

## Association of social and psychological aspects of quality of life and educational level of patients with different orofacial cleft

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### Abstract

**Objective:** To determine the social and psychological domains of quality of life of children with orofacial clefts in the context of different types of clefts and educational levels.

**Method:** The cross-sectional study was conducted at Clapp Hospital and Mayo Hospital, Lahore, Pakistan from September 1, 2020, to January 31, 2021, and comprised subjects of either gender aged 6-18 years having orofacial clefts. Data was collected using the CLEFT-Questionnaire along with a basic demographic sheet. Data was analysed using SPSS 23.

**Results:** Of the 80 subjects, 40(50%) each were males and females. The overall mean age was  $12.41 \pm 3.39$  years. A significant association of types of orofacial clefts with social function ( $p < 0.05$ ) and psychological function ( $p < 0.05$ ) was observed. The highest mean score of  $27.89 \pm 3.41$  and  $26.11 \pm 1.76$  was noted for unilateral left side cleft lip, and primary palate, respectively. No significant association of level of education with social function ( $p > 0.05$ ) and psychological function ( $p > 0.05$ ) was noted.

**Conclusion:** Different types of orofacial clefts affected the psychological and social aspects of quality of life of patients differently, but the difference was not significantly correlated with the education level.

**Keywords:** Cleft lip, Cleft palate, Cleft lip palate, Quality of life, Psychological, Social, Educational level.

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### Introduction

Orofacial clefts (OFCs) are frequently occurring congenital anomalies characterised by a slit/gap in the palate, lip or both. OFCs are commonly associated with syndromes, but non-syndromic clefts are not uncommon.<sup>1</sup> Environmental and multiple genetic factors are implicated with uncertainty in aetiology in a large percentage of cases.<sup>2</sup> Non-syndromic OFCs may be complete or incomplete, unilateral or bilateral, and may involve the hard (primary) palate and/or the soft (secondary) palate<sup>3</sup> presenting as cleft lip (CL), cleft palate (CP), or Cleft lip and palate (CLP).

A meta-analysis revealed a pooled prevalence rate of non-syndromic orofacial clefts (NSOFCs) ranging from 1.53% to 1.82‰ with CL alone being 0.56‰, CLP 0.82‰ and CP alone 0.27‰.<sup>4</sup> In Pakistan, 10,026 cases were diagnosed with OFCs in 2015 with a male preponderance<sup>5</sup> compared to 35,000 OFC cases in India every year.<sup>6</sup> It is expected that the prevalence of OFCs in Pakistan is also very high. Though the prevalence of OFCs does not strongly correlate with sociodemographic status, most of the burden of OFCs is carried by low and middle-income countries (LMICs) which experience 83.5% of disability-adjusted life years (DALYs).<sup>7</sup>

Children with OFC's face structural issues involving soft and hard anatomical components of the face, like nose, lips,

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teeth, alveolus, palate with facial malformations, dental occlusion issues and orthodontic issues. They also have functional issues, like problems with feeding and swallowing, hearing and speech<sup>8</sup> and the burden of care related to the management of the structural and functional issues as well as psychosocial problems.<sup>6</sup> All OFCs are oral public health issues of significant importance worldwide, affecting both the health as well as the quality of life (QoL) of the patients.<sup>9</sup>

Studying the QoL of individuals might be helpful to assess the impact of OFCs on individuals' life.<sup>10</sup> QoL is a broad definition covering medical as well as psychosocial issues. Thus, it not only covers activities of daily life, but also the perception of the health of the individual, social and psychological condition, and overall satisfaction with life.<sup>11</sup>

With a high prevalence and burden of OFC<sup>6,7</sup> in LMICs there is the need for research on psychosocial effects of OFCs on patients.<sup>12</sup> The current study was planned to determine the social as well as psychological domains of QoL of children with OFCs in the context of different types of OFCs educational levels.

### Patients and Methods

The comparative cross-sectional study was conducted at Clapp Hospital and Mayo Hospital, Lahore, Pakistan from September 1, 2020, to January 31, 2021. After approval from the ethics review committee of Riphah International University, Lahore, the sample size was calculated using open-source OpenEpi Version 3 calculator<sup>13</sup> taking a population of 1 million, prevalence of 1.91,<sup>14</sup> confidence

level 99.9% and design effect 1. The sample was raised using non-probability convenience sampling technique. Those included were patients of either gender aged 6-18 years having OFCs. Cases of Stickler, Pierre-Robin, DiGeorge, Edward, Patau and Down's syndrome were excluded.

After taking informed consent of the parents/patients, data was collected using the CLEFT-Questionnaire (CLEFT-Q) tool<sup>15</sup> along with a basic demographic sheet. CLEFT-Q is a self-reporting questionnaire for OFC cases aged 8-29 years, and consists of 6 subscales for facial appearance, 2 for facial function and 4 for QoL domain. QoL includes psychological, school and social function, and speech distress. Scoring is done on a 4-point Likert scale, ranging from 1= "never" to 4= "always. Higher scores indicate better QoL outcome as well as satisfaction.<sup>14</sup> The study used the psychological and social function subscales to evaluate and compare QoL, with each subscale having 10 questions.

Data was analyzed using SPSS 23. Descriptive statistics were used. Frequencies and percentages were calculated for categorical variables, while mean±standard deviation and median values were calculated for CLEFT-Q items. Difference between various groups was assessed using one-way analysis of variance (ANOVA) and Kruskal-Wallis Test.  $P < 0.05$  was taken as statistically significant.

**Results**

Of the 80 subjects, 40(50%) each were males and females. The overall mean age was 12.41±3.39 years. Cleft lip with complete cleft palate, primary cleft palate, and complete cleft lip with primary cleft palate were most common diagnosis 10(12.5%) each, while unilateral right cleft lip with secondary cleft palate was the least common 1(1.3%).

A significant association of types of orofacial clefts with social function ( $p < 0.05$ ) and psychological function ( $p < 0.05$ ) was observed. The highest mean score of 27.89±3.41 and 26.11±1.76 was noted for unilateral left side cleft lip, and primary palate, respectively. No significant

association of level of education with social function ( $p > 0.05$ ) and psychological function ( $p > 0.05$ ) was noted (Table-1&2).

**Table-1:** One-way ANOVA & Kruskal-Wallis test Statistics for Type of Orofacial Cleft (OFC) and education level versus mean scores of the domains of social function score (n=80).

Categorical Variables n(%)	Score Min - Max	Psychological Function			
		Kruskal-Wallis Test Median	p-value	ANOVA Statistics Mean±SD	p-value
<b>Education</b>					
No education 15(18.8)	12-27	22.00	0.866	21.27±4.99	0.072
Primary 34(42.5)	13-34	22.50		21.44±6.20	
SSC Level 22(27.5)	13-40	25.50		23.95±6.70	
HSC Level 7(8.8)	17-33	28.00		27.86±5.70	
College 2(2.5)	16-22	19.00		19.00±4.24	
<b>Type of Orofacial Cleft</b>					
Unilateral left cleft lip 4(5)	15-32	22.00	0.024	22.75±7.41	0.015
Unilateral right cleft lip 2(2.5)	23-28	25.50		25.50±3.54	
Bilateral cleft lip 8(10)	15-25	15.50		16.75±3.41	
Unilateral left lip & primary palate 9(11.3)	23-34	27.00		27.89±3.41	
Unilateral right lip & primary palate 6(7.5)	14-27	22.50		21.33±5.28	
Unilateral left lip & secondary palate 3(3.8)	17-26	20.00		21.00±4.58	
Unilateral right cleft lip & sec palate 1(1.3)	25-25	25.00		25.00±0.00	
Complete cleft lip & primary palate 10(12.5)	13-31	14.00		18.40±6.82	
Complete cleft lip & secondary Palate 2(2.5)	17-32	24.50		24.50±10.61	
Complete cleft palate 8(10)	22-33	25.50		25.75±3.37	
Primary cleft palate 10(12.5)	13-28	22.00		21.10±4.53	
Cleft lip left and complete palate 10(12.5)	13-33	26.50		24.80±6.71	
Cleft lip right and complete palate 7(8.8)	13-40	24.00		23.86±8.78	

**Table-2:** One-way ANOVA & Kruskal-Wallis test Statistics for Type of Orofacial Cleft (OFC) and education level versus mean scores of the domains of social function score (n=80).

Categorical Variables n(%)	Score Min - Max	Social Function			
		Kruskal-Wallis Test Median	p-value	ANOVA Statistics Mean±SD	p-value
<b>Education</b>					
No education 15(18.8)	16-28	21.00	0.061	20.93±4.06	0.917
Primary 34(42.5)	11-35	22.00		21.88±5.75	
SSC Level 22(27.5)	12-30	22.50		21.18±5.88	
HSC Level 7(8.8)	18-28	22.00		22.86±3.08	
College 2(2.5)	20-21	20.5		20.50±0.71	
<b>Type of Orofacial Cleft</b>					
Unilateral left cleft lip 4(5)	13-22	20.50	0.009	19.00±4.24	0.03
Unilateral right cleft lip 2(2.5)	16-22	19.00		19.00±4.24	
Bilateral cleft lip 8(10)	12-20	18.00		16.25±3.06	
Unilateral left lip & primary palate 9(11.3)	23-28	26.00		26.11±1.76	
Unilateral right lip & primary palate 6(7.5)	16-23	19.50		19.50±2.88	
Unilateral left lip & secondary palate 3(3.8)	12-24	22.00		19.33±6.43	
Unilateral right cleft lip & sec palate 1(1.3)	18-18	18.00		18.00±0.00	
Complete cleft lip & primary palate 10(12.5)	15-35	19.50		21.60±6.70	
Complete cleft lip & secondary Palate 2(2.5)	21-26	23.50		23.50±3.54	
Complete cleft palate 8(10)	21-28	24.00		23.88±2.47	
Primary cleft palate 10(12.5)	12-28	21.50		21.20±4.54	
Cleft lip left and complete palate 10(12.5)	11-33	22.00		22.20±7.42	
Cleft lip right and complete palate 7(8.8)	18-30	25.00		23.57±4.35	

ANOVA: Analysis of variance; Type of Orofacial Cleft.

## Discussion

The study revealed that OFCs affected the psychological and social aspects of QoL of patients. This is an important finding, since there is dearth of relevant literature.<sup>16</sup> One study reported that CLP was associated with psychological impact affecting a child's self-esteem and psychological function.<sup>17</sup> A systematic review focussing on resource-poor areas studied the impact of social stigma on CLP children, and revealed that among the themes identified, social impact accounted for 46% while psychological distress for 20% and this resulted in a bad impact on public image of CLP children.<sup>18</sup> In contrast, another systematic review did not find psychosocial issues to be a major concern in CLP cases, though issues like behaviour, satisfaction with one's facial looks, anxiety and depression were reported with some differences among the types of orofacial clefts,<sup>19</sup> indicating that behaviour of society impacts the psychological and social function.

The current study found that CL with complete CP, primary CP, and complete CL with primary CP were most common, while unilateral right CL with secondary CP was the least common. Also, there was a significant association of type of PFC with psychological and social functions, with highest scores noted for unilateral left-sided CL and primary palate, and the lowest scores for bilateral CL, indicating that visible deformity was a source of psychological and social impact. The findings were in line with literature.<sup>20,21</sup> Even cases with unilateral CLP have been reported to be affected as regards orofacial dysfunction as well as social wellbeing compared to normal children.<sup>22</sup> Corcoran M et al. also reported impact on oral health-related QoL in such patients.<sup>23</sup> On the other hand, da Silva F et al. reported the association between internalising behaviour and pre-incisive foramen and trans-incisive foramen types of OCFs with anxiety in 50% and depression in 27.1%.<sup>24</sup> Adam G et al. revealed a significant difference in responses of children for CLP, CP and CL with cleft alveolus (CA), and children with CLP had more psychosocial concerns related to aesthetics.<sup>25</sup> A study exploring psychological resilience in cleft children reported varying levels of psychological, social, cognitive and emotional effects with different types and subtypes of clefts. They also reported better psychosocial experience related to satisfaction with looks and incidents of teasing.<sup>26</sup>

Educational performance of OFC cases is affected in all areas of academics and across all grades.<sup>27</sup> Adam G et al. revealed that middle school children were more affected compared to elementary and high school,<sup>25</sup> with special educational requirements noted in 12% cases with CL and 47.6% with CLP.<sup>28</sup> In contrast, the current study found no significant association of the level of education with

psychological and social functions.

In terms of limitations, the data was obtained from one province only, and the general view is that the findings cannot be generalised, but since the social environment is pretty much the same, it seems that for Pakistan the results can be generalised.

## Conclusion

Different types of OFCs affected the psychological and social aspects of QoL of patients, but there was no significant difference in the psychological and social aspects of QoL of patients with different education levels.

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**Conflict of interest:** None.

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