries were recommended in some patients, satisfactory results were achieved in all of 15 patients who were followed-up.

Patient report

Patient No. 2

A female neonate presented with cleft No. 0/14 with holoprosencephaly, a single nostril, and associated cardiac malformation (Fig. 1). She developed birth asphyxia, jaundice and died from sepsis on the 27th day after birth.

Patient No. 3

A baby boy presented with cleft No. 0/14 median facial cleft with bifid nose, duplicated columella, significant of notching of the vermillion border, microphthalmia and microcephlus. CT scan revealed bony defects at midface and orbital hypertelorism. MRI revealed microphthalmia of right eye with associated agenesis of corpus callosum of the brain (Fig. 2).

Patient No. 6

A girl presented with a median cleft, bifid nose, widening of columella, and notching of the vermillion border. The nasal and lip correction was performed with satisfactory results at the age of 18 years (Fig. 3).

Patient No. 7

One of male twins presented with cleft No. 1/13, microphthalmus and microcephalus. CT scan revealed hypoplasia of maxillary antrum, hypertelorism and low lying of frontal lobe of the brain. Lip and soft tissue reconstruction with median canthopexy and palatoplasty was performed at the age of one year (Fig. 4). His cause of death was not identified.

Patient No. 8

A patient presented with left cleft No. 3, and right cleft No. 6 with left microphthalmos. Soft tissue reconstruction with tissue expander was performed at 1 year. He was lost to follow-up and at age 17 years, he still had some deformities but was satisfied with the treatment (Fig. 5).

Patient No. 14

A baby girl presented with coloboma of upper eyelids. Eyelid reconstruction was performed with subsequent revision at the age of ten years (Fig. 6).

Patient No. 20

A boy presented at the age of seven years with paramedian nasal cleft No. 2. Nasal reconstruction was performed. He was lost to follow-up; however, satisfactory results were achieved at the age of 22 (Fig. 7).

Table 1. Demographic data of participating patients with craniofacial clefts

Patient No.	Name	Gender	Age of presentation	Province	Diagnosis	Surgical treatment	Age of the last follow-up (years)	Outcomes of the last follow-up
1	NP	M	1993	Khon Kaen	No. 0/14, median cleft with holoprosencephaly	None	-	Dead
2	A	F	1997	Khon Kaen	No. 0/14, median cleft with single nostril	None	-	Dead
3	TI	M	1999	Chaiyaphum	No. 0/14, median cleft	Nasal and lip reconstruction	-	Dead
4	KW	M	1961	Nakhon Phanom	No. 0/14, median cleft	Nasal reconstruction	48	Satisfied
5	M M	F	1993	Khon Kaen	No. 1/13, Rt. paramedian cleft	Nasal reconstruction	20	Satisfied
6	PC	F	1992	Maha Sarakham	No. 0/14, tissue excess median cleft	Nasal reconstruction	18	Satisfied
7	WS	M	1998	Nong Bua Lam Phu	No. 2/12, Lt. paramedian cleft	Soft tissue and palatal reconstruction	-	Dead
8	AN	M	1993	Chaiyaphum	No. 5/9, rt. and No. 3/11, Lt. oblique cleft with Lt. anophthalmus	Soft tissue reconstruction with tissue expansion	20	Satisfied
9	CS	F	1991	Chaiyaphum	No. 3/11, Rt. oblique cleft	Soft tissue and bony reconstruction	21	Satisfied
10	SP	F	1977	Khon Kaen	No. 3/11, Rt. oblique cleft	Soft tissue and bony reconstruction	22	Satisfied
11	DP	F	1998	Roi Et	No. 3/11 Rt. and No. 5/9 Lt. oblique cleft	Soft tissue and bony reconstruction	16	Satisfied
12	YK	F	1994	Khon Kaen	No. 3 Rt. oblique cleft	Soft tissue and bony reconstruction	19	Satisfied
13	RC	F	1981	Sakon Nakhon	No. 3/11 Lt. oblique cleft	Soft tissue and bony reconstruction	29	Satisfied
14	LW	F	1999	Nong Bua Lam Phu	No. 3/11 bilateral oblique cleft, coloboma of both eyelids	Eyelid reconstruction	11	Satisfied
15	DC	F	1995	Chaiyaphum	No. 3/11 Rt. oblique cleft, Rt. eyelid coloboma	Eyelid reconstruction	15	Satisfied
16	WI	F	1990	Nakhon Phanom	No. 3/11 Rt. and No. 5/9 Lt. oblique cleft	Soft tissue and bony reconstruction	22	Satisfied
17	PS	F	1996	Khon Kaen	No. 3/11, bilateral oblique cleft, bilateral eyelid coloboma	Eyelid reconstruction	15	Satisfied
18	JR	F	1994	Maha Sarakham	No. 3/11, bilateral oblique cleft	Soft tissue reconstruction	-	Lost to follow-up
19	CP	F	1995	Kalasin	No. 3/11, bilateral, oblique cleft, Rt. upper and lower eyelid coloboma	Eyelid closure, Soft tissue reconstruction	15	Satisfied
20	NK	M	1992	Chaiyaphum	No. 2 Lt. paramedian cleft, nasal cleft	Nasal reconstruction	22	Satisfied

Rt. = right; Lt. = left

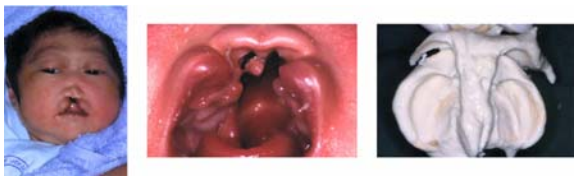

Fig. 1 Frontal, intraoral views and dental model of patient No. 2, the female neonate presented with cleft No. 0/14 with holoprosencephaly and a single nostril.

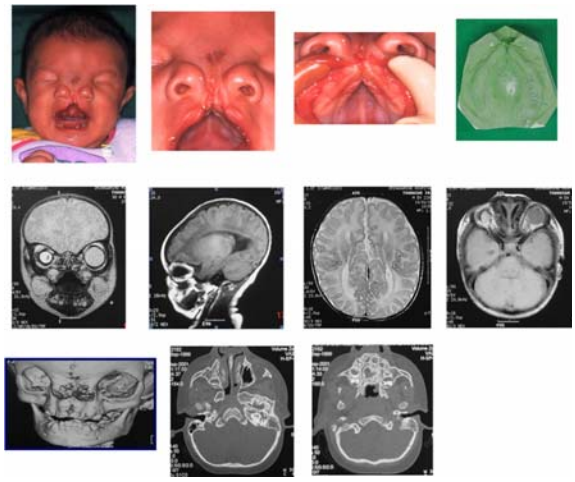

Fig. 2 Photos, dental model CT scan and MRI of the baby boy presented with cleft No. 0/14 median facial cleft with bifid nose, duplicated columella, significant of notching of the vermillion border, microphthalmia and microcephalus.

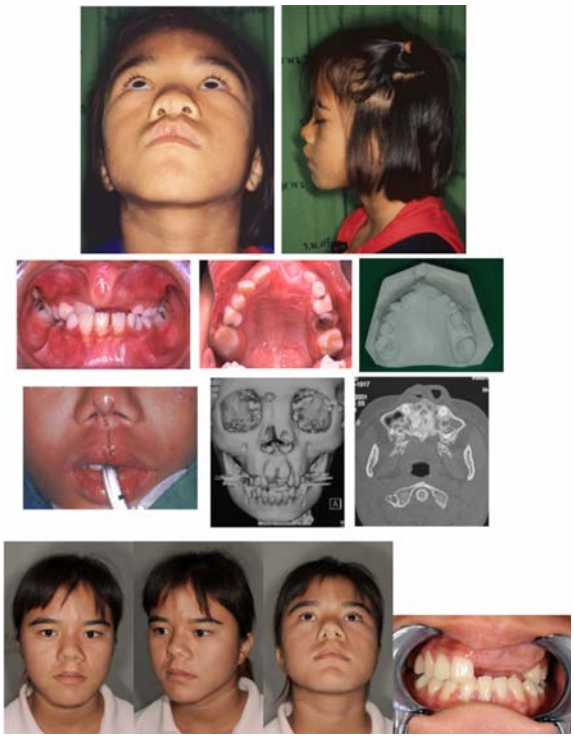

Fig. 3 Photos, dental model and CT scan of a girl presented with a median cleft

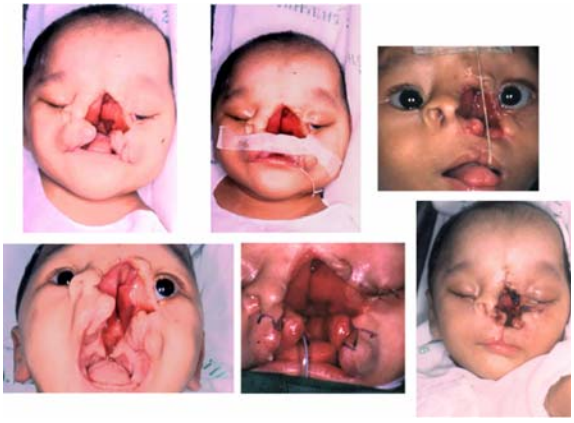

Fig. 4 Photos of the one of male twins presented with cleft No. 1/13, microphthalmus and microcephalus.

Discussion

The classifications of craniofacial clefts are based on anatomic findings by Tessier[8], embryonic basis by Van der Meulen[9] and by dividing the clefts into four categories: the oro-nasal cleft, the oral ocular clefts, the lateral facial clefts, and the orbital cranial clefts[10]. However, the Tessier's classification is currently accepted as the standard classification. The etiology has been focused on the nutrition problems and genetic factors[10].

Interdisciplinary team set up in Khon Kaen University since 1999 to provide comprehensive patient care with centralization and long-term treatment plan[11]. A protocol was adapted according to cleft deformities, age group, team consultation, holistic outcomes, and the consideration of growth and long-term effects. Plain film, CT scan and MRI are important tools for evaluation of the deformities associated anomalies, planning of the surgical reconstruction and assessment of outcomes[4,12-14]. CT scans are used to evaluate soft tissue and bony structures during primary and secondary reconstruction, details of anomalies of the midface and in patient with frontonasal dysplasia[15]. MRI scans are used to evaluate associated intracranial anomalies in median and paramedian clefts. For patient No. 3, CT scan revealed bony defects involving frontal, nasal and maxilla with fronto-ethmiodal defect and orbital hypertelorism and MRI revealed congenital

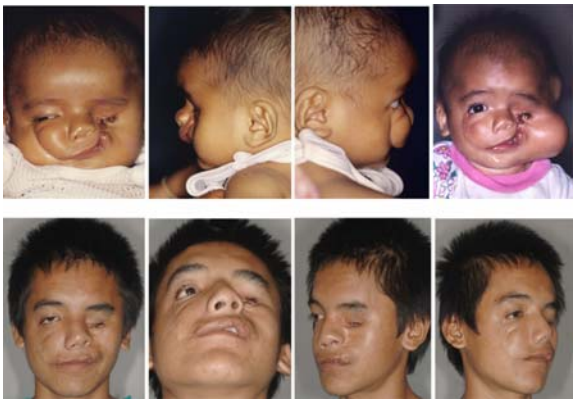

Fig. 5 Pre- and post- operative photos of a patient presented with left cleft No. 3, and right cleft No. 6 with left microphthalmos, treated with soft tissue reconstruction with tissue expander.

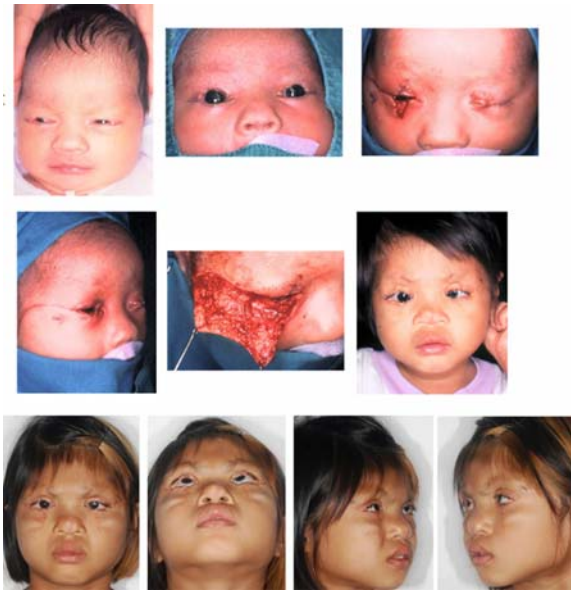

Fig. 6 A girl patient presented with coloboma of upper eyelids. Eyelid reconstruction was performed with subsequent revision at the age of ten years.

microphthalmia of right eye with agenesis of corpus callosum. For patient No. 10, CT scan revealed bony defects of right orbit and maxilla. Patients with median cleft and holoprosencephaly may require detailed imaging of face and brain. A rapid prototyping technique may be used for pre-operative prefabricate templates of oblique clefts[16].

Early orthopedic treatment of oblique clefts has been reported[17] and provided assistance with oral feeding. Individual problems in the continuing dental

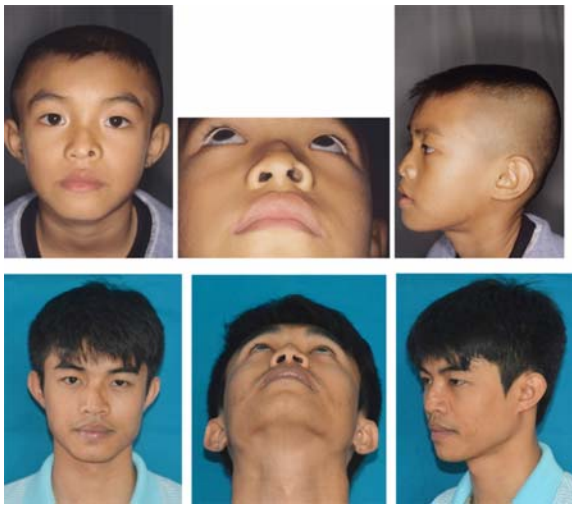

Fig. 7 Pre- and post- operative photos of a boy presented with paramedian nasal cleft No. 2.

and orthodontic management were addressed such as highly variable developing dental condition. Patients with more severe clefts may require different forms of prosthesis and oral implants[18].

Craniofacial clefts require corrections of both soft tissue and skeletal deformities. The urgency depends on the impact of functional and anatomical integrity such as maintaining the respiratory and correcting the exposure of eye globe[19]. In our study, an early reconstruction of eyelids was performed in patient No. 15, 17 and 19. Integrated concepts should be used for primary reconstruction with considering all deformities related to craniofacial clefts and associated anomalies. The principles of soft tissue reconstruction depend on characteristics of cleft and reconstruction of all essential soft tissue in restoration of functions and anatomical landmarks. Tissue expansion may be used in severe cases to provide more tissue, allow tension-free reconstruction and improve esthetic results[20] which was used in patient No. 8.

Median clefts (cleft No. 0/14), involving the midline, were classified into tissue deficiency type or holoprosencephaly, tissue excess type or frontonasal hyperplasia, and the abnormal clefting with normal tissue volume (dysraphia)[21]. These clefts are reconstructive challenges, requiring multiple operations throughout life and often have unpredictable growth[22]. They may manifest as hypotelorism to more severe forms with absent nose, brain anomalies and mental retardation. Most of the patients die within the first three months and rarely live to the end of infancy

period. It is recommended to wait until the patient is one or two years old before corrective surgical procedure is considered and/or performed[23]. They are also at high risk of developing hypopituitarism[24]. Cleft No. 0/14 was tissue excess type or frontonasal dysplasia, which may be presented with hypertelorism, bifid nose, and mental retardation[25]. In our study, the surgical correction of hypertelorism was performed in patient No. 3.

Cleft No. 1/13 and 2/14 were paramedian clefts. These anomalies are different and surgical procedures may include nasal reconstruction and the correction of orbital hypertelorism[26,27].

Cleft No. 3/11, 4/10 and 5/0 were oblique clefts. Cleft No. 3/11 may be the most common type. The challenges are short nose, deficiency of soft tissue between the alar base and lower eyelid, disrupted lower canaliculus, coloboma of medial part of lower eyelid and microphthalmus. Cleft No. 4/10 was one of the rare clefts[14]. The challenges are cleft of the upper lip, lateral to the nasal ala, and extention into lower eyelid lateral to the inferior punctum. Anophthalmus may also be reported[28].

A surgical correction for cleft No. 3/11 and No. 4/10 has been adviced[29-32], including the use of interdigitating skin flaps along the line of the facial cleft. Rotation advancement cheek flap may be used subsequently to improve esthetically favorable results[33]. Cleft No. 10 may be implicated by the presence of coloboma of the middle third of the upper eyelids and eyebrows[34]. In our study, coloboma reconstruction of bilateral cleft No. 10 was performed in patient No. 15, 17 and 19. Cleft No. 5/9 were the rarest clefts and their challenges are cleft just medial to the oral commissure and passes into the lateral half of lower eyelid[35]. The early repair with proper soft tissue and bony reconstruction is recommended[36].

Combined clefts and associated anomalies are the groups with more challenges[37,38]. The secondary reconstruction and bony surgery depend on their severity. Many studies recommend bone grafting approximately at the age of five years[31,39-42]. Calvarial bone grafts are used to fill the cleft and alveolus and for onlay grafts to maxilla, orbital rim, orbital floor, and pyriform rim[30,43]. Early bone grafting may be performed on severe clefts[14]. Lacrimal drainage surgery is performed to correct the problems of epiphora. The long-term results are challenges to be evaluated. Early soft tissue corrections may be performed for the scars in facial units. Esthetic subunit reconstruction may be performed before school age and bone grafting during mixed dentition period[44,45].

The proper management of these clefts is challenging because of socioeconomic problems. These problems cause difficulties in follow-ups according to the planned protocol. In addition to hospital-based management, the establishment of foundation and comprehensive care model with families, local health professionals and school, will benefit the most to this group of patients.

There is limited information in the literature about long-term outcomes and optimal results of craniofacial clefts. This study, however, shows strengths in reporting series of long-term management and outcomes. Some limitations in this study are due to unavailability of complete treatment data and follow-ups. The treatment of craniofacial clefts in developing countries is constrained because of economic and health care facilities factors to complete follow-ups and treatment at the optimal period of growth.

Conclusion

Diagnosis, management, and treatment of clefts and craniofacial deformities are complex and require coordinated care and comprehensive management. Holistic care, consideration of patient's and family's needs and expectations, and the collaboration with health policy and school are important. Well-coordinated protocols of an interdisciplinary team in Craniofacial Center and continuing evaluation with appropriate scheduling and age groups until commencement of speech and completion of facial growth are critical factors for successful treatment.

What is already known on this topic?

Craniofacial clefts are abnormal disfigurements of cranium and face with deficiencies, excesses, or normal amount of tissue occurring along linear region. The incidence is rare, and mostly in developing countries. The reconstructive procedures of these clefts are extremely difficult in terms of achieving long-term goals.

What this study adds?

This study presents long-term management and results of patients with craniofacial clefts Thailand. There is little information on the report for clinical series and long-term management of patients. The limitations of their management and the satisfactory results are demonstrated. The results from this study could be useful for future management of these patients.

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Potential conflicts of interest

None.

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ความท้าทายและการดูแลระยะยาวในผู้ป่วยที่มีภาวะการแหว่งของศีรษะและใบหน้าในประเทศไทย

บวรศิลป์ เชาวน์ชื่น, พลากร สุรกุลประภา, ปรารถนา เชาวน์ชื่น, Keith Godfrey

วัตถุประสงค์: *เพื่อรายงานความท้าทายและการดูแลระยะยาวในผู้ป่วยที่มีภาวะการแหว่งของศีรษะและใบหน้าที่ได้รับการรักษา ในโรงพยาบาลศรีนครินทร์ คณะแพทยศาสตร์ มหาวิทยาลัยขอนแก่น ประเทศไทย*

วัสดุและวิธีการ: *ผู้ป่วยที่มีการแหว่งของศีรษะและใบหน้าที่ได้รับการรักษาในโรงพยาบาลศรีนครินทร์ระหว่างปี พ.ศ. 2536 โดยการทบทวนข้อมูลทั่วไป การจำแนกชนิด ภาพถ่าย ภาพรังสี การบันทึกทางทันตกรรม ชนิดของการผ่าตัดเสริมสร้าง และการดูแลระยะยาว*

ผลการศึกษา: *ผู้ป่วยทั้งหมด 20 ราย เป็นชาย 6 ราย หญิง 14 ราย แบ่งเป็น การแหว่งกึ่งกลางลำตัว 6 ราย การแหว่งข้างกึ่งกลางลำตัว 2 ราย และการแหว่งแบบเฉียง 12 ราย อายุของการรักษาครั้งแรกตั้งแต่ 1-39 ปี อายุของการรักษาครั้งสุดท้าย ตั้งแต่ 11-48 ปี อายุของการติดตามการรักษาครั้งสุดท้ายตั้งแต่ 11-24 ปี วิธีการผ่าตัดเสริมสร้างได้แก่ วิธีการต่างๆ ทางศัลยกรรมตกแต่งทั้งการซ่อมแซมเนื้อเยื่ออ่อนและการปลูกถ่ายกระดูกเพื่อเสริมสร้างใบหน้า ผู้ป่วยที่มีการแหว่งกึ่งกลางลำตัวและข้างกึ่งกลางลำตัว 4 ราย เสียชีวิต ผู้ป่วย 1 รายขาดการติดตามการรักษา ผู้ป่วย 15 รายได้รับการติดตามการรักษาและมีความพึงพอใจผลการรักษา*

สรุป: *การวินิจฉัย การประเมิน และการรักษาผู้ป่วยที่มีการแหว่งของศีรษะและใบหน้ามีความซับซ้อน การดูแลที่ป่วยกลุ่มนี้มีความท้าทาย เนื่องจากภาวะเศรษฐกิจสังคม ทำให้เป็นการยากในการติดตามผู้ป่วยตามแนวทางการรักษาที่ได้วางแผนไว้ ภาวะความพิการร่วมมีความสำคัญ แนวทางการรักษา ที่มีการประสานงานกันเป็นอย่างดีของทีมสหวิทยาการในศูนย์การดูแลผู้ป่วยพิการทางศีรษะและใบหน้า รวมถึงการติดตามและประเมินผู้ป่วยตามช่วงอายุที่เหมาะสม จนผู้ป่วยเติบโตเป็นผู้ใหญ่ที่สมบูรณ์เป็นปัจจัยที่สำคัญอย่างยิ่ง การจัดตั้งมูลนิธิ การสร้างรูปแบบการดูแลที่สมบูรณ์แบบร่วมกับครอบครัวผู้ป่วย ทีมสุขภาพระดับชุมชนและโรงเรียนจะเป็นประโยชน์มากในผู้ป่วยกลุ่มนี้*