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Self-perceived health related quality of life in adolescents with repaired cleft lip and palate

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ABSTRACT

Background: Cleft lip and palate is one of the most frequent birth defects and is associated co-morbidities such as facial abnormalities, difficulty in feeding, speech impairments and hearing difficulties. The psychological consequences of this anomaly are often not addressed effectively resulting in silent suffering for these individuals. The dissatisfaction with surgical outcome as well as the stigma and discrimination may affect the quality of life for both patients and their family. The study evaluates the self-perceived quality of life in children with repaired cleft lip/palate.

Methods: Adolescents between the age of 11-18 years who were operated for cleft lip and palate in their early years were administered the WHO QOL-BREF questionnaire and their response were analysed in 4 domains, Physical health, Psychological, Social relationship and environmental.

Results: Among the 46 children enrolled, 29 were boys and 17girls. The mean scores across each domain were as follows: Physical health-68.5, psychological-66, social relationship-88.5 and environmental-79.1. The psychological stressors frequently encountered were: teasing by their peer group, unattractive physical appearance and dissatisfaction with facial features post-surgery.

Conclusions: Among the 4 domains, the mean value of domain 3 (Social relationship) was the highest-88.5 and the mean value of domain 2 (Psychosocial) is the lowest-66. Continued psychological counselling and support during the turbulent adolescent years will help these children face the challenge of integrating with the society.

Keywords: Adolescents, Cleft lip, Quality of life, WHO QOL-BREF

INTRODUCTION

Cleft lip and palate is one of the most prevailing congenital anomalies in India that may affect the lips, nose, alveolar region and palate with a prevalence of 2 per 1000 live births. The management of the condition is a lifelong process and is multidisciplinary, dealing with issues such as facial abnormalities, difficulty in feeding, speech impairments, dental malocclusion, abnormal resonance and hearing difficulties. Since it affects the facial function and aesthetic harmony, the psychological consequences are also significant. The sequelae can cause stigma and discrimination among peers, and may affect the quality of life for both patients and their families. ²⁻⁴

Adolescence is a vulnerable period for body image development and psychosocial adjustments. For adolescents with cleft lip and palates, studies have reported the increased prevalence of anxiety, depression, inhibition, low self-esteem, reduced cognitive function and achievement in school, and parental stress.^{3,4}

Many adolescents with cleft lip and Palate may perceive their facial appearance or speech as less attractive than normal adolescents belonging to the same age group. There is a very high incidence of teasing over facial appearance among those with cleft lip and palate.^{5,6} In recent times, there are advances in the surgical technique and sequencing of procedures which has allowed for the

improved outcome of repair of cleft lip and Palate. Similar advances have been made in the awareness and attention to the psychosocial effects that Cleft Lip and Palate may have on individuals. However, the most relevant measure of the success of treatment is the individual's perception of his/her quality of life. The general assumption is that adolescents with cleft lip and palate will experience some kind of psychosocial distress as a result of their condition. However, literature reviews describing the psychological status of individuals with cleft lip and palate show varying results. While some studies show that, adolescents with cleft do not suffer from any significant psychopathology, others have shown that the self-perceived quality of life is less than in peers without clefts. Keeping this in mind we decided to evaluate the quality of life in adolescents who have undergone cleft lip/palate correction in our cleft and craniofacial centre.

METHODS

This descriptive cohort study was conducted between April 2015 and September 2015 at a tertiary care teaching hospital in South India after clearance from the institutional ethics committee using the WHOQOL-BREF questionnaire.

Instrument

The original WHOQOL Questionnaire has 100 items. These included four items for each of 24 facets of quality of life, and four items relating to the overall quality of life and general health facet. The WHOQOL-BREF contains a total of 26 questions. To provide a broad and comprehensive assessment, one item from each of the 24 facets contained in the WHOQOL-100 has been included. In addition, two items from the Overall quality of Life and General Health facet have been included. Domain scores are scaled in a positive direction (higher scores denote better quality of life), with a score range of 4-20. Domain 1- physical health domain, domain 2-psychological domain, domain 3-social relationships domain, domain 4- environmental domain.

The contact details of children presently in the age group 11 to 18, who had undergone surgical correction of cleft

lip/palate earlier was collected from the cleft and craniofacial centre. Those with syndromic clefts were excluded. The others were contacted by phone/mail and a mutually convenient date was fixed for meeting the individual in the Paediatric outpatient department. After getting written informed consent for participation in the study from the parents and assent from adolescents >14 years, a thorough medical history was elicited and a detailed physical examination done with the findings noted in pre-designed pro-forma. The Sexual maturity rating (SMR) Tanner score was assessed by team members of same gender. The WHOQOL-BREF questionnaire was then administered to the patient and the scores marked in the pro forma.

The domain scores were calculated by the summation of the score obtained from each question in the WHOQOL-BREF questionnaire. This is known as the "Raw Score". The raw score is then converted into "Transformed Score" using the table given in the WHO manual. The value obtained from the transformed score was further used to calculate the Mean and the Standard deviation. To make WHOQOL-BREF instrument culturally appropriate for Indian adolescents, one question in the social domain "Are you satisfied with your sex life?" was modified to "Are you satisfied with the respect you receive from others? Coexisting problems identified during the process of physical examination or during the questionnaire administration were dealt by concerned specialists from the cleft and craniofacial team.

RESULTS

Among the 46 adolescents who were administered the questionnaire, there were 29 (63%) boys and 17 (37%) girls. The age distribution and SMR of the participants is depicted in Table 1.

Table 1: Demographic data.

Gender	Age (year)		SMR Stage (%)					
	11-14	15-18	1	2	3	4	5	
Boys	10	19	0	1	13	11	4	
Girls	6	11	0	3	8	4	2	
Total	16	30	0	8.7	45.7	32.6	13	

Table 2: Transformed Scores in each domain.

Domain	N	Min. v alue	Max. Value	Mean	Std. Deviation
Domain 1 (physical health)	46	31	100	68.5	17.4
Domain 2 (psychological)	46	19	100	66	20.8
Domain 3 (social relationships)	46	56	100	88.5	14.2
Domain 4 (environmental)	46	38	100	79.1	16.9

Overall 80% of the patients were satisfied with their health. None of the patients required medical treatment to

function in their daily life. 91% of patients were satisfied with their sleep. About 76% of them were satisfied with

their personal relationships and with the support they received from their friends. All of them were satisfied with the support they received from their parents and family members. 41% of patients were not able to accept their bodily appearance, while 26% of were mostly able to accept their bodily appearance. About 8.6% of the patients complained that, they could not enjoy their life, but 91.4% of them were able to enjoy like their peer groups. About 19.5% of them felt that their life was less meaningful, but the remaining 80.5% of them felt that, their life was meaningful and wanted to reach greater heights. 6.5% of the patients complained that they could not concentrate on their studies, while 28% and 65.5% of them were able to concentrate moderately and extremely well respectively. Overall domain scores are depicted in Table 2. The values were low for the following facets:

- Teased by their peers (Psychological domain)
- High expectations after surgery (Psychological domain)
- Physical Appearance (Physical domain)

DISCUSSION

Normally adolescence is a period of transition and experimentation, a time of emotional turmoil. Patients with repaired cleft lip and palate may have a higher proportion of behavioural, emotional, social and environmental problems compared to the normal adolescent peer group. These problems are often undiagnosed and untreated.

Quality of life (QOL) assessments that are easily administered and which do not impose a great burden on the respondent are needed for use in large epidemiological surveys, clinical settings and clinical trials.² Most participants were able to respond to the questionnaire completely on their own. Only very rarely did some participant feel the need to interact with their parents in answering some questions.

The study was conducted at the cleft and craniofacial outpatient unit under the department of paediatrics in a tertiary care teaching hospital in south India to assess the self-perceived health related quality of life in adolescents with repaired cleft lip/palate. All of them underwent surgery in our hospital in their early ages and had multiple visits to Surgical, dental and speech department as a part of their follow-up.

In this study, the mean value of domain 1, 2, 3 and 4 were 68.5, 66, 88.5 and 79.1 respectively. Among the 4 domains, the scores in domain 3 (Social relationships) was the highest and that in domain 2 (Psychosocial) is the lowest. The low mean value of Domain 2 signifies the psychosocial problems/issues that the patients experience in their daily life. The problems frequently faced by them are teasing by their peer groups, unattractive physical appearance and dissatisfaction due to high expectations post-surgery.

According to our study, most of the adolescent patients who underwent surgical correction of Cleft Lip and Palate were satisfied with their personal relationships and with the support they got from their parents and friends. Other studies have shown that, the support provided by the parents of these patients have modified their perception of their cleft lip impairment.⁸⁻⁹

Around 28% of the patients were not able to accept their bodily appearance and were quite often depressed which could have been due to high expectations following surgery. Previous studies have shown that teasing by their peers over their facial appearance was an important predictor of psychological and behavioural problem.^{6,8-11}

Research shows that phonation problems cause difficulty in communication in these patients. 12-14 Apart from being physically less attractive, communication problems during adolescent period can cause anxiety and depression. 15,16 There were 4 participants who were experiencing hearing deficit due to tympanic membrane damage sustained in young age. Addressing the comorbidities associated with cleft lip/palate effectively will go a long way in improving the quality of life later.

Surgery and speech therapy play an important role in boosting their self-esteem, self-confidence, and satisfaction. 17,18

In our study, none of the patients were in a state of depression, 87% of them said they never had negative feelings and about 13% of them said that they had negative feelings quite often. Unrealistic, high expectations following surgical correction might have caused disappointment. All of them were very satisfied with the treatment provided in the hospital.

Limitations

The limitations of our study are the small numbers and the absence of age matched control of normal children.

This study highlights the presence of psychological stress in children with operated cleft lip/palate and the need for continued psychological support and counselling well into adolescence.

CONCLUSION

Most of the adolescent patients who underwent surgical correction of cleft lip and palate were satisfied with their personal relationships and with the support they got from their parents and friends. Counselling and explaining the realistic features of the face following surgery will improve their acceptance of physical appearance following surgery. Continued psychological counselling will help these children face the challenges of integrating with the society.

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Institutional Ethics Committee

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