

PSYCHOLOGICAL IMPLICATIONS IN PARENTS OF CLEFT LIP AND PALATE CHILDREN

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ABSTRACT

Objective: To determine quality of life of parents of children with cleft lip and palate and to compare it with parents of non cleft lip and palate children. **Method:** World Health Organisation Quality of Life (Bref, Field Trial version, 1996) for parents of children with cleft lip and palate. Total of 40 parents were questioned, 20 were parents of CLP children and the other 20 were parents of non cleft children. **Results:** The scores of quality of life for parents of the cleft children were significantly lower than the parents of non-cleft children. **Conclusion:** The parents of children with clefts had a lower Quality of Life score as compared to the parents of children with no clefts.

Keywords: Cleft lip and palate, Psychosocial, Quality of life

INTRODUCTION

Clefts of the lip and palate (CLP) are by far the most common, major congenital malformations of the face. The prevalence of cleft lip and palate is 1 in 500 to 1000 live births worldwide, with highest incidence in Afghans (4.9 per 1000 live births) and lowest in Negroid (1 in 3000).¹ In India from hospital-acquired data, the incidence is 1.97 per 1000 live births.² The psychosocial variables play a pivotal role in normal functioning of an individual. Subjects with cleft lip and palate therefore require an interdisciplinary approach for proper management and rehabilitation. Despite the interdisciplinary approach of treatment, an approach to get into the insight of psychosocial variables among subjects with cleft lip and palate is not explored adequately. It is likely that the prevalence of psychological problems might be higher than what the literature suggests, since only 20% of cleft teams worldwide had carried out psychological assessment of either the patients or their parents.¹ Although health related quality of life is becoming an important outcome

measure in research on the children with cleft lip and palate in the Western countries, there is so far no published report on this aspect in children with cleft lip and palate in India. The present study was aimed to determine the quality of life of parents of children with clefts and compare it with parents of age matched non cleft groups.

METHOD

The cross sectional study was carried out in the Unit of Orthodontics, Oral Health Sciences Center in collaboration with Department of Psychiatry and Clinical Psychology, Department of Plastic surgery and Department of Pediatrics, Post Graduate Institute of Medical Education and Research, Chandigarh, India. The sample consisted of 40 subjects in the age range of 0-3 years, out of whom 20 were in experimental group (having cleft lip and palate) and the other 20 were normal subjects that served as control group. The parents of these subjects were questioned for quality of life. Demographic variables like patient's age, sex and education of parents of cleft

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subjects; locality, family, cleft repair, orthodontic treatment, orthognathic surgery as well as socio-economic status were noted. Subjects having only isolated cleft palate, mental retardation, any syndrome and organic diseases were excluded from the study.

The psychological implications of cleft lip and palate on their parents were determined, and compared with parents of non cleft lip and palate children using WHO Quality of Life scale (Bref Field Trial Version) Quality of Life Inventory.³

It was a self-administered generic questionnaire developed in Hindi, and contained 26 items. It covered 5 domains i.e. physical health, psychological functioning, social relationships, environment and general well being. Each domain was scored on a scale of 1 to 5, and higher score indicated better quality of life and vice-versa. The mean score of each domain was calculated by dividing total domain score by the number of items.

STATISTICS

The data was entered in an Excel worksheet (Microsoft office XP Professional) to form a master sheet for the analysis. The data was statistically analyzed by SPSS (version 12.0) software. All data was subjected to descriptive statistics. Differences among the groups for demographic profiles were analyzed using chi-square test. ANOVA (analysis of variance) was used for comparison of means between groups and within groups. “t-test” and chi-square test were also used to analyze the quality of life of parents of infants who had cleft with the parent of normal infants and the level of significance established was at the 95% level.

RESULTS

The results of the demographic variables are discussed in table-1. All the demographic profiles except locality of parents of cleft lip and palate and normal subjects were comparable. The number of parents of cleft lip and palate children belonging to rural areas was significantly more than the parents of non cleft children ($p < 0.001$). The scores of quality of life of parents of the cleft children were significantly lower than the parents of non-cleft children. (Figure 1). The mean score of total QOL (Quality Of Life) in the cleft group was 16.6 and that in the non-cleft group was 18.1, and this was statistically significant. The domain

Table 1: Various Demographic variables among parents of cleft lip and palate children (CLP) and parents of non cleft lip and palate children (NONCLP)

Age (mean and SD)		CLP	NON CLP	p-value
		1.1 ±0.64	1.4 ± 0.46	
Sex	Male	10	9	0.34
	Female	10	11	
Education of parent	Graduate	10	12	0.76
	High	7	5	
	Middle	1	2	
	Primary	1	1	
	Uneducated	1	Nil	
Locality	Urban	7	16	0.000***
	Rural	13	4	
Family	Nuclear	9	12	0.26
	Joint	11	8	
Status	High	1	Nil	0.37
	Upper middle	6	8	
	Lower middle	14	12	
	Lower	Nil	Nil	

* $p < 0.05$, *** $p < 0.001$

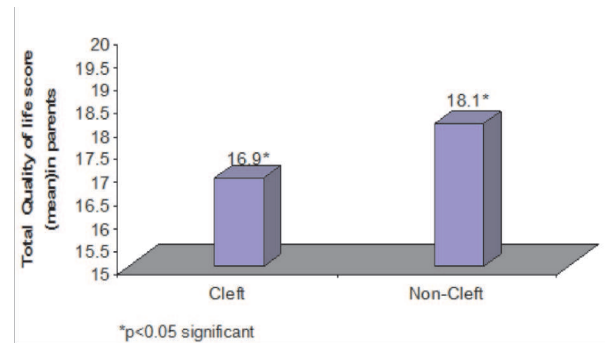


Figure 1: Total Quality of Life score (mean) in parents of cleft and non cleft children

score of general quality of life was also lower in the cleft group but did not show statistical significance. Similarly, the mean scores of environment and social functioning were significantly lower in the cleft group. The psychosocial scores in cleft group were comparable to those of the noncleft group.

DISCUSSION

The results of the present study showed that the mean total quality of life scores in parents of children who had cleft were lower than that of parents of the noncleft children. The domain score of general quality of life was also lower in the cleft group but did

not show statistical significance. Similarly, the mean scores of environment and social functioning were significantly lower in the cleft group. The psychosocial scores in cleft group were comparable to those of the noncleft group. The environment and social functioning of the parents indicated a better psychological adaptation despite the handicap of the child.⁴ It mainly affected the mean total quality of life scores. This was in accordance with the study by Goodstein⁵ who evaluated personality and adjustment of parents of cleft lip and palate children and indicated that though there is some genuine concern and apprehension on part of the parents, there is no substantial or important difference between the parents of cleft and noncleft children. Parents of CLP infants were not satisfied with the environment they were living in, including the health and transport facilities. They were less satisfied from the support of their near ones. However, they were able to carry their daily routine activities of life, which indicated that they had already become ready to take up the challenge of having a cleft child.⁶

CONCLUSION

The following conclusions were drawn from the present study:

1. The number of parents of cleft lip and palate children belonging to rural areas was significantly more than the number of parents of non cleft children.
2. Similarly, the parents of children with cleft lip and palate had a lower Quality of Life score as compared to the parents of children with no cleft lip and palate.

Longitudinal studies involving subjects with the clefts and age and gender matched controls are needed to identify the duration of psychosocial problems and to determine whether specific developmental stages were influential in the occurrence of these problems. Studies that could take into account the influence of facial growth, which is not

complete until the late teenage years, and children and adolescents with cleft lip and palate may undergo a number of surgical procedures during this time will provide more insight of psychosocial issues in the parents of these patients.^{7,8} Facial growth changes and the experience of surgery should also be examined as possible factors influencing psychosocial function. In particular, facial appearances may change as a result of growth or treatment interventions and, depending on whether these changes are pleasing or otherwise to the individual, improvements or deterioration in psychosocial functioning may result.^{9,10} The parents of cleft lip and palate children had emerging feeling of compassion and love for the child though initially they were shocked of having a cleft child. Some element of anxiety was there but overall the psychological adjustment could be reflected.

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