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## INTRODUCTION

The primary purpose of treatment in oral clefts patients is to improve their appearance and social well-being. The oral cleft patients' satisfaction with their aesthetics after treatment may be of great significance since it is considered a pivotal in psychosocial development especially in teenagers. Moreover, satisfactory facial appearance of treated oral clefts patients enhances their self confidence and self-esteem.<sup>1</sup>

Since oral cleft treatment and rehabilitation process comprises of team work by experts from different disciplines, there is evidence that functional rehabilitation and acceptable appearance for oral cleft patients can be achieved.<sup>1-2</sup> However,

## ORAL CLEFTS;

### PARENTS AND PATIENTS LEVEL OF SATISFACTION WITH THE OUTCOME OF TREATMENT IN MALAYSIA

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**ABSTRACT... Objectives:** The present study was carried out in Malaysia to explore satisfaction of non-syndrome cleft lip and plate (CLP) patients and their parents with treatment outcome. **Study Design:** Descriptive cross sectional study. **Setting:** This study was carried out in two tertiary care hospitals of Malaysia, namely University of Malaya Medical Centre (UMMC) and Hospital Kota Bharu/ Hospital Raja Perempuan Zainab II (HKB/ HRPZII) during August 2007 to March 2009. **Materials and Methods:** Total eighty three CLP patients (age > 10 years) and eighty three parents were included. The Cleft Profile Evaluation Proforma designed by Royal College of surgeons Cleft Lip and Palate Audit Group was used to assess satisfaction with oral cleft related features. It consisted of an eight item list speech, hearing, lip, nose, teeth, bite, breathing and facial profile. **Results:** The results of present study revealed that majority of the patients (89.8%) and parents (86.7%) were satisfied with the care and attention provided by the oral cleft team overall. Moreover, It was found that (90.3%) of CLP patients and (83%) parents were satisfied with the overall treatment results. After treatment, speech was very satisfactory for (57.8%) and very unsatisfactory for (8.40%) patients. The hearing after treatment, was very satisfactory for (62.7%), and very unsatisfactory for (7.2%) patients. Out of total 83 patients, appearance of nose was very satisfactory for (36.1%) patients and for (15.7%) patients it was very unsatisfactory. The speech of their child after treatment was very satisfactory for (48.2 %) parents, satisfactory for (37.3%) of the parents, unsatisfactory for (7.4%) parents and very unsatisfactory for (6.0%) parents. The hearing of their child after treatment was very satisfactory for (65.1 %) parents, satisfactory for (30.1%) of the parents, unsatisfactory for (2.4%) parents and very unsatisfactory for (2.4%) parents. It may be concluded that most of patients and parents were satisfied with the treatment provided. There was complete agreement between the patients and parents with regard to their satisfaction about facial appearance.

**Key words:** Oral Clefts, Patients, Parents, Satisfaction, Treatment Outcomes.

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certain patients may still express concerns about the appearance and functional efficiency after treatment.<sup>3,4</sup> In oral cleft patients, formation of scar tissue as well as a decreased growth of the mid face often causes maxillary retrognathism, which has negative effect on ability of mastication, speech, appearance and general wellbeing of the oral cleft patients.<sup>3,5</sup>

The oral cleft patients' self-assessment about treatment outcome and evaluation by professionals has been reported in literature.<sup>6-8</sup> The Noar et al 1991 reported that 85.7% of patients were satisfied with the treatment, although 54% of patients were unhappy with some features of their faces.<sup>9</sup> Moreover, Marcusson

et al. (2002) reported that 50% to 70% of adult oral cleft patients were satisfied with their facial appearance, yet 58% of patients desired further treatment. However, According to Ramstad et al. (1995), 35% of patients stated that they would like to have some form of additional treatment.<sup>10</sup> The oral cleft patients self-evaluation about outcome of treatment in terms of restoration of function and appearance may be biased as past experiences of oral cleft condition may influence assessment, although this is not always the case.<sup>11,12</sup>

The oral cleft patients' parents opinion has been explored for psychosocial well-being in past. However, either behavioural problems or aesthetic aspect has been evaluated by investigators only.<sup>13,14</sup> The parents' satisfaction with appearance, functional and psychologic stability of children after treatment is of vital importance. Parents' feedback on post treatment outcome is more reliable in evaluating psychosocial well-being of children. Because oral clefts children may not reveal to teachers, clinicians and researchers.<sup>15</sup>

Since oral clefts affects the most sensitive region of the face and surgical treatment may result in scars. Thus oral cleft patients' satisfaction may vary and this may influence the ability of affected individual to search and settle in a job. In addition, social acceptance and even finding a life partner may be challenge for oral cleft patients. Therefore, aim of this study to assess level of satisfaction of parents and patients after treatment with respect to function of speech, hearing, lip, nose, teeth, bite, breathing and facial profile. The patients and parents in this study with low level of satisfaction may be identified for further treatment including psychologic counselling. This will ultimately improve the quality of life of oral cleft patients and parents.

## MATERIAL AND METHODS

This was a cross sectional study. The cleft lip and palate patients who had undergone surgery for correction of unilateral or bilateral cleft lip, cleft palate, or cleft lip and palate were included. The CLP patients with incomplete record, psychological illness due to reasons other than CLP or those who were not able to understand

or communicate well due to any reason were excluded. The convenient sampling technique was employed due to the limited availability of non-syndrome CLP patients. Each consecutive CL and /or CP patient and their parents, who fulfilled the inclusion criteria and consented in written, were interviewed in utmost privacy. The Cleft Profile Evaluation Proforma designed by Royal College of surgeons Cleft Lip and Palate Audit Group was used to assess satisfaction with oral cleft related features. It consisted of an eight item list speech, hearing, lip, nose, teeth, bite, breathing and facial profile. For each item the patients and their parents were asked to rate their satisfaction.<sup>16</sup> Ethical approval of the study was obtained from the Ethical Review Committee of University Malaya. Data were analysed using Statistical Package for Social Sciences (SPSS version17). The satisfaction of CLP patients and parents with the treatment outcome is reported as frequencies and percentages. The difference between the child and their parent's satisfaction with speech, hearing and other appearances was analysed by paired t-test. The result was considered to be significant if the p-value was less than 0.05.

## RESULTS

There were total 83 oral cleft patients including 51.8% female and 48.2% male. Majority of patients 80.72% were in age range 10-18 years. Total 80.7% patients had secondary school level education (Table-I). Among parents interviewed in this study were 40 fathers and 43 mothers, Moreover, most of parents were government servant (Table-II). Results revealed 86.8% of oral clefts patients were satisfied with care and attention received over the years from the specialists. Moreover, total 90.4% oral cleft patients were satisfied about the results and outcome of the treatment. (Table-III). The level of satisfaction of patients and parents regarding speech and hearing after treatment is presented in Table-IV. In addition, satisfaction of patients and parents regarding appearance of teeth, lips, nose, breathing and bite functions summarized in Table-V.

Patient Variables	Frequency	Percentage %
<b>Age</b>		
10-18 years	67	80.72
> 18 years	16	19.28
<b>Sex</b>		
Male	43	51.8
Female	40	48.2
<b>Level of education</b>		
Primary School	16	19.3
Secondary School	67	80.7

**Table-I. The socio-demographic characteristics of oral cleft patients**

There was statistically no significant difference (p-value < 0.05) between the patients and parents' satisfaction after treatment.

Variable	Father (Frequency (%) (n= 40))	Mother (Frequency (%) (n =43))
<b>Occupation (parents)</b>		
Govt Servant	26(65.0)	19(44.2)
Labour	4(10.0)	5(11.6)
Own business	7 (17.5)	12 (27.9)
Private job	3(7.5)	7( 16.3)
<b>Level of education</b>		
Primary	3(7.5)	4 (9.3)
Secondary	15 (37.5)	28(65.1)
College/university	22 (55.0)	11 (25.6)
<b>Monthly gross household income (RM)</b>		
100 – 500	19 (22.9)	
600 – 900	12 (14.5)	
> 1000	46 (55.4)	
No response	6 (7.2)	

**Table-II. Socio-demographic characteristics of parents of oral cleft patients.**

Variable	Frequency (%)			
	Very Satisfied	Satisfied	Least satisfied	Not Satisfied
<b>Patients</b>				
Care & treatment received	34(41)	38(45.8)	5(6)	6(7.2)
Treatment Results	36(43.4)	39(47)	6(7.2)	1(1.2)
<b>Parents</b>				
Care & treatment received	30 (36)	42 (50.6)	10 (11)	1 (1.2)
Treatment Results	27 (32.5)	42 (50.6)	10 (12)	4 (4.8)

**Table-III. Satisfaction of patients and parents with care and outcome of treatment**

Variable	Frequency (%)			
	Very Satisfactory	Satisfactory	Unsatisfactory	Very Unsatisfactory
<b>Patients</b>				
Speech	48 (57.8)	24 (28.9)	4 (4.8)	7 (8.40)
Hearing	52 (62.7)	20 (24.1)	5 (6.0)	6 (7.2)
<b>Parents</b>				
Speech	40 (48.2)	31 (37.3)	7 (7.4)	5 (6)
Hearing	54 (65.1)	25(30.1)	2 (2.4)	2 (2.4)

**Table-IV. Post treatment satisfaction of speech and hearing as evaluated by patients and parents**

Variable	Frequency (%)			
	Very Satisfactory	Satisfactory	Unsatisfactory	Very Unsatisfactory
<b>Patients</b>				
Appearance of Teeth	31 (37.3)	24 (28.9)	15 (18.1)	13 (15.7)
Appearance of Lip	31 (37.3)	29 (34.9)	12 (14.5)	11 (13.3)
Appearance of Nose	30 (36.1)	29 (34.9)	11 (13.3)	13 (15.7)
Breathing via Nose	38 (45.8)	31 (37.3)	8 (9.6)	6 (7.2)
Profile of Face	37 (44.6)	35 (42.2)	5 (6.0)	6(7.2)
Bite	52 (62.7)	27 (32.5)	2 (2.4)	2 (2.4)
<b>Parents</b>				
Appearance of Teeth	24 (28.9)	30 (36.1)	9 (10.8)	20 (24.1)
Appearance of Lip	36 (43.4)	25 (30.1)	9 (10.8)	13 (15.7)
Appearance of Nose	39 (47)	18 (21.7)	16 (19.3)	10 (12)
Breathing via Nose	45 (54.2)	24 (28.9)	10(12)	4 (4.8)
Profile of Face	41 (49.4)	31 (37.3)	6 (7.2)	5 (6)
Bite	38 (45.8)	36 (43.4)	5 (6)	4 (4.8)

**Table-V. Post treatment satisfaction of patients and parents with appearance**

## DISCUSSION

In this study majority of the patients (89.8%) and parents (86.7%) were satisfied with the care and attention provided by the oral cleft team. Almost similar satisfaction level have been reported 88.0% of the parents of 15 year old oral cleft patients and 87.0% parents of 20 years old oral cleft patients were satisfied from over all treatment and cleft care.<sup>17</sup> This finding is supported by the results shown in previous study from London, UK, where this proportion was 85.7%.<sup>9</sup> These results are encouraging as far as the outcome of the operation is concerned which in turn indicates that the surgeons involved put their full efforts in treating their oral cleft patients.

The dissatisfaction level among the parents regarding overall treatment and care provided in the current study (4.3%) was supported by that from Jeffery and Boorman (4%) and Turner et al (7%).<sup>5,17</sup> The dissatisfaction usually surrounded poor communication between specialists and parents about the exact plans for surgical procedures and orthodontic treatment. Moreover, prolonged delays before operations also unfavourably influenced the rating of satisfaction given by parents.<sup>17</sup> This result of our study with regard to satisfaction about overall treatment and care is seconded by the fact that less number of parents felt any need for improvement in the services. The current study estimated that majority, 86.7%, patients and 85.5% of parents were satisfied with their speech after treatment. These results are in agreement with another study which reported that 89.3% of the oral cleft patients and 83.4% of their parents were satisfied with their speech.<sup>9</sup> The use of standardized questionnaires for patient self-evaluation is very valuable instrument for evaluation of outcomes in the cleft care.<sup>3</sup> Cleft treatment generally aims to achieve good aesthetic and functional long-term results.<sup>3,5</sup> Facial aesthetics gain increasing importance for self-perception, especially in persons between 18 and 30 years of age.<sup>18</sup> However, there were 13.20% of patients who were dissatisfied with their speech in the current study. Among the 83 patients, 86.8% patients and 95.2% of the parents were satisfied or very satisfied with the hearing, while 13.2% patients and 4.2%

parents were dissatisfied with hearing in the present study. Speech and hearing difficulties are a common occurrence in patients with oral cleft and may present a possible barrier to satisfactory communication.<sup>7</sup> The teeth appearance results of the present study showed that 66.2% patients and 65.0% parents were satisfied or very satisfied. The reasonable proportion of these participants (33.8% patients and 24.1% of parents) were dissatisfied with the appearance of their teeth which was slightly higher than 14.3% patients dissatisfaction reported.<sup>9</sup> The teeth surely contribute to the appearance of the face and dental anomalies can be a target for abuse.<sup>19</sup> The current study also revealed that 27.8% of the patients were dissatisfied with the appearance of lip, 29.0% with nose and 13.2% with profile. These values are in closer to the results from Noar 1991, who reported the dissatisfaction of patients for lip, nose and profile as 35.7%, 46.4% and 35.7% respectively.<sup>9</sup> The slight disagreement between the two studies with regard to the proportion of patients who were dissatisfied with the appearance of nose and face can be explained by the fact that the two populations were different in their socio-demographic as well as cultural characteristics.

In our study there was no significant difference in the evaluation of facial appearance by the parents and oral cleft patients with regard to their satisfaction level about their speech, hearing, teeth, lips, nose, breathing through nose, profile and bite ( $p$ -value > 0.05). Moreover, Noor and Musa also found that there was no significant difference between the patients and parents as far as the evaluation of teeth, lip, nose, and profile were concerned.<sup>7</sup> In addition, Turner et al also reported no significant difference between the patients (10years old patients) and their parents' satisfaction scores for teeth, lip, nose and profile; however he had reported significant difference for teeth and lip for 15 years old patients. One previous study is in disagreement to ours, as he had found a significant difference for lips, speech, and profile between the patients and their parents' satisfaction level.<sup>9</sup> This difference in findings between two studies could be explained in various ways. Firstly we have not analysed the

comparison based on age group of the patients. Secondly the population in Malaysia is quite different in characteristics from that of UK. Thirdly there is more coherence, coordination between the parents and their children, consequently there are stronger societal and familial values of the typical eastern culture. The results suggest that, provided the patient's expectations are realistic, treatment provided could improve quality of life of oral cleft patients. However, if the patient's desires cannot be fulfilled by surgical treatment alone, patient should be advised to consider psychological therapy.

## CONCLUSIONS

This may be concluded that oral cleft patients and parents in present study were overall satisfied with the treatment provided. There was complete agreement between the patients and parents with regard to their satisfaction about facial appearance.

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*One of the most sincere forms of respect is actually listening to what another has to say.*  
 – Bryant McGill –”

**AUTHORSHIP AND CONTRIBUTION DECLARATION**

Sr. #	Author-s Full Name	Contribution to the paper	Author=s Signature
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2	Shahid Ali Mirani	Critical review of manuscript and response to reviewers comments	
3	Safia Khatoon	Results write up	
4	M. Ilyas Shaikh	Literature review	
5	M. Amin Sahito	Data entry in SPSS	