

Psychosocial Maternal Perception of the Outcome of Pre Surgical Infant Orthopedics in Infants Born with Cleft Lip and Palate

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Background: The setback of having a child with cleft lip and palate deeply affects the parents psychology. The Pre Surgical Infant Orthopaedics (PSIO) is a promising procedure for improvement in facial morphology prior to primary lip repair. **Objective:** The current study examines the perception of effects of PSIO procedures on the facial appearance of newborns with cleft lip/palate by their mothers and finds its correlation if any, with the change in psychosocial status of the mothers. **Study design:** The mothers of 50 infants (0-6 months) born with cleft lip/palate rated the nasal morphology, extent of cleft defect and overall facial morphology on a Likert's scale before and after PSIO procedure. This was correlated with changes in mother's depression, anxiety and stress levels by using the validated Hindi-version of Depression Anxiety and Stress scale (DASS-42) index before and after PSIO. **Results:** The mothers reported a significant improvement in all the morphological parameters for their infants with PSIO which correlated well with significant reduction in the DASS scores from 22.54 (severe) to 7.10 (normal) for depression, 20.64 (extremely severe) to 6.46 (normal) for anxiety and 24.7 (severe) to 8.4 (normal) for stress. **Conclusions:** The changes in facial morphology by PSIO procedures are well perceived by mothers and significantly improves their depression, anxiety and stress levels.

Keywords: Presurgical Infant Orthopedics (PSIO); Psychosocial status; parents; Cleft lip and palate

INTRODUCTION

The birth of a child is one of the most profound events for parents¹. However, a child born with a birth defect like cleft of lip (CL) and palate (CP/CLP) comes as a great shock for many families². In a study by Nguyen and Jagomägi, the mothers of babies born with cleft felt afraid, anxious, tired, sad, or very sad or a combination of these³. The location of the orofacial cleft can be a great cause of distress to the parents of the affected child who may feel uncomfortable in getting the child out in public⁴. In certain cases, such stigmatization of the condition result in an avoidant attitude of the families that may lead to compromise in the adequate care of the newborn and the mother post partum⁵. There has been a plethora of studies assessing the psychosocial status of the individuals with cleft lip and palate^{6,7} but a few have focused on the mental status of the parents of such children. The parent's psychosocial wellbeing has a great bearing on the upbringing of the child particularly with such special children who have to face their own psychosocial struggle. Johansson and Ringsberg evaluated parent's experiences of having a child with unilateral or bilateral CL or CLP and reported mixed feelings of the parents towards the baby such as happiness, despair and also a guilt that the baby had a malformation⁸. Nusbam et al have reported that the facial deformity comes as a setback to the parents who do not expect having a child with such congenital malformation⁹. As reported by Penn et. al while assessing familial attitudes towards birth of a child with genetic defect, the participants believed that the congenital malformation in the infant results due to something being wrong with the mother¹⁰. Hence, the occurrence of cleft also results in reduced social acceptance of not only the baby but the family as well, especially, the mother.

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In order to reduce the extent of distortions of orofacial tissues prior to the primary lip repair, the idea of pre-surgical infant orthopedics (PSIO) was introduced by the Scottish prosthodontist C. Kerr McNeil in 1950¹¹. The combination of columella lengthening through presurgical nasoalveolar molding by Grayson in 1993 further added to the advantage of correcting nasal deformities¹². The primary aim of such procedures includes the reduction in the width of the cleft defect, alignment of the distorted cleft segments prior to cheiloplasty, and facilitation of surgical repair with minimal tension¹³. The PSIO procedures may involve the use of intraoral appliances, nasal stents and lip taping procedures aimed at the reduction of the cleft defect and correction of nasal deviation, asymmetry and deficient columella.

Though various studies have been undertaken to assess the actual morphological benefits of PSIO, few have evaluated the parental observations of the change in their infant's appearance after the pre surgical orthopedics which eventually can have a great bearing on their psychosocial status. Depression, Anxiety and Stress scale (DASS-42) by Lovibond and Lovibond in 1995 is one such method of evaluation of these parameters as its psychometric properties can be successfully applied to both the healthy and psychiatric populations¹⁴.

Thus, the current study was undertaken to assess the maternal perception of the effect of PSIO procedures on their infant's facial appearance and the resultant change in the psychosocial status of mothers of infants born with cleft lip and palate as evaluated through DASS index.

MATERIALS AND METHOD

This study was conducted on the mothers of infants born with cleft lip and palate who were referred to our department for pre-surgical infant orthopedics over a period of 5 years (2014 to 2019). All the parents with cleft infants less than 2 months who agreed to get the presurgical infant orthopedics for them during the mentioned period were recruited for the study. Prior to the start of the therapy the parental perception of their infant's facial appearance was evaluated by asking the parents to rate certain facial features deemed to be deformed due to clefting like morphology of nose, the gap between cleft lip and the overall facial features on a Likert's scale. The following parameters were rated on a scale of 1 to 5 (1= Very poor, 2 = Poor, 3= Fair, 4= Good, 5= Very good) -

- Symmetry of Nose
- Nose prominence
- Nostril/ Nasal Cavity appearance
- Distance between cleft lip segments
- Overall facial appearance

Also, the depression, anxiety and stress in mothers related to their baby's congenital deformity was evaluated using Depression Anxiety and Stress Scale (DASS-42). The validated Hindi version of this index was used as the assessment tool in the current study.

Thus, the parental perception assessment sheet and DASS questionnaire were given to 55 mothers of such children who agreed to participate in the study. Any guidance for answering any of the questions of the index was given by a single treating operator performing PSIO. The PSIO therapy involved use of intra oral appliances with

nasal stent or nasal elevator only with lip taping depending on the particular indications of the case. The patients were recalled every week in the first month and thereafter 10 to 15 days as indicated for the next 2 to 3 months. The questionnaire was repeated once the pre-surgical orthopedics was deemed satisfactory and prior to referring the baby for primary surgical repair of the lip. To eliminate the bias while rating the facial parameters post treatment, the pre treatment scores were not made available. The results in the current study are derived from mothers of 50 infants who could satisfactorily complete the PSIO therapy and pre and post mean Depression, Anxiety and Stress were assessed. The pretreatment data for any drop outs was not taken into consideration.

The distribution of the mean DASS scores was evaluated using the Shapiro-Wilk test for normalcy and the data was at large non normally distributed as shown by the Q plots. Hence, the Wilcoxon signed-rank test was used to compare pre and post values. Also, the percentage of subjects falling in the severe and extremely severe categories of all the three categories of DASS index was assessed at both the time intervals.

Correlations were drawn between average changes in facial appearance/features and average scores in each of the DASS index elements. The percentage changes in each of these were evaluated.

RESULTS

The average treatment time with PSIO was 3 months. The mothers noted improvement in all of the facial appearance parameters after the PSIO therapy which was highly statistically significant for each. The results are given in Table-1. The greatest change was observed by the parents in overall facial appearance followed by nasal appearance. On the other hand, the mean depression score pre-treatment was 22.54 (severe) while post-treatment it reduced to 7.10 (normal) (Table 2a). The mean anxiety prior to the start of the therapy was found to be 20.64 (extremely severe) and reduced to 6.46 (normal) after the PSIO was accomplished. The mean stress score was 24.7 (severe) at the time of reporting and was found to decrease to 8.4 (normal) once the therapy was over. Since the data was non normally distributed, Wilcoxon signed Rank test was applied to assess the change in each of Depression, Anxiety and Stress. The reduction in all 3 parameters of the DASS index was found to be statistically significant (Table 2a).

In this study, 38% of the participants were found to be in extremely severe category of depression prior to the start of the treatment while 26% were in the severe depression category (Table 2b). However, post-therapy none of the participants fell in the extremely severe category and only 1 was seen to be in severe depression category. On the other hand, extreme anxiety was seen in 50% of participants and severe anxiety in 14% of participants on the birth of a child with a cleft. These values improved by the end of therapy with only 6% of participants reporting extremely severe anxiety and only 2% experiencing extreme anxiety. The stress values showed a similar trend with 26% participants in the extremely severe and 20% in the severe category at the time of reporting. These values also showed reduction at the end of therapy with 6% in the extreme stress category and none of the participants in the severe stress category.

Correlations were calculated between the listed perceived facial characteristic and each element of the DASS index (Table 3). The correlations are plotted in the form of Graphs (Fig.1 a-f)

Table 1: Maternal perception of change in facial appearance of infants after PSIO

	Rating By mothers						
	Pre	Post	Average change	Percentage change	Std. Deviation	t	Sig. (2-tailed)
Symmetry of Nose	1.7	4.2	2.5	148%	.76238	-23.373	.000
Nose prominence	1.6	4.3	2.7	165%	.97813	-19.374	.000
Nostril/ Nasal Cavity appearance	1.7	4.5	2.7	169%	.69985	-28.290	.000
Distance between cleft lip segments	1.6	4.3	2.7	168%	.83397	-23.062	.000
Overall facial appearance	1.5	4.3	2.8	178%	.92162	-21.022	.000

Table 2a: Mean DASS scores- Pre and post

	DASS 42					
	Pre	Post	Average change	Percentage change	Wicoxon signed rank test	Sig. (2-tailed)
Depression	22.54	7.10	-15.4	-68%	-6.047 ^b	.000
	Severe	Normal				
Anxiety	20.64	6.46	-14.2	-69%	-6.159 ^b	.000
	Extremely severe	Normal				
Stress	24.70	8.40	-16.3	-66%	-6.124 ^b	.000
	Moderate	Normal				

Table 2 b: Mean DASS Scores (Pre) in severe and extremely severe categories

	Depression	Anxiety	Stress
Extremely Severe	38 (19/50)	50 (25/50)	26 (13/50)
Severe	26 (13/50)	14 (7/50)	20 (10/50)

Table 3: Correlation of DASS elements with parental perception of changes in child's facial appearance

	Symmetry of Nose	Nose prominence	Nostril/ Nasal Cavity appearance	Distance between cleft lip segments	Overall facial appearance
Depression	-0.022	-0.069	0.077	0.051	-0.159
Anxiety	-0.052	-0.211	-0.107	-0.022	-0.292
Stress	0.087	0.034	0.182	0.277	-0.045

Figure 1: Graphical representation of changes in DASS elements with perceived changes in facial appearance.

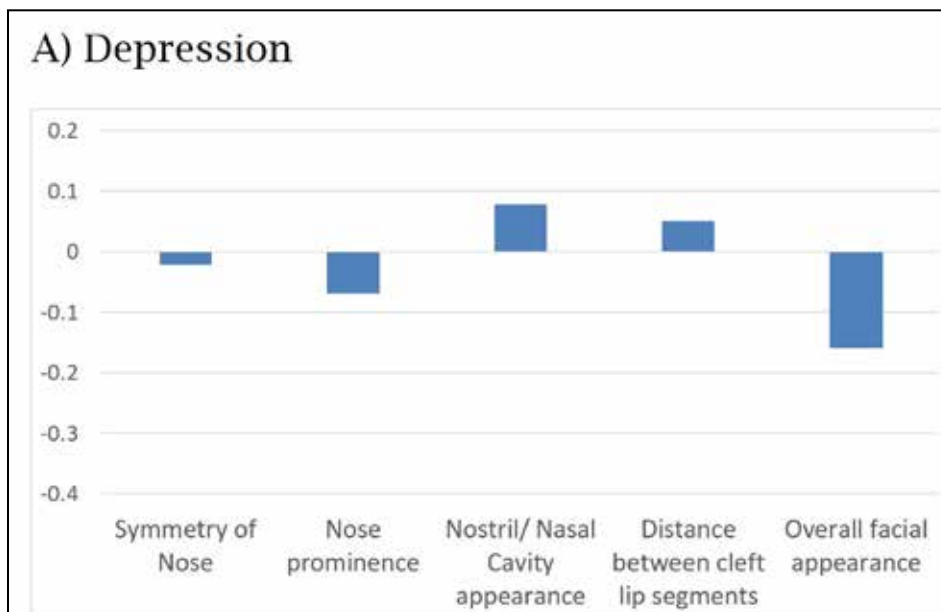


Figure 1: Graphical representation of changes in DASS elements with perceived changes in facial appearance. (continued)

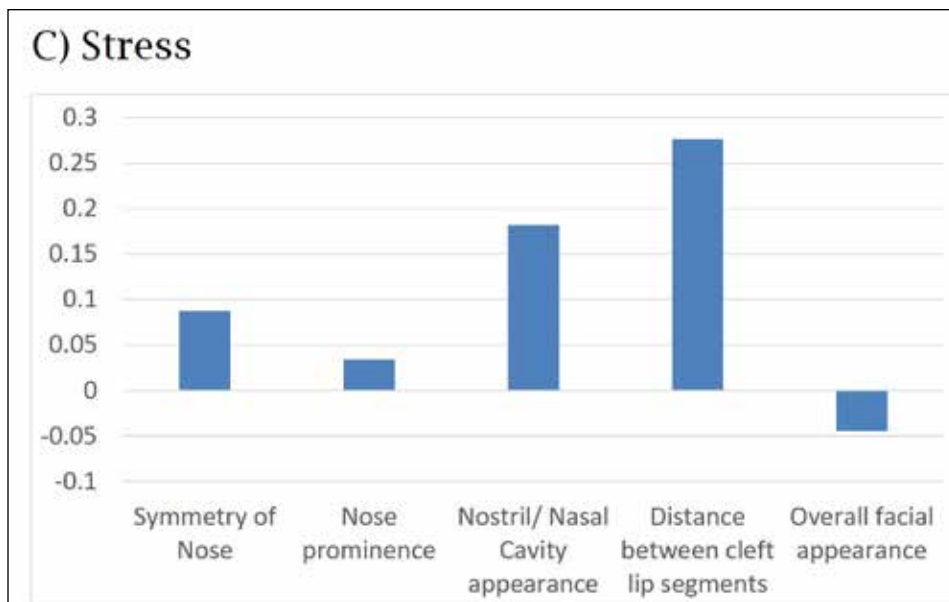
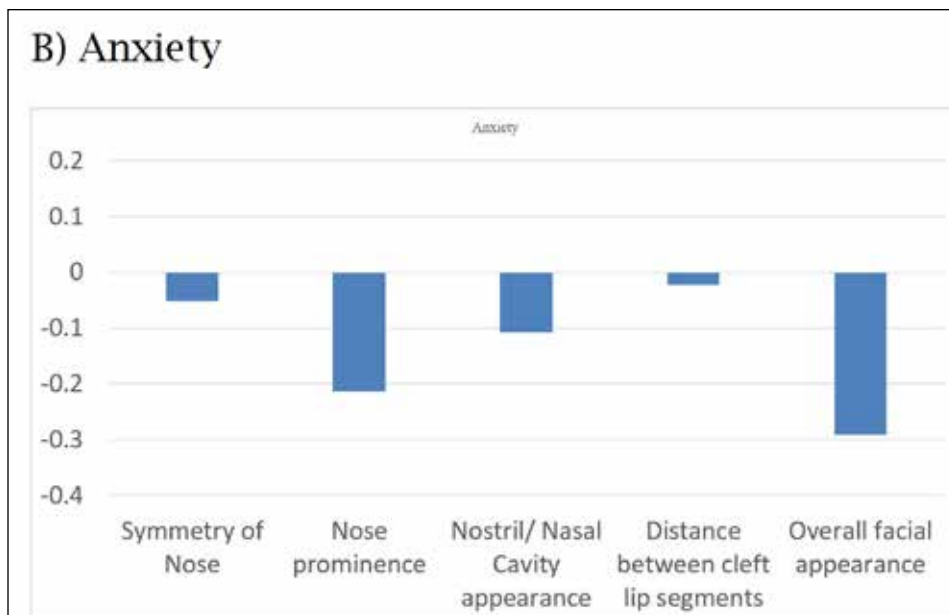


Figure 1: Graphical representation of changes in DASS elements with perceived changes in facial appearance. (continued)

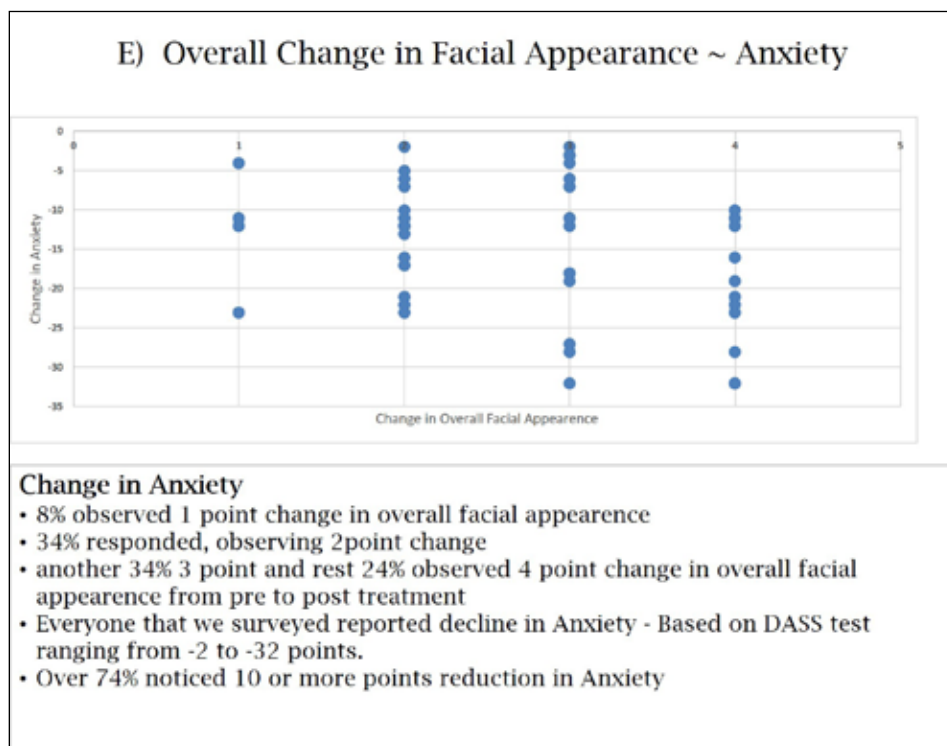
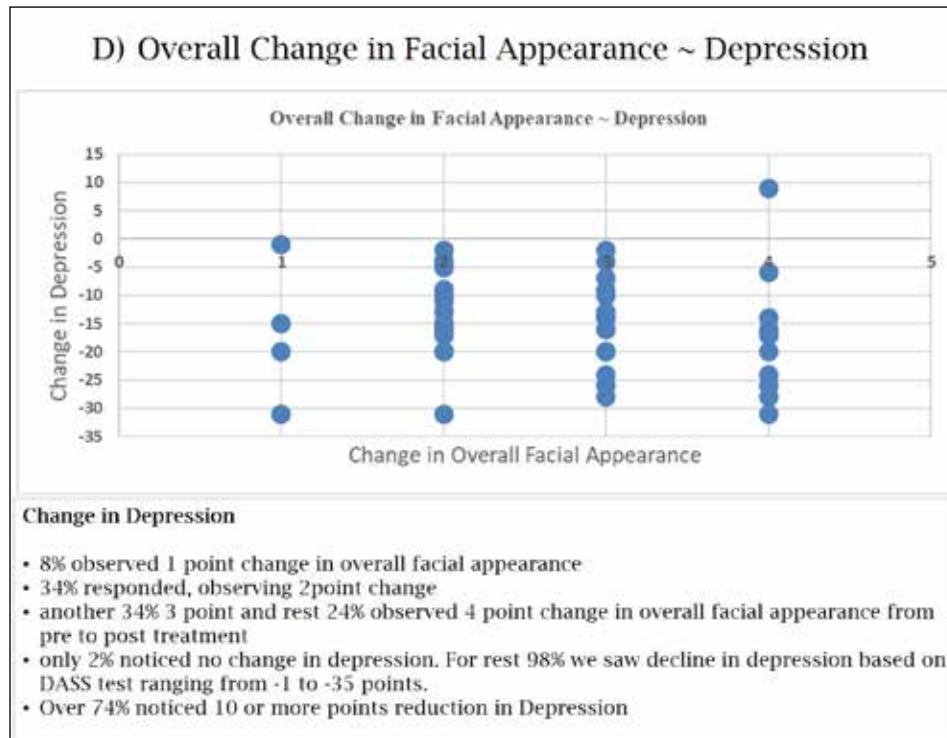
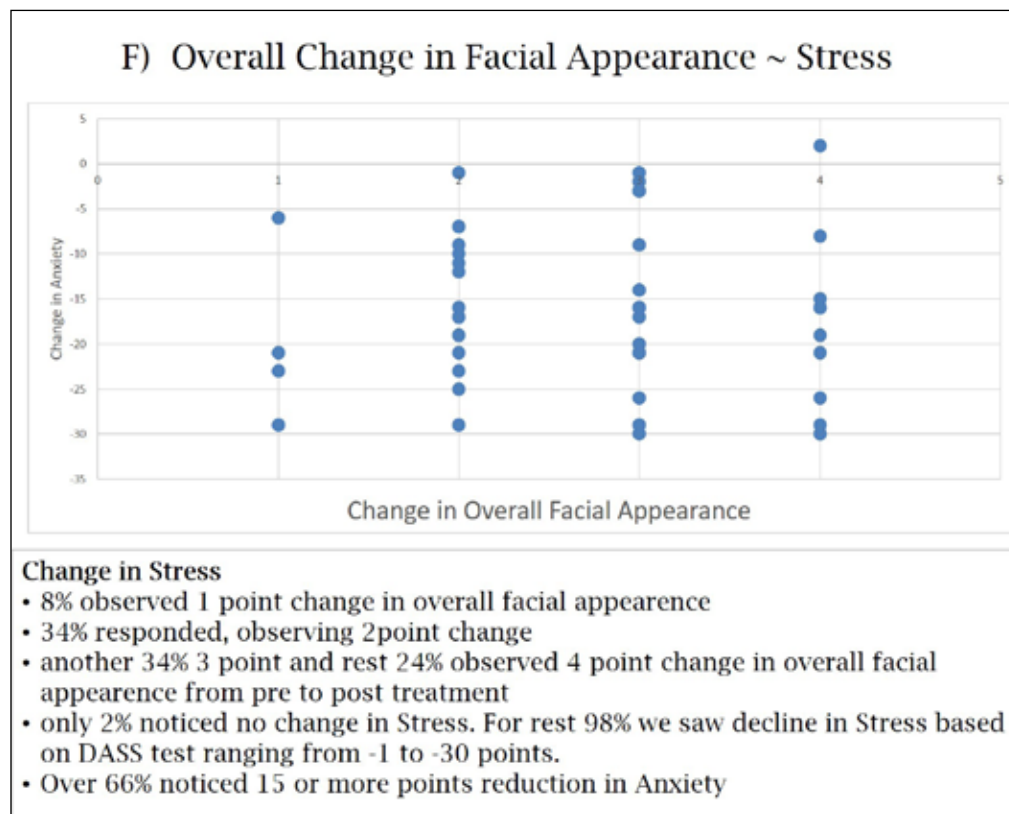


Figure 1: Graphical representation of changes in DASS elements with perceived changes in facial appearance. (continued)



DISCUSSION

Clefts of the oro-facial region may be described as minor cosmetic malformations but are perceived as severe defects by most of the parents^{15,16}. Johnson et al. have summarized the various studies reporting the terminations of pregnancies solely based on the prenatal diagnosis of an isolated facial cleft with the incidence ranging from 0 to 92%¹⁷. This fact determines the extent of psychosocial fear and stress of having a child with a facial deformity. With the latest advancements in Ultrasound examinations, no doubt the possibility of prenatal counseling of the parents prior to the birth of a child with cleft is becoming a routine. However, most of the parents with a cleft child, who report to us, belong to lower socio-economic strata and generally get the prenatal ultrasound done at the primary health care facility. These centers cater to an overwhelming patient load and usually only 2D ultrasound machines are available with limited time being devoted for each scan. The detection rate for orofacial clefts in a low-risk population using transabdominal 2D ultrasound was found to be relatively low¹⁸. Hence, the prenatal diagnosis of cleft lip and palate is made less often and the parents reporting to us are often not mentally prepared for the birth of a child with congenital deformity.

The various problems associated with such a defect like compromised physical appearance, speech difficulties, feeding problems, repeated infections, commitment to attend clinical appointments causing absence from school/work and financial burden leads to stigmatization of the problem¹⁵. A number of studies have quantified the morphological changes brought about by the pre surgical orthopedic procedures carried out prior to the primary lip repair^{19,20,21}, but

only a few have assessed the parent's perception about the outcome of this procedure. In this study, we found that the mothers could very well appreciate the morphological changes in all the 5 parameters evaluated for facial appearances. Since the most important factor for the parental apprehension in the case of a baby with a cleft is the visible facial deformity, our objective was to assess whether the changes brought about by the procedure of PSIO which is aimed at the improvement of orofacial morphology has any impact on the psychosocial status of the parents

For the quantification of the psychosocial effect of the cleft lip and palate, the validated Hindi version of the DASS score²² was used as this language is the commonly understood language in the type of population reporting to our institute. As mentioned previously, the psychometric properties of DASS-42 can be successfully applied to both healthy and psychiatric population and hence was the index of choice in our study. The concise form of DASS 42, DASS 21, has already been reported as a useful instrument for assessing depression, anxiety and stress levels in post natal women by Miller et. al²³.

The mean depression scores before the start of the therapy were found to be in the severe category. Similar findings have been reported by Murray et. al. who found the mothers of infants with CL/P were more depressed than the mothers of non-affected control infants 2 months after birth²⁴. In a study by Montiroso the depressive symptoms were evaluated by 21-item self-reported Beck Depression Inventory²⁵. Though the depressive symptoms were not found to be greater in mothers of infants with CL/P 2 months postpartum but the lack of positivity in the interaction of mothers with their cleft babies was evident and hence the authors concluded

that negative maternal feelings could not be totally recorded with this self-reported subjective measure. The extent of depression can be gauged by the fact that in our study, while 38% of the mothers reported depression in the extremely severe category, 26% were in the severe category. However, after the PSIO procedure, the depression levels reduced by 68% and the average values were in the normal category.

Johns et. al. conducted a study using the Edinburgh Postnatal Depression Scale (EPDS) on 206 mothers with an infant having cleft lip/cleft palate or both²⁶. They reported anxiety in 57.3% of such mothers besides other emotions of difficulty in coping, scared and feeling sad. In the current study, extremely severe anxiety was seen in 50% of the mothers of cleft babies which could be not only because of aesthetic and feeding concerns for their child but also due to apprehension for the future challenges that might be faced by the child. Another 14% of the mothers were found to experience severe anxiety for their infants. These challenges may encompass worry about the health care and financial burden that they might have to face as the child grows. At the end of the PSIO procedure, the level of anxiousness was found to reduce to normal levels with a reduction of 69%.

An increased parental stress during infancy and toddlerhood was reported in a study of 47 parents of children with oral clefts²⁷. The shock and distress experienced by the mother upon giving birth to an infant with a cleft may affect parent-infant interactions^{24,28}. In our study, the mothers of cleft infants were found to be in moderate category of stress with nearly one-fourth of the respondents in the extremely severe category. This, however, improved to normal levels after pre-surgical orthopedics.

The correlations drawn between the mother's perception of improvement in facial morphology and reduction in their DASS scores revealed that, for nearly one and a half times improvement in the appearance parameters, there was a reduction in depression by 68%, anxiety by 69% and stress 66%. The maximum scoring change was given to overall facial appearance which was 180% improved. Hence the parents appreciated the improved facial aesthetics brought about by PSIO procedures even prior to surgery. Thus the improvement in esthetics brought about PSIO procedure was well perceived by the parents and such changes helped in a significant reduction of depression, stress and anxiety even before the actual union of the cleft lip through primary surgical repair.

In a study by Chattopadhyay *et al* in North Indian population (similar to our study population), 50 percent of the parents reported that they avoided family gatherings due to child's condition²⁹. Thus, the psychological aspects of parenting especially in the case of children with special needs are important as the method of upbringing a child is greatly affected by the level of stress the parent experiences. The higher levels of depression and anxiety lead to increased aggression, restrictive parenting, and a more negative approach

in solving matters related to children³⁰. Thus, an effort was made through this study to gauge the impact of having a newborn with a cleft deformity on the parents, particularly the mother. The role of the mother in the care of a newborn is indispensable and even today in many of the societies the mother has to bear the brunt of the society for any kind of deformity in the newborn. Also, nearly all the infants undergoing the therapy were accompanied by mothers at each visit unlike the fathers who may not necessarily report for each appointment. Hence in our study we sought mother's response to understand the psychosocial aspect of the cleft deformity and the PSIO procedures. In the study by Johns et. al reporting post partum depression in mothers of infants with cleft lip and palate, the total EPDS (Edinburgh Postnatal Depression Scale) scores describing the anxiety, and incidence of feeling scared was higher in the mothers of infants with cleft lip or cleft lip and palate who did not receive a prenatal diagnosis²³.

The post PSIO procedure values showed that the average depression, anxiety and stress levels in parents of babies with cleft reduced to normal after 3 months of therapy. Undoubtedly with the passage of time, the initial shock of having a baby with facial deformity gets diluted but restoration to normal levels definitely indicates some reassurance owing to the intervention carried out to reduce the extent of disfigurement. To assess such a correlation mothers opinion about the change in child's facial appearance was recorded prior to and at the end of PNAM therapy.

The limitations of our study include the absence of a control group wherein no PSIO intervention was given to assess the effect of increased acceptance of the deformity by the mother over a period of time which could not be assessed by us. The other socioeconomic factors, familial support, literacy levels etc can have a great effect on the responses of the participants at various stages of the study. Additionally, we did not attempt to assess postnatal stress for mothers unrelated to cleft care as there have been studies that found nearly 30% of mothers experience at least one of the emotions of depression, anxiety or stress, in the *mild, moderate, severe* or *extremely severe* categories during 6 weeks to 6 months postpartum^{23,26}.

CONCLUSION

The birth of the child with cleft leads to Depression, anxiety and stress of severe and extremely severe grades in the parents particularly the mother as revealed in this study. The procedure of Pre Surgical Orthopaedics is initiated within the first week of the birth of a child with cleft lip and palate deformity which is a crucial time for such families. The PSIO procedure brings about marked improvement in facial morphology which is well perceived by the mothers and undoubtedly uplifts their morale to work for the betterment of their child. This is reflected in the significant improvements in the depression, anxiety and stress levels which reduce to normal levels post-treatment.

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