

Study of myths and beliefs among the parents of a child with cleft lip and palate

ABSTRACT

Aim: The aim of the study was the identification of predictors of psychology and beliefs among parents of children affected by cleft lip and cleft palate.

Methods: The study included a sample of 157 parents of children having cleft lips and cleft palates. Parents were given a questionnaire related to their beliefs and reasons behind deformity.

Results: Out of 157 participants, 90 were fathers, and 67 were mothers. The children with deformities included 105 boys and 52 girls. The majority of parents (43) believed that the eclipse was one of the reasons for the deformity and the other was God's wrath for the mother's sins. The time of birth was considered a factor for cleft lip and palate by 27 parents. The study revealed that the self-esteem of fathers was higher than mothers and they were more concerned of being undesirably judged by others due to deformity of their children than the mothers.

Conclusion: It can be inferred that the parents of a child with cleft lip and palate differ in their psychosocial adjustments. Also, mothers experience more psychosocial problems than fathers. The superstitious beliefs still prevail in rural areas despite advanced medical facilities and awareness.

Keywords: Cleft lip, cleft palate, psychosocial problems

INTRODUCTION

Cleft lip and palate are congenital orofacial deformities with global incidence varying from 1:500 to 1:1000 live births. Even in the 21st century, with educational and cultural advances and in the era of omnipresent social media, where every birth is celebrated publicly online by photographs, the birth of a child having craniofacial anomaly or cleft lip and/or palate causes an acute embarrassment, a sense of shock, shame, disbelief, and the event is branded as a curse on mother or the child or a bad omen.^[1,2]

This hostility towards the facially deformed has existed since time immemorial. In primitive times, an individual with a facial deformity was either out-casted or killed. The family having a child with abnormality has been looked upon as low esteemed and exiled. The ancient myths from the Roman civilization were beliefs like the birth of a cleft infant would ruin the household; place of the planets or the moon

especially would determine the anomalies such as cleft lip and palate; and many misconceptions like the carrying woman could give birth to deformed infants if she sees such children during pregnancy.^[3-5]

As with any other medical treatment, cleft lip-palate correction, its prognosis, and rehabilitation are largely

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influenced by local sociocultural beliefs, and prejudices, and often determine the need for consultation and medical treatment. Negative perceptual prejudices are relatively high, especially among the rural population of developing countries. These prejudices affect the parental attachment with the child, leading to social discrimination, ridicule, stigmatization, abandonment of the child, increased chances of infanticide, and poor psychological growth of the child.^[6,7]

AIM AND OBJECTIVE

The aim of the present study was to recognize predictors of psychology and beliefs amongst the parents of such infants and children having cleft lip as well as cleft palate in rural regions of Central Maharashtra. This paper explores some of the superstitions, folklore, and folk beliefs as they reflect culturally stereotyped attitudes toward cleft lip/cleft palate. The primary objective was to know about the parents' beliefs and views on the reason behind the cleft deformity, social interaction, sibling interaction, stress level, and awareness of treatment among the parents. Another objective was to motivate the parents to consider their child's birth normal with the deformity which could be corrected like other congenital diseases.

METHODS

The present study was a prospective study that comprised 157 participants who enrolled either of the child's parents. The deformity of cleft lip and palate was diagnosed in the child who reported to the Department of Oral and Maxillofacial Surgery between the period of January 2016 to December 2020. Parents were asked to answer a printed questionnaire in the local language related to their beliefs and views on the reason behind cleft deformity, social interaction, sibling interaction, stress level, and awareness of treatment.

Ethical approval was taken from the institutional review board. The study was approved by the institutional research ethics committee with reference number PIMS/DU/RDC/2020/32,2 dated 19/1/21 (IEC-PIMS-DU), and it certifies that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

RESULTS

The study participants were 157, who were either of the parents of children with deformity of cleft lip or cleft palate or maybe both. The questionnaire was filled out by 90 fathers and 67 mothers. One hundred five children were boys and

fifty-two were girls. Out of the total deformities reported, there were 43 cases (27.4%) of cleft lip only, 44 (28%) cases of cleft palate alone, while 70 (44.6%) subjects had both cleft lip and palate [Table 1].

The majority believed that cleft deformity was due to witchcraft, curses, God's wrath, wicked spirits, luck, relatives' animosity, etc. Forty-three parents considered eclipse during pregnancy as a reason for the deformity. While God's wrath for the mother's sins was believed by 40 parents. The date and time of birth was also considered as a factor for the development of cleft reported by 27 parents. 9% of the respondents had faith that excessive alcohol consumption, viral infection, genetic factors, cigarette smoking, irradiation, or drugs could be one of the reasons behind cleft formation [Table 2].

Fathers had a much higher self-esteem than the mothers, and they were somehow more concerned about being judged by others. The grandparents were negatively affected more emotionally than either mother or father [Table 3]. Sibling interaction was negatively affected in 82 cases. Social

Table 1: Descriptive statistics

Gender of the affected child	
Male	105 (66.87%)
Female	52 (33.13%)
Parent	
Father	90 (57.33%)
Mother	67 (42.67%)
Deformity	
Cleft lip only	43 (27.4%)
Cleft palate only	44 (28%)
Cleft lip and palate	70 (44.6%)

Table 2: Reasons for deformity as expressed by parent

Reason	n
Solar/Lunar eclipse during pregnancy	43
God's wrath for the mother's sins	40
Date & time of birth	27
Relative's animosity	14
Others (Witchcraft/curses/bad luck)	20
Scientific reasoning	13

n* - Number of parents

Table 3: Relatives having negative influence after the birth of a child with cleft deformity

Reason	n
Mother	9
Father	48
Maternal Grandparent	15
Paternal Grandparents	65
Others	20

n* - Number of parents

interaction was reduced by parents in 78 cases. In 97 cases, parents were aware of the treatment and were prepared for the same for the well-being of the child. Eighty-six respondents reported that they had never seen a child having the deformity cleft lip priorly, but the rest of the parents reported that they had seen such deformity at least once. All the parents were motivated and made to believe cleft lip and palate anomalies to be treatable and like other congenital anomalies.

DISCUSSION

Cleft lip (CL) and cleft palate (CP) are congenital deformities caused by unusual embryonic facial development in the course of intrauterine life. Cleft lip and/or palate (CLP) is a major public health problem affecting 1.47 in thousand live births globally, and in India, the estimated incidence is around 0.25 to 2.29 per 1000 births.^[8] In India, the calculated prevalence rate/100,000 was 33.27 for males and 31.01 for females.^[8-10] The social stigma associated with cleft lip-palate and craniofacial anomalies is a major obstacle for modern treatment;^[7] financial constraints and low level of education are other factors.^[11] In rural areas of developing countries, prenatal diagnosis of the cleft is not possible due to a lack of facilities.^[6]

In a study by Weatherley RC *et al.* 2005,^[9] it was stated that (page number 564)... “64% of parents did not limit their child’s social interaction and were not ashamed to be seen in public. Twenty-six percent exercised some constraints, and 10% kept their children totally isolated, not permitting them to leave the house or attend school.” Also, regarding the etiology behind the event, the majority (84%) related the cleft to “God’s wish or will” and only 10% related it to sins done during the previous lives or in the past. Just one parent could recognize the impact of genetics, while others had a family history, which was positive. They considered that their child’s life would be better after the correction of an anomaly; parents of girls were especially concerned about facial esthetics as they thought that it would be difficult for them to find an appropriate match at the time of marriage. The second important reason was prospective education.^[9]

Though there has been a multidisciplinary scientific approach to the problem of clefts involving plastic surgeons, pediatric surgeons, pediatricians, maxillofacial surgeons, orthodontists, and speech and language pathologists with well-established treatment protocols, traditional methods with their perceptual prejudices continue to hold their sway among the poorly educated populace.

Interaction with parents in our study revealed that even in the modern era of technology and vast information available,

people are rooted in superstitions and primitive beliefs. Only one out of every tenth parent believed that cleft lip or palate formation has some genetic or environmental etiology. The rest believed it to be their bad luck and cited various superstitious beliefs for the child with a cleft defect. The male parent was more affected negatively than the female parent and, in some cases (24.2%), the mother was abandoned along with the child by her husband and family.

Around 55% of the respondents had never seen a child with a cleft before the birth of their own child, so the birth of a child with a cleft was a shocking and embarrassing experience for them. Around 62% of the respondents were aware that cleft deformity has a cure as being advised by medical practitioners in their rural locality and were keen to get their child treated and deformity corrected. Still, 38% of the respondents were reluctant and unaware of surgical treatment of cleft deformity. The expectation for the treatment was mainly for social integration, followed by functional improvement and esthetic improvement.^[12]

Educating parents about the causation of clefts during the prenatal period often reduces parental anxiety or depression, motivating them to seek early treatment and in turn, improves psychological and cosmetic results of cleft corrections.^[13] Unquestionably, the child, as well as the parents of such a child, should be aware of the causes and treatment of anomalies like CLP.^[4] Considering education as a part of the treatment plan, the parent’s attitudes can be modified, and it will improve their motivation for a better treatment outcome.

LIMITATIONS OF THE STUDY

The limitation of the present study is that it is a cross-sectional nature of the study, which could not establish a causal relationship. Also, the results would have been diverse if it was done in a community-based setting using a mixed-method approach, i.e., qualitative and quantitative methods. Therefore, we would also recommend conducting more studies relating to the perceived social stigma by the child, which would, in turn, have an emotional impact on their parents.

CONCLUSION

Facial abnormalities like cleft lip and palate and many other such deformities are not just mental but also a very big social stigma for individuals and families, which makes them less acceptable in society. It hampers the social well-being of an individual, which gives the immense desire to patients to seek corrective surgery. The various superstitions and

misconceptions about facial deformity still persist, even when there is prior knowledge of the deformity. The knowledge, attitude, and behavior of society and family is indeed a primary need to understand and empathize with such individuals by giving them equal recognition in the society.

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Conflicts of interest

There are no conflicts of interest.

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