

## EFFECTS OF SENSORY DISTURBANCES IN CLEFT LIP AND PALATE PATIENTS

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## ABSTRACT

*This study aimed at assessing the effects of sensory disturbances in patients diagnosed with cleft lip and palate (CLP) in Lahore. The age range of the study sample was 15 years and below. The survey was conducted at a private hospital of Lahore in 2014.*

*A cross-sectional survey was carried out. All children aged 15 years and below who were diagnosed with Cleft Lip and Palate (CLP), were included in the sample. All other age groups and patients, who came to the hospital with people other than their parents, were excluded. The data for this study were collected by carrying out an interview with the parents of the patients using a pre-tested questionnaire. The questionnaire included questions pertaining to the daily activities of the children and depression. Satisfaction of parents and family towards their child's appearance was also assessed as well as other peoples' satisfaction towards the appearance was seen. Actual depression was not measured, however, the depression like symptoms were noted and were considered to be the former for this study.*

*Data analysis was done using the IBM SPSS version 20. The results showed the CLP patients having the highest frequency (44.4%) of the condition in children less than 5 years followed by 5-10 year old (38.5%) and 10-15 year old children (17.1%). Restriction of school activities was seen to be highest among 5-10yr olds ( $p=0.000$ ).*

*Chi-square analysis revealed a statistically significant association between discomfort in eating, sensory disturbances and depression like symptoms ( $p=0.026$ ). Family satisfaction towards the child's appearance was related to depression and sensory disturbances and this was also significant ( $p=0.069$ ). Parent's satisfaction ( $p=0.025$ ) and other peoples' satisfaction ( $p=0.01$ ) towards the child was also significant and also led to depression. A highly significant relationship was found between pain and sensory disturbances ( $p=0.001$ ); restriction of school activities and patient age ( $p=0.000$ ); and sensory disturbances, depression and difficulty in sleep ( $p=0.000$ ).*

*CLP can lead to poor psychosocial functioning in children mainly causing depression, behaviour problems, low self-esteem and anxiety timely treatment options and psychosocial support is mandatory for such children to improve their lives.*

**Key Words:** Sensory, Cleft, Satisfaction.

## INTRODUCTION

The term cleft lip and palate inadequately describes the potential complexities of the deformity which may involve nose, lips, alveolus or palate. As a consequence

breathing, appearance, dentition, dental occlusion facial growth, speech and hearing are all affected leading to psychosocial implications.<sup>1</sup>

The cleft of lip and alveolus, hard and soft palate are the most common congenital abnormalities of the craniofacial structure. Worldwide incidence of the cleft lip and palate is one in 600 (1:600).<sup>2</sup> The overall worldwide prevalence of the cleft lip with or without the cleft palate was 9.92 per 10,000. The prevalence of the cleft lip was 3.28 per 10,000, and that of the cleft lip and palate was 6.64 per 10,000,<sup>3</sup> birth prevalence of clefts is somewhere between 27,000 and 33,000 clefts

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**Received for Publication:** November 7, 2014

**Accepted:** November 22, 2014

per year.<sup>2</sup> Lowest incidence occurs in Native American tribes of Montana, USA, which is 1:2076.<sup>4</sup>

TABLE 1: DISTRIBUTION OF PARENTS' GENDER (n=286)

| Gender | Frequency | Percent |
|--------|-----------|---------|
| Male   | 127       | 44.4    |
| Female | 159       | 55.6    |
| Total  | 286       | 100.0   |

TABLE 2: DISTRIBUTION OF AGE OF CLP PATIENTS (n=286)

| Patient age | Frequency | Percent |
|-------------|-----------|---------|
| <5 years    | 127       | 44.4    |
| 5-10 years  | 110       | 38.5    |
| 10-15 years | 49        | 17.1    |
| Total       | 286       | 100.0   |

TABLE 3 : RESTRICTION OF SCHOOL ACTIVITIES IN VARIOUS AGE GROUPS OF CLT PATIENTS (n=286)

| Retriction of School Activities | Patient age |            |             | Total | Chi-Square |
|---------------------------------|-------------|------------|-------------|-------|------------|
|                                 | <5 years    | 5-10 years | 10-15 years |       |            |
| Yes                             | 28          | 109        | 48          | 185   | 0.000      |
| No                              | 99          | 1          | 1           | 101   |            |
| Total                           | 127         | 110        | 49          | 286   |            |

TABLE 4 : PAIN AND SENSORY DISTURBANCES CROSS-TABULATION (n=286)

| Pain              | Sensory disturbances |          | Total | Chi-Square |
|-------------------|----------------------|----------|-------|------------|
|                   | Mild                 | Moderate |       |            |
| Mild              | 175                  | 63       | 238   |            |
| Moderate          | 21                   | 15       | 36    |            |
| Moderately severe | 3                    | 9        | 12    |            |
| Total             | 199                  | 87       | 286   |            |

TABLE 5: SENSORY DISTURBANCES, DIFFICULTY IN EATING AND DEPRESSION (n=286)

| Depression | Sensory disturbances | Difficulty in Eating |    | Total | Chi-Square |
|------------|----------------------|----------------------|----|-------|------------|
|            |                      | Yes                  | No |       |            |
| Yes        | Mild                 | 126                  | 25 | 151   | 0.020      |
|            | Moderate             | 57                   | 24 | 81    |            |
|            | Total                | 183                  | 49 | 232   |            |
| No         | Mild                 | 30                   | 18 | 48    |            |
|            | Moderate             | 6                    | 0  | 6     |            |
|            | Total                | 36                   | 18 | 54    |            |
| Total      | Mild                 | 156                  | 43 | 199   |            |
|            | Moderate             | 63                   | 24 | 87    |            |
|            | Total                | 219                  | 67 | 286   |            |

It may not be the end of life but for children with cleft problem, the problem goes beyond the obvious disfigurement of face and extends to repeated infections, social stigma, and mental impairment that affect the speech, hearing, and teeth formation. These children are teased about their cleft-related features such as speech, teeth, and lip appearance and lose self-confidence.<sup>5</sup>

Research has shown that attractive children are seen by others as brighter, as having more positive social behaviour and receive more positive treatment than their less attractive cleft counterparts. These children suffer with emotional "burn out" in adolescence.<sup>6</sup>

## METHODOLOGY

The aim of the present study was to observe the quality of life in children diagnosed with cleft lip and cleft palate. The cross-sectional survey was held in the Arif Memorial Hospital of Lahore during the months of June and July 2014. Either parent each of all children

TABLE 6: SENSORY DISTURBANCES, DIFFICULTY IN SLEEP AND DEPRESSION (n=286)

| Depression | Sensory disturbances | Difficulty in Sleep |     | Total | Chi-Square |
|------------|----------------------|---------------------|-----|-------|------------|
|            |                      | Yes                 | No  |       |            |
| Yes        | Mild                 | 9                   | 142 | 151   | 0.020      |
|            | Moderate             | 27                  | 54  | 81    |            |
|            | Total                | 36                  | 196 | 232   |            |
| No         | Mild                 | 20                  | 28  | 48    |            |
|            | Moderate             | 0                   | 6   | 6     |            |
|            | Total                | 20                  | 34  | 54    |            |
| Total      | Mild                 | 29                  | 170 | 199   |            |
|            | Moderate             | 27                  | 60  | 87    |            |
|            | Total                | 56                  | 230 | 286   |            |

TABLE 7: SENSORY DISTURBANCES, PARENT'S SATISFACTION WITH THEIR CHILD'S APPEARANCE AND RELATED DEPRESSION (n=286)

| Depression | Sensory disturbances | Parent's Satisfaction with child appearance |     | Total | Chi-Square |
|------------|----------------------|---------------------------------------------|-----|-------|------------|
|            |                      | Yes                                         | No  |       |            |
| Yes        | Mild                 | 9                                           | 142 | 151   | 0.025      |
|            | Moderate             | 27                                          | 54  | 81    |            |
|            | Total                | 36                                          | 196 | 232   |            |
| No         | Mild                 | 20                                          | 28  | 48    |            |
|            | Moderate             | 0                                           | 6   | 6     |            |
|            | Total                | 20                                          | 34  | 54    |            |
| Total      | Mild                 | 29                                          | 170 | 199   |            |
|            | Moderate             | 27                                          | 60  | 87    |            |
|            | Total                | 56                                          | 230 | 286   |            |

TABLE 8: SENSORY DISTURBANCES, FAMILY'S SATISFACTION WITH CHILD'S APPEARANCE AND DEPRESSION (n=286)

| Depression | Sensory disturbances | Family satisfaction |     | Total | Chi-Square |
|------------|----------------------|---------------------|-----|-------|------------|
|            |                      | Yes                 | No  |       |            |
| Yes        | Mild                 | 6                   | 145 | 151   | 0.069      |
|            | Moderate             | 0                   | 81  | 81    |            |
|            | Total                | 6                   | 226 | 232   |            |
| No         | Mild                 | 6                   | 42  | 48    |            |
|            | Moderate             | 6                   | 0   | 6     |            |
|            | Total                | 12                  | 42  | 54    |            |
| Total      | Mild                 | 12                  | 187 | 199   |            |
|            | Moderate             | 6                   | 81  | 87    |            |
|            | Total                | 18                  | 268 | 286   |            |

TABLE 9: SENSORY DISTURBANCES, PEOPLE'S REACTION TO CHILD'S APPEARANCE AND DEPRESSION (n=286)

| Depression | Sensory disturbances | People's reaction to child |            |               | Total | Chi-square |
|------------|----------------------|----------------------------|------------|---------------|-------|------------|
|            |                      | Positively                 | Negatively | Indifferently |       |            |
| Yes        | Mild                 | 32                         | 104        | 15            | 151   | 0.01       |
|            | Moderate             | 9                          | 72         | 0             | 81    |            |
| No         | Total                | 41                         | 176        | 15            | 232   |            |
|            | Mild                 | 5                          | 40         | 3             | 48    |            |
|            | Moderate             | 0                          | 6          | 0             | 6     |            |
|            | Total                | 5                          | 46         | 3             | 54    |            |
| Total      | Mild                 | 37                         | 144        | 18            | 199   |            |
|            | Moderate             | 9                          | 78         | 0             | 87    |            |
|            | Total                | 46                         | 222        | 18            | 286   |            |

diagnosed with Cleft Lip and palate during this time frame was included in the sample.

Patients arriving with guardians or other relatives were excluded from the sample. The data for this study were collected by interviewing the patients' parent; either mother or father, using a pre-tested questionnaire. The questionnaire included questions about their children's quality of life, questions related to family acceptance of their children, social life, depression and anxiousness and the type of cleft their children were having.

Data entry and analysis was done using the IBM SPSS version 20. Chi-square analysis and test of significance were performed.

## RESULTS

The final sample size was 286. Data entry and analysis were done using the IBM SPSS version 20. The results showed the effects of Sensory disturbances in Cleft Lip and Palate (CLP) diagnosed children. Among the parents who filled out the questionnaire, 55.6% were mothers and 44.4% were fathers (Table 1). The total number of CLP children were 286 out of whom the highest frequency (44.4%) was of children less than 5 years followed by 5-10 year old (38.5%) and 10-15 year old children (17.1%). (Table 2)

The maximum restriction of school activities occurred in the age group of 5-10 years of children and this was statistically significant ( $p=0.000$ ) (Table 3). It was noted that sensory disturbances were the highest (238 out of 286) with mild pain as compared to moderate and moderately severe pain. This relation was found to be highly significant ( $p=0.001$ ) (Table 4).

The children who were suffering from depression were observed to have higher incidence of mild sensory disturbances and subsequent difficulty in eating

( $p=0.020$ ) (Table 5). As opposed to the difficulty in eating due to the sensory disturbances, it was seen that the latter did not affect the sleep of the children, although they still suffered from depression ( $p=0.000$ ) (Table 6).

Lastly, the reaction of parents', family members and people in general to children's appearance was observed to be negative and intolerant towards the child and this led to depression in these patients. The depression reduced in the cases where parents, family and other people were indifferent or had accepting behaviour towards the children (Tables 7, 8 & 9).

## DISCUSSION

This survey was carried out to examine the effects of sensory disturbances in CLP patients on their daily basic activities, interactions with parents, family and people and their responses towards them creating a negative emotional status i.e. depressive like symptoms.

In the past, researchers have examined specific aspects of psychological functioning and have thus identified behavioural problems<sup>7,8</sup>, social problems<sup>9,10</sup>, anxiety and depression<sup>11</sup>, and dissatisfaction with facial appearance<sup>12,13</sup>. Worldwide, children affected by CLP have to struggle with their anxiety due to in competencies related to their daily activities like eating and sleeping. In our study, we saw similar anxiousness and depression like symptoms in children, perceived by their parents, as a result of CLP related sensory disturbances. We found that when children were socially accepted more in the society and as well as at home, the children had a more positive outlook towards life as compared to when they were unaccepted. The CLP caused a lot of sensory lack of functioning and disturbance for the children, and because of this, they could not eat properly. However, interestingly, this disturbance did not affect the sleep pattern of the children even though they had signs of depression in them! Pain, however,

was consistent with the mild sensory disturbances in these CLP patients.

By looking at these results, it is evident that children and their self-esteem are very fragile. It is imperative that once a diagnosis is made, children should be accepted more in every way by their parents, family and friends so as to keep their positivity alive. Timely treatment is of the essence and measures should be taken to reduce the pain and sensory disturbances in these CLP patients so that their daily routine is not hindered and they can lead a positively productive life.

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