

Perception and Satisfaction of Parents of Cleft Lip Patients Following Surgical Intervention in Khartoum Teaching Dental Hospital (KTDH)

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Abstract - Background: Clefts of the lip and palate are known to be the most common craniofacial congenital disabilities in humans, with birth prevalence ranging from 1 in 500 to 1 in 2000 depending on the population. Facial disfigurement with its consequent reduction in quality of life is one of the major handicaps suffered by the affected person, apart from other problems such as difficulty with feeding, ear infection, and speech. Multispecialty care for cleft lip and palate (CLP) is focusing primarily on physical rehabilitation. This includes correcting facial disfigurement and optimizing the quality of speech. The current study aims to professionally evaluate the esthetical outcomes of the surgical repair of primary cleft lip repair, and its relation to parents' expectations and satisfaction among Sudanese patients with Cleft lip and palate at Khartoum Teaching Dental Hospital.

Methods: This is a descriptive, cross-sectional hospital-based study., participants were patients who had undergone surgical repair for orofacial clefts in KTDH (2017–2018). Outcomes of the surgical repair of cleft lip were assessed using the Asher-McDade scale according to the unilateral cleft lip surgical outcome evaluation (UCL-SOE)

Results: A total of 105 patients operated for cleft lip surgical corrections with a mean age of 6.7 years (SD). Eighty-five parents are very satisfied with their children's appearance (81%), while 13(12.4%) are satisfied and the least percent of the parents 7(6.7%) are unsatisfied. More than two-thirds of professionals are satisfied with the surgical outcomes 77(73, 3%), while 26 (24%) are unsatisfied and the least percent of the parents 2(1.9%) are very satisfactory. There is no significant relationship between parent satisfaction and their level of education (p -value =0.114).

Conclusion: Eighty-five parents are very satisfied with their children's appearance (81%), while 13(12.4%) are satisfied and the least percent of the parents 7(6.7%) are unsatisfied. There is no significant relationship between parent satisfaction and their level of education (p -value =0.114). More than two-thirds of professionals are satisfied with the surgical outcomes 77(73, 3%), while 26 (24%) are unsatisfied and the least percent of the professionals 2(1.9%) are very satisfied.

Recommendation: Oral health education programs for families regarding cleft lip (early management and their role in the

improvement of their children – functional and sc) patient for the parents about cleft lip surgery and outcome. The establishment of the craniofacial center includes (OMFS, Plastic Surgeon, ENT Surgeon, Speech & Phonetic Team, Nutrition, Anesthesia, Pediatric) to contribute to the success of cleft lip surgery and improvement of the quality of life to them. Surgeon should follow evidence-based guidelines in the treatment of cleft patients.

Keywords: Satisfaction, cleft lip, parents.

I. INTRODUCTION

Clefts of the lip and palate are known to be the most common craniofacial congenital disabilities in humans, with birth prevalence ranging from 1 in 500 to 1 in 2000 of the population. Facial disfigurement with its consequent reduction in quality of life is one of the major handicaps suffered by the affected person, apart from other problems such as difficulty with feeding, ear infection, and speech (1).

Multispecialty care for cleft lip and palate (CLP) is focusing primarily on physical rehabilitation. This includes correcting facial disfigurement and optimizing the quality of speech. These are only two of many aspects of cleft care that are addressed by a cleft team. Although psychological support may be available in high-capacity cleft centers, however, the psychological outcome of cleft care is rarely investigated and the emotional aspects of cleft rehabilitation are largely neglected. An individual's satisfaction with their own appearance (as well as their ability to communicate verbally) has an important influence on psychological wellbeing. Only a few studies have examined levels of patients' satisfaction with the clinical outcome as a measure of cleft care. All these studies had limitations, most were single-center studies, and all used small samples with no differentiation between age groups (2).

Historical reference to the cleft lip deformity dates back to the Greek physician Hippocrates who referenced the presence of this condition but not its repair in his writings.

Around 150 A.D., the Roman physician Galen used the term “lagocheilos” to describe a similar condition. Chinese physicians are credited as the first to repair the cleft lip deformity around 390 A.D where they performed their repair by simply bringing the cleft segments together towards the midline and securing them with silk ties and resin. Around a thousand years later, the Flemish physician Y Perman (1295-1350), performed the first modern cleft lip repair, or cheiloplasty, using a simple repair by incising the cleft margins, pulling the opposing raw surfaces together and securing them with sutures. Today, with the modern advances in medicine, there are many techniques to repair the unilateral cleft lip deformity. Despite the numerous eponymous techniques, all are derived from three basic “methods” for unilateral cleft lip repair: the straight-line technique, the triangular flap technique, and the rotation- advancement technique. Each has its advantages and limitations; therefore, no individual technique has gained universal acceptance. A surgeon’s decision to use a certain repair is most often dependent on his or her training and exposure to the various techniques available (3).

The earliest publications on cleft lip repair were modifications of the straight-line repair as described by Rose and Thompson. (4,5) This method is conceptually the simplest method to understand and perform. The basic concept of this repair technique involves the use of angled incisions made at the opposing cleft margins. The lateral cleft segment is then mobilized to join the medial segment creating a philtrum column where the scar lies. Limitations of this technique are the creation of a short upper lip with a notch at the vermilion-cutaneous junction which is a common complication of a poorly performed cleft lip repair. Furthermore, nasal symmetry is often hard to achieve and is often left for a secondary repair Triangular FLap methods, although once popular, are less commonly used in modern cheiloplasty. Several surgeons such as Tennison, Skoog, and Randall have popularized variations of this technique These repairs recruit tissue from the lateral cleft element by creating a “triangular flap” and inserting this flap into the medial segment. This is a unilateral Z-plasty technique al method recognizes the common problem of a short lip typical of straight-line closure methods and avoids this complication by elongating the medial segment. It elongates the medial segment by the base dimension of the Triangular flap inserted into it. Typically, the triangular flap is placed high in the philtral column just under the columellar labial junction. The downfall of this technique is it creates an unnatural scar that crosses the philtrum in a highly visible portion of the lip.(6,7,8) In 1957, Millard published his preliminary results using a novel method that he referred to as the rotation advancement method . Since that time, his technique has undergone numerous modifications but still

remains the most commonly used technique for unilateral cleft lip repair. This technique involves the rotation of the medial cleft element, increasing its length and advancement of the lateral cleft element into the back cut near the columellar-labial junction. In his words, Millard emphasized the importance of re-establishing symmetry to the lip and nose at the time of the initial lip repair. He achieved this by establishing normative measurements between certain anatomic landmarks and emphasized adherence to these measurements. However, these landmarks are often arbitrary and require considerable time and experience to master. Malposition of these landmarks will lead to an asymmetric lip and an unsatisfactory aesthetic result.(9,10,11) In 1995, Fisher published his technique for unilateral cleft lip repair. This procedure incorporates basic concepts from each of the methods previously described and adheres to the model of establishing symmetry of the lip and nose(12)

II. MATERIAL AND METHOD

2.1 Study Design:

A descriptive cross-sectional hospital-based study.

2.2 Study Area:

Khartoum Teaching Dental Hospital (KTDH) is one of the central referral hospitals for all oro-facial clefts patients from all over Sudan. The hospital also hosts the center for the annual Nojoud Camp for the Surgical Repair of Orofacial Clefts, where over 100 patients with orofacial clefts are treated every year, since 2010.

2.3 Study Population:

105 patients out of 300 patients were the sample size. Patients who had undergone surgical repair for orofacial clefts in KTDH in the period from first to mid-March 2017 at KTDH including Nijoud Camp almost 600 Patients which number patients screened about 300 patients.

2.4 Sampling and Sample Size:

Full coverage of all the patients who underwent surgical repair of orofacial clefts in the period from first to mid of March 2017 (including Nijoud Camp patients).

2.5 Inclusion Criteria:

1. The patient’s undergone surgical repair of orofacial clefts in KTDH from 2016 to 2017.
2. The age of the patient at the time of the repair is no more than 20 years old for cleft lips.
3. No further procedures were performed for the patient after the surgical repair.
4. The patient’s parent/caregiver/guardian agreed to participate by signing informed consent.

2.6 Exclusion criteria:

- any patient has a syndrome.
- any immunes compromise patients.
- any patient operated and need revision.
- any patients disagree or don't want to involve in this study

2.7 Data Collection:

Outcomes of surgical repair of cleft lip had been assessed using the asher-McDade scale (according to the (UCL-SOE).) as follows: (1)

2.7.1 Lip Scoring:

1. Excellent No postoperative asymmetry at the operative site. This was given the score of 1.

2. Mild: The resultant asymmetry in one component.

3. Unsatisfactory: The resultant asymmetry in three components.

2.7.2Nose Scoring:

1. Excellent: No postoperative asymmetry.

2. Mild: The resultant asymmetry in one component.

3. Unsatisfactory: The resultant in three components.

All participants had been examined at KTDH, Khartoum University Surgical Unit, by one examiner. Satisfaction with facial appearance and function had been carried out by an interview questionnaire for the parents, using a 3points scale as follows:

1. Very satisfied.
2. Satisfied.
3. Not satisfied.

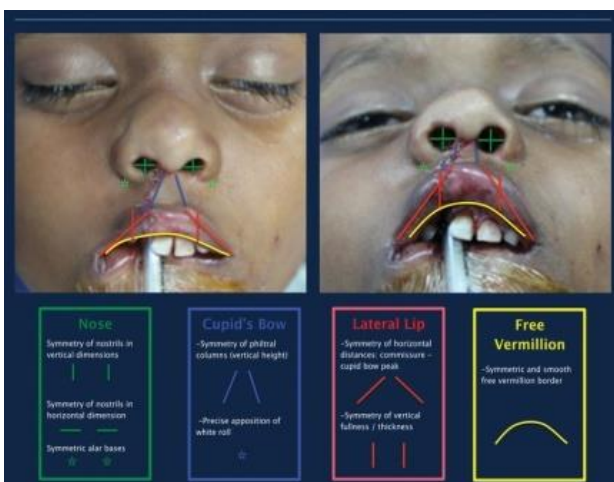


Figure (1) The UCL SOE scores symmetry of 4 individual anthropomorphic components of the cleft repair (Cupid's bow, lateral lip, nose, and free vermilion).



Figure (2) Each element is scored on a 3-point scale: 2 (excellent), 1 (mild asymmetry), 0 (unsatisfactory). The scores of the 4 individual components are then summed for a total score of 0 (lowest) to 8 (highest)

2.8 Data Analysis:

- Data had been collected for all patients who underwent primary cleft lip repair at KTDH and belong to Nojood Elkhaier cleft society.
- Verbal consent from the patient parents was obtained.
- Data had been entered into the computer master sheet and analyzed using SPSS.
- Association between parent education and level of satisfaction using chi-square test.

2.9 Data collection tools:

- ❖ Data was collected using a data collection sheet.

2.10 Ethical Considerations:

- Ethical approval was obtained from the ethical research committee of the Faculty of Dentistry and graduate college, U of K.
- The approval for the performance of the study was obtained from the Ethics Committee of KTDH.
- Consent was obtained from the University of Khartoum.
- Informed the patient /parents verbally.

III. RESULTS

3.1 Sample Profile:

The study sample included a total of 105 patients operated for cleft lip surgery, in the period of March 2016 to March 2017, with 1:1.5 male to female ratio. The study sample age ranged between two months and 6 years, with a mean age of 6.7±6.6 years.

Table (1) Distribution of Parent's Education

	Frequency	Percent
Illiterate	24	22.90%
primary school	35	33.30%
high school	31	29.50%
University	15	14.30%
Total	105	100%

Table (2) shows the family history of orofacial clefts among patients.

Family history	Frequency (%)
Yes	33(31.4%)
No	72(68.6%)
Total	105(100%)

Out of 105 patient, only 33(31.4%) have a family history of the cleft lip that showed in the table (2), 6 (18.2%) participants have a sister or brother with cleft lip, and 27(81.1%) have a second or third-degree relative with cleft lip

From table (3) it was noticed that 85(81%) of parents were very satisfied with the results of surgery, while 13(12.4%) were satisfied and the least percent of parents 7(6.7%) were unsatisfied.

Table (3): the (N%) of parents Satisfactions towards cleft lip surgery:

	Very satisfactory (N%)	Satisfactory (N%)	Unsatisfactory	Total
Appearance of the lip	82(78.1%)	14(13.3%)	9(8.6%)	105(100%)
length of Philtrum	77(73.3%)	18(17.1%)	10(9.5%)	105
continuity of Vermillion boarder	79(75.2%)	20(19%)	6(5.7%)	105
Competency of the lip	74(70.5%)	22(21%)	9(8.6%)	105
Appearance of the nose	64(61%)	26(24.8%)	15(14.3%)	105
Continuity of the nose	70(66.7%)	25(23.8%)	10(9.5%)	105
Base of the nose	73(69.5%)	18(17.1%)	14(13.3%)	105
Profile of the face	85(81%)	16(15.2%)	4(3.8%)	105
Surgery satisfaction	85(81%)	13(12.4%)	7(6.7%)	105

From table (4) showed that 77(73,3%) of professionals were satisfied with the results of surgery, while 26 (24%) were unsatisfied and the least percent of the parents 2(1.9%) were very satisfactory.

Table (4): the (N%) of professional Satisfactions towards cleft lip surgery

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Competency of the lip	74(70.5%)	22(21%)	9(8.6%)	105
Appearance of the nose	64(61%)	26(24.8%)	15(14.3%)	105
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Base of the nose	73(69.5%)	18(17.1%)	14(13.3%)	105
Profile of the face	85(81%)	16(15.2%)	4(3.8%)	105
Surgery satisfaction	85(81%)	13(12.4%)	7(6.7%)	105

From the table (5) the most satisfactory was the parents whose have a high school education 23(74.2) followed by the unsatisfied parent who had primary education 12(34.3%) and followed by very satisfied parents who had secondary education when using chi square test was not significant $p\text{-value} = 0.114$.

Table (5): Education versus overall parent's satisfaction:

	very satisfactory	Satisfactory	Unsatisfactory	Total
Illiterate	0(0.0%)	12(50%)	12(50%)	24
primary school	0(0.0%)	23(65.7%)	12(34.3%)	35
Secondary school	2(6.5%)	23(74.2%)	6(19.4%)	31
University	0(0.0%)	11(73.3%)	4(26.7%)	15
Total	2(1.9%)	69(65.7%)	34(32.4%)	105

*Chi square test performed, $P\text{ value} = 0.114$, $P\text{ value is not significant}$

IV. DISCUSSION

4.1 Discussion:

The overall assessment of the surgical outcome of cleft surgery according to -Asher-McDade scale showed: the surgical success was almost 83% by parents & 73% by professional where the global cleft lip surgery success was almost 92 % it is one of the most successful procedures with a success rate of > 90 %. (24).

This may be due to age, surgery, method, hygiene, and postsurgical care.

The age of the patient plays a vital role according to the equation state that lip before walk and palate before the talk. The younger the patient, the better the outcome socially can interact with society .in poor country they come late due to lack of awareness, lack of facility in the periphery, and limited facilities in the center.

Although there are some different schools of thought on the matter, most surgeons believe that the ideal patient age for undergoing cleft lip repair surgery is between 10 to 12 weeks old according to the rule of 10. In the current study the age group from eight weeks to 288 weeks (6 years) and in the Taiwo et al the age group was from day one to 26 years old but in Oti and Adeyato *etal* No mentioned for the age group, this might reflect the lower success rate in this study. (19)(18)(1).

The techniques of cleft lip surgery are different and depend on the type of cleft lip. Millard method is the most popular technique . the success of surgery is dependent on

technique and other factors. In the current study, Millard and its modified technique was used it and in Otietalused Millard as they mentioned but Adayato and Taiwoetal didn't mention the technique. (1)(18)(19)

The satisfaction of the surgery in the current study according to professionals view was satisfactory 73.3% followed by unsatisfactory 24.8% and very satisfactory 1.9%, this is almost similar to the finding by Otietal and according to their visual analog scale where the None indicated unsatisfied and 10 indicate highly satisfied Average scores of satisfactions of parents were 6.6, 6.8 and 7.2 for nose, lip and general facial appearance (GFA) respectively. Satisfaction scores for surgeon were 6.1 (nose), 6.0 (lip) and 6.5 (GFA), while those of the lay assessor were 5.2 (nose), 5.4 (lip) and 6.0 (GFA).(18)

Adeyatoetal study of the evaluation of the lip by both the laypeople and professionals were similar, and there was no difference (0.588) in their rating. However, there was a significant disagreement ($P=0.001$) between them in the nose assessment. (1)

The hygiene of patient plays an essential role in the success of the surgery. they should have good hygiene primarily; they should take care of the cleanliness of themselves on a regular basis. In the current study I notice, the hygiene of the patients was poor in low-educated parents but it was good in educated parents but in other studies, no mention of this element which plays a role in the success.

The present study was the first to investigate the parents' perception of the surgical outcome of primary cleft lip repair amongst Sudanese cleft lip patients.

Regarding parent's satisfaction, it was noticed that the parents were satisfied with the higher results (81%) than the surgeon (73.3). This can be seen clearly in the competency of the lip, continuity of the vermilion border& nose, base of the nose, length of the philtrum, and appearance of the lip& nose.

In Campelletal study, the laypeople satisfaction was very good (0,82) but in surgeon was good (0,71) were similar with this study.in A detail etal the evaluation of lip was similar between surgeon and laypeople but this disagreement on nose appearance .in c.li et al the satisfaction of the parent in primary cleft lip repair was good but not satisfied with teeth and nose but not concerned with surgeon satisfaction but in this study, concern on both. (13)(1)(21)

It was noticed that parents with a low level of satisfaction were those with low:

- Education
- Financial problem

- Social
- The huge improvement between pre- and post-surgical image

The level of the education of the parents was poor that why the satisfaction was low but when the level of parent's education was high the judgment of the satisfaction was high and they don't accept any deviation. In the current study, the majority of education was primarily followed by high school, illustrate and university

The financial issue was a problem for most of the patients that why the patient comes late and lack knowledge that affects the level of satisfaction. on the current study most of the parents were poor, (came late and the cost of operation was free of charge and they seeking and waiting for it from the year to year).

The social life that affects the patient him\her and could not cope with others in life makes life so hard for them. In the current study most of the patients and their parents, their lives change after surgery

The current study reveals a huge improvement in parent's satisfaction with their children's appearance pre and post-surgery.

Surgeons have a high level of satisfaction due to critique and seek a better view. The surgeons seek perfection and focus on every small detail and consume time to be perfect. Meanwhile, seeking every day for better results, better technique, and a better environment to be in best view and satisfaction ever.

4.2 Conclusion:

- Eighty-five parents were very satisfied with their children's appearance (81%), while 13(12.4%) were satisfied and the least percent of the parents 7(6.7%) were unsatisfactory.
- There was no significant relationship between parent satisfaction and their level of education (p-value =0.114).
- More than two-thirds of professionals are satisfied with the surgical outcomes 77(73, 3%), while 26 (24%) are unsatisfied and the least percent of the parents 2(1.9%) were very satisfied.

4.3 Recommendation:

- Oral health education programs for families regarding cleft lip (early management and their role in the improvement of their children – functional and sc) patient for the parents about cleft lip surgery and outcome
- The establishment of the craniofacial center includes (OMFS, Plastic Surgeon, ENT Surgeon, Speech &

Phonetic Team, Nutrition, Anesthesia, Pediatric) to contribute to the success of cleft lip surgery and improvement of the quality of life to them,

- Surgeon should follow evidence-based guidelines in the treatment of cleft patients.

4.4 Limitations

The population of this study was small (105), the result cannot be generalized to represent the entire Sudanese cleft lip population, although it can be used as an indicator

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