

# INVESTIGATING PSYCHOSOCIAL IMPACT OF CLEFT LIP AND PALATE ON PATIENTS AND PARENTS

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## ABSTRACT

*The objectives of this study are to evaluate the psychosocial impact of cleft lip and palate (CLP) condition among non-syndrome patients and their parents in Malaysia. Total eighty three CLP patients (age > 10 years) and eighty three parents were selected from university of Malaya medical centre (UMMC) and Hospital Kota Bharu/ Hospital Raja Perumpuan Zainab II (HKB/ HRPZII) Kelantan Malaysia. The Questionnaires were used for determining impact of CLP condition on psychosocial status of patients and parents. It was found that due to CLP condition majority of patients were teased. In addition, the self-confidence of CLP patients was also adversely affected. Among the parents 22.9 % felt upset always, 36.1 % felt upset often while 8.4 % felt upset sometimes about their child oral cleft in the current study. Only 26.5% of the patients reported that they have problems at school due to their CLP condition. About 54.2% of patients were having very good relationship with other children, 37.3 % had reasonably good and 8.4% were having quite good relationship with other children. The prevalence of teasing was quite high among the oral cleft patients. The self-confidence was adversely affected because of the cleft condition among majority of the patients.*

**Key Words:** cleft lip and palate, psychosocial impact, parents, Malaysia.

## INTRODUCTION

One of the major global public health problems is Cleft lip and palate which is affecting one in every 500-1000 births.<sup>1</sup> It is the most common defect of face present at birth.<sup>2</sup> Oro facial clefts are the most common facial malformations in all populations and ethnic groups. Every day about 700 children with CL and/or CP are born in the whole world, which means that a baby with oral cleft is born every 2 minutes or 240,000 children per year.<sup>3</sup> The overall incidence of oral cleft is typically quoted as 1 in 700 live births in Europe.<sup>4</sup> CL with or without CP is an epidemiologically and etiologically distinct entity from isolated CP.<sup>5</sup> CL is associated with CP in 68% to 86% of cases.<sup>6</sup> The numbers of standardized tools have been used by researchers to assess psychological functioning of CLP patients with age range 8 to 21 years. The key psychological

aspects including anxiety, depression, self-esteem, and behavioural problems of CLP patients have been evaluated and reported in literature.<sup>7</sup>

The birth of a child is always a time of great family adjustment, and it is especially stressful when the child is born with a birth defect such as CLP.<sup>8,9</sup> The parents of children born with CLP condition often experience feelings of sadness, guilt, anger and fear for their child's future social acceptance. In addition, feeding infants with CLP is a big challenge and often embarrassing for parents. The loss of the ability to breast-feed is especially traumatic for some mothers.<sup>10</sup> In part, through good psychosocial support and proper instructions, most families are able to work through their own emotional turmoil and effectively master the skills needed to feed and nurture these babies.<sup>11</sup> This study was designed to determine the psychosocial impact of the CLP among non-syndrome patients and their parents.

## METHODOLOGY

This cross sectional study was conducted in two tertiary care hospitals of Malaysia, namely University of Malaya Medical Centre (UMMC) and Hospital Kota Bharu/ Hospital Raja Perumpuan Zainab II (HKB/ HRPZII) during August 2007 to March 2009. The convenient sampling technique was employed due to the limited availability of non-syndrome CLP

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patients. Total 83 CLP patients (age > 10 years) and eighty three parents 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 formal permission was obtained from the administrators of the study hospitals for assessing psychosocial issues of CLP patients via questionnaire and interview. The written consent was also obtained patients and their parents. Then, principal investigator administered the modified validated questionnaires among the CLP patients and their parents.<sup>12</sup> The duly filled questionnaire was checked for completeness and if needed, corrections were done on the spot. The statistical package for social sciences (SPSS version 12.0) was used for data analysis. The frequencies and percentages were recorded for categorical variables. The Ethic Committee University of Malaya reviewed and approved the present study.

## RESULTS

The age and gender distribution of cleft lip and palate patients is listed in Table 1. The results for various psychosocial variables are presented in Table 2. The results revealed that the prevalence of teasing among CLP patients in the past was 51.8% but after/ during treatment, it reduced to 32.5%. About 67.5% of the CLP patients were not worried about teasing. When asked about frequency of teasing only 6.0% of cases reported that teasing was very often, while in 16.9% cases it was often and in 77.1% of cases the teasing was seldom. The 53% of CLP patients reported to someone about teasing as compared to 47% patients who did not inform anyone about teasing. The self-confidence of 9.6% patients was very much affected while 15.7% of the patients replied that their self-confidence was not affected at all.

Total 51.8% of CLP patients were very well settled at school while 42.2% were reasonably well settled and 6.0% were quite well settled at school. Only 26.5% of the patients reported that they have problems at school due to their cleft condition. About 54.2% of patients were having very good relationship with other children, 37.3% had reasonably good and 8.4% were having quite good relationship with other children. Regarding getting upset when talking and thinking about the cleft condition the 36.1% of the parents often got upset, 27.7% used to get upset but not much anymore, 22.9% always got upset, 8.4% got upset sometime and only 4.8% of the parents responded that they never got upset.

## DISCUSSION

Total 51.8% of CLP patients in this study reported that they were teased due to cleft condition. This

TABLE 1: THE AGE AND GENDER DISTRIBUTION OF CLEFT LIP AND PALATE PATIENTS

Age	Frequency	Percentage
10 -18 years	67	80.72
>18 years	16	19.28
<b>Gender</b>		
Male	43	51.8
Female	40	48.2

TABLE 2: THE PREVALENCE OF PSYCHOSOCIAL PROBLEMS AMONG CLP PATIENTS

Type of psychosocial variable	Frequency	Percentage
<b>Teasing</b>		
Yes	43	51.8
No	40	48.2
<b>Worry about the teasing</b>		
Yes	27	32.5
No	56	67.5
<b>Effect on the self confidence</b>		
Very much affected	8	9.6
Quite affected	24	28.9
Little affected	38	45.8
Not affected at all	13	15.7
<b>Settlement at School</b>		
Very well	43	51.8
Quite well	35	42.2
Not getting well	5	6.0
<b>Relationship with other Children</b>		
Very good	45	54.2
Reasonably good	31	37.3
Quite good	7	8.5

finding is supported by earlier studies, who found that majority of the CLP patients suffer from teasing sooner or later.<sup>12-14</sup> The majority of CLP patients are teased due to their shape of face, nose, lip or because of their speech.<sup>10</sup> About 32.5% of patients in the current study reported that they were still being teased by other children contradictory to the finding by Noor and Musa who reported this proportion to be 66.7%.<sup>12</sup> The lower proportion in our study can probably be due to the possibility that more number of children have

already undergone major portion of their treatment and their facial appearance has improved and hence are not being teased now. The results of the current study further revealed that 32.5% patients felt worried about teasing which is very close to the proportion reported by Turner et al.<sup>14</sup> Although children were often worried by the teasing, they rarely discussed this with anyone.<sup>15</sup>

In present study 84.3% of the patients felt that their self-confidence was affected or decreased because of their cleft condition. This finding is in agreement with that of Noor and Musa.<sup>12</sup> Furthermore this finding is also supported by Turner et al.<sup>14</sup> They reported that about 78% of the 10 to 20 year old CLP patients felt that their self-confidence is very much affected and they had lower self-confidence directly due to oral cleft. Similarly Noor JH has reported decrease in self-confidence of 75% of CLP patients.<sup>13</sup> The majority (73.5%) of the children in the current study had no problem at school, however, Noor and Musa in their study found that 41.7% of children with CLP had problems in school because of cleft disability.<sup>12</sup> In current study 22.9% parents of CLP patients felt upset always, 36.1% felt upset often while 8.4% felt upset sometimes due to their child oral cleft. Other study from Malaysia reported 43% of the parents of oral cleft children felt upset often which is in agreement to present study.<sup>12</sup> The counselling of the oral cleft patients and their parents should be arranged. So that the CLP patients can tackle their psychosocial problems for instance decreased self-confidence, increased teasing, problems of adjustment at school may be resolved. Furthermore, the masses in general and children in particular should be given awareness regarding respect for the oral cleft patients.

## CONCLUSION

The prevalence of teasing was quite high among the oral cleft patients. Self-confidence was adversely affected. The majority of parents felt upset due to cleft condition of their child.

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## CONTRIBUTION BY AUTHORS

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| <b>1 Syed Yousif Ali Shah:</b>  | Principal author, concept of paper, data collection and write up |
| <b>2 Shahid Ali Mirani:</b>     | Contributed in results and discussion write up                   |
| <b>3 Muhammad Ameen Sahito:</b> | Assisted in data entry and proof reading                         |