

## KNOWLEDGE, AWARENESS AND PRACTICE ON THE INCIDENCE AND MANAGEMENT OF THE CLEFT LIP AND PALATE AMONG PARENTS - AN INTRA INSTITUTIONAL QUESTIONNAIRE STUDY

**Type of manuscript:** Questionnaire study

**Running Title:** Knowledge, awareness and practice about cleft lip and palate among parents

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## **ABSTRACT:**

**Background:** Cleft lip and palate (CLP) is one of the most commonly occurring craniofacial deformities. In addition to the physical difficulties seen in the child, social and economic stresses are also known to be increased in the families of such children. A factor that exaggerates the situation is decreased awareness and education of the condition. Adequate knowledge and awareness of CLP deformity may help to counter the negative beliefs and attitudes toward the condition.

**Objective:** The objective of this study was to assess the level of knowledge, awareness and practice on the incidence and management of CLP among parents.

**Materials and Methods:** A cross-sectional descriptive study with the aid of a structured interview administered questionnaire was conducted among 45 parents accompanying cleft lip and palate babies for surgeries in Saveetha Institute of Medical and Technical Sciences, Chennai, Tamil Nadu, India. The main outcome measure was the level of awareness and the mean cumulative knowledge score.

**Results:** The results of the study show that education played an important role in the awareness and knowledge of such conditions and hence had a significant and positive effect. **Conclusion:** Though educated parents had a positive attitude toward cleft deformities, the less educated counterparts still require enlightenment and education of the same to improve the lives of such children. Taking advantage of media in the present era, radio, television and newspaper can be used as a medium to spread knowledge regarding the same.

**Key words:** cleft lip and palate, awareness, knowledge, parents

## **INTRODUCTION:**

Orofacial clefts are the most common congenital deformities and they constitute cleft lip and palate <sup>[1]</sup>. It occurs due to a gene mutation affecting the development of lips and oral cavity at four weeks of pregnancy <sup>[2]</sup>. There are three kinds of birth defects: Cleft palate, lips, and palate (CLP), also known as a Cleft Lip (CL) <sup>[3]</sup>.

All over the world, the incidence of CLP is approximately 1 in every 500-700 births per year. The birth of such a child, though some parents might have been intimated by scans before birth, brings feelings of shock, shame, anxiety, confusion, guilt, inadequacy, rejection, depression, hopelessness, and stigmatization to the family members, especially the parents <sup>[4]</sup>. Most of these emotions are due to superstitious beliefs and lack of knowledge that promote a negative attitude towards the deformity that may at times force the families to take decisions like infanticide <sup>[5]</sup>.

The parents, especially the mother, are made to feel that the cleft was due to their character and way of life and are held responsible by the society <sup>[1]</sup>. The underlying cause of such an ideology is the poor level of awareness and education amongst such groups of people.

The beliefs and traditions of people can be changed only by altering the individual's knowledge, attitudes, and beliefs about health issues and health education. A good understanding of the causes, treatment, and prevention of CLP may help to counter the negative beliefs and attitudes toward the condition and even reduce the morbidity of cleft lip and palate (CLP). This might also educate them about the management of the condition surgically and help in improving the quality of life of such children. Many organisations come forward to provide treatment to people with low socioeconomic status <sup>[6]</sup>. Better understanding of the condition and parents' knowledge of the cleft, may improve their child's overall health and development <sup>[7]</sup>.



Through this research, we hope to improve parents' understanding, awareness, and practice of these congenital diseases.

## **MATERIALS AND METHOD:**

This is a cross-sectional descriptive study undertaken on 45 parents of cleft patients who were admitted for treatment at Saveetha Dental College and Hospital and Saveetha Medical College and Hospital, Chennai, Tamil Nadu, India. A convenient sample of 45 respondents was selected after obtaining informed consent. Ethical approval was obtained from the relevant institutional bodies prior to commencement of the study. The tool undertaken for data collection was a structured researcher administered questionnaire.

The questionnaire elicited information with regard to the demographic characteristics of the respondents as well as their knowledge and level of awareness about causes and treatment of CLP. Furthermore, 16 items of the questionnaire were selected to test knowledge. Knowledge score was computed. The knowledge variable was dichotomized as a correct or incorrect answer. Incorrect answers were deemed as incomplete, incorrect and don't know answers. A score of 1 and 0 was allocated to every correct and incorrect answer, respectively, with maximum and minimum obtainable scores being 20 and 0, respectively. A score less than 50% was deemed to be inadequate knowledge while a score greater than or equal to 50% was considered to be adequate knowledge.

## **RESULTS:**

Out of a total of 55 participants who have taken part in the survey, a total of 10 participants were excluded as 6 were illiterate and 4 were attenders and not parents of the patient/child. Out of the total considered 45 participants, 16 self-designed, closed ended questions were provided (Table 1).

In consideration of the patient's awareness of the incidence and management of cleft lip and palate, 68% of the participants were aware of their child's health condition [Figure 1]. Responding to whether the parents were correctly guided at the time of birth to the right center for the management of the condition, only 28% of the participants responded positively whereas 72% of participants were not. 68% of the parents have said that they have been looked down upon by society for giving birth to a child with cleft and only 32% of the parents were not discriminated against in the society. Considering the possibility of a familial history of similar conditions, 69% of the participants had a similar condition in the family and 31% of the participants had no such history. Only 31% of the parents were explained clearly about all the treatment modalities required to correct their child's condition and 69% were neglected about the knowledge of the same [Figure 2].

Considering if their child was evaluated for milestone achievements, 84% of parents stated that they were not evaluated and only 16% have mentioned that they were evaluated frequently at their hospital at the child developmental center. Regarding the awareness of the parents of the age groups in which each surgery has to be performed, 77% of the participants were unaware and only 23% of the parents were aware of the age group in which each surgical procedure needs to be done [Figure 3].

On considering the awareness of the preventive measures which should be taken during pregnancy, 89% of the parents weren't aware of them and only 11% were aware of these preventive measures. [Figure 4]. 72% of the total participants had a history of consanguineous marriage [Figure 5]. Responding to whether the participants were aware of the medical problems relating to consanguineous



marriage, 73% were unaware of it, whereas 27% percent were aware of it and yet proceeded with the marriage [Figure 6]. When asked the reason which influenced their decisions for treatment, 35% of the parents mentioned it to be aesthetic correction and 15% were influenced by functional correction for the child. However, 18% wanted their kin to have a normal upbringing and 32% of parents were forced to get the treatment for their child by others [Figure 7].

On considering if they were trained on using a feeding plate for properly feeding the baby after birth, 81% were not trained properly and only 19% were given proper training for the use of a feeding plate. When asked if they practice these feeding techniques, 63% dont practice these techniques even after getting proper training from professionals [Figure 8].

63% of the total participants have made a positive effort to follow up periodically till the completion of all treatments proposed by the team of doctors specialized in the correction of this condition. Only a total of 37% have discontinued the completion of all necessary treatments for the correction of a condition as such for their child [Figure 9]. When asked if the parents believe that their child will have more self confidence after undergoing surgical correction for the cleft defects, 86% of the parents mentioned that they are confident and only 14% were negative in their response [Figure 10].

## **DISCUSSION:**

Several measures have been implemented to prevent the incidence of CLP and its surgical management aids in making the lives of such children better, improving the quality of life. As a result, the prevalence of cleft lip and palate (CLP) may even be reduced if enough information about its causes, treatments, and prevention is available <sup>[8]</sup>.

As the study was conducted in a large well established university and teaching institution that treats CLP in a metropolitan city, it was not surprising that more than half of the respondents in this study had seen or heard about CLP. However, the majority of respondents were unaware of the cause, the appropriate treatment time, or whether CLP could be prevented.

Numerous Asian <sup>[9]</sup> and African <sup>[10]</sup> populations, both in the urban and rural areas, have been reported to lack knowledge of CLP. In Nepal, the most common reason for late presentation is ignorance of treatment options. Many people attribute the influence of cultural and religious factors on perceptions and knowledge to superstitious beliefs <sup>[11]</sup>.

To test and evaluate the knowledge of the parents, ten out of the sixteen questions have been discussed. The results indicate that those who were educated had better awareness about CLP. A more detailed analysis of the education levels would be of help to conclude that formal education will give parents of such patients a better understanding of the condition and confidence to treat it.

Though the majority of the parents in our study did not get adequate information about CLP at the time of birth, they had reported for treatment due to the effort of organizations that help treat this condition. One of the other reasons for delayed treatment is that these families are looked down and forced to take up a negative attitude by society. The results suggest that the current public awareness programs sponsored by governmental and non-governmental organizations are ineffective. The respondents did not appear to have gained a better understanding of CLP from the antenatal health talks and counseling

sessions they attended during monthly reviews. This is probably due to the hurried schedule of these sessions and the fact that they are not specifically focused on CLP [12,13].

In spite of decreased awareness at birth, the parents are willing to learn about the condition and are prepared to undertake all measures to give their children a better future. The parents exhibit a positive attitude though many of them received only discouragement from their families and friends. The parents have utmost trust and faith in their doctors and believe that their children will be more confident after the surgery. A wide range of knowledge regarding the same can also be obtained from several studies conducted in our institute [13-22]

## **CONCLUSION:**

From the study, we can conclude that despite incomplete education and not receiving proper information from birth centers, parents have approached hospitals for treatment for the betterment of their children with a positive attitude. Awareness programmes, camps and social media must be utilised to improve the knowledge regarding such conditions. This study highlights the lack of knowledge and awareness as the prime factors in management of cleft lip and palate.

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## Tables:

**Table 1: Questionnaire and reported answers**

SL NO	QUESTION	YES (%)	NO (%)
1.	Are you aware of your child's health condition?	68	32
2.	Were you guided correctly at the time of birth to the right center for management of this condition?	28	72
3.	Have you been looked down by society for giving birth to a child with cleft?	68	32
4.	Did anyone in your close family suffer from a similar condition?	69	31
5.	Were you explained clearly about all the treatment modalities required to correct this condition?	31	69
6.	Was your child evaluated at the child developmental center for milestone achievements?	16	84

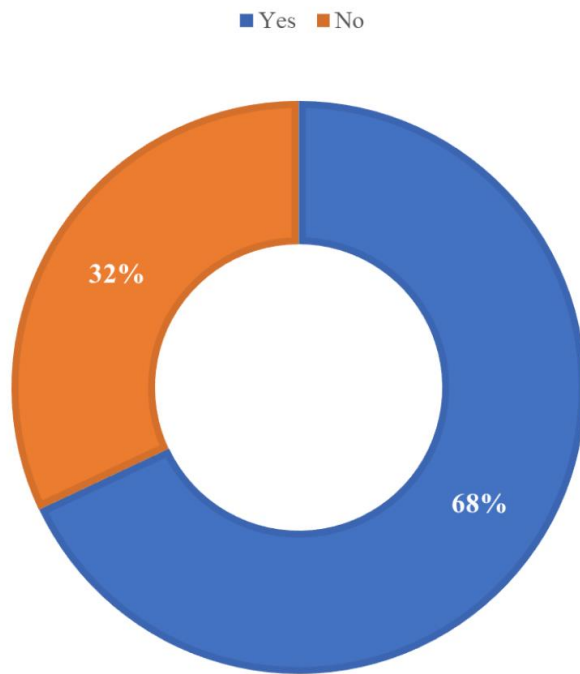


7.	Are you aware of the age group in which each surgery has to be performed?	23	77
8.	Are you aware of the preventive measures which should be taken during pregnancy?	11	89
9.	Is your marriage consanguineous?	72	28
10.	Were you aware of the medical problems relating to consanguineous marriage?	27	73
11.	Were you trained to use a feeding plate for feeding the baby after birth?	19	81
12.	Do you practice proper feeding techniques?	37	63
13.	Do you make the effort to follow up periodically till the completion of all treatments proposed by the team of doctors specialized in the correction of this condition?	63	37
14.	Are you aware about the do's and don'ts after a cleft repair surgery ?	28	72
15.	Do you believe that your child will have more self confidence after undergoing surgical correction for the cleft defects?	86	14

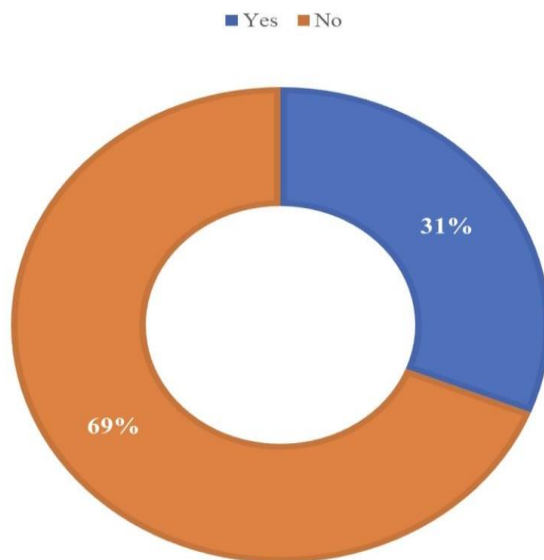
SL NO	QUESTION	Aesthetic correction (%)	Functional correction (%)	Normal upbringing (%)	By force of others (%)
16.	What influenced your decision to get your child treated?	35	15	18	32

**Figures:**

**Figure 1: Awareness of the child’s health condition**



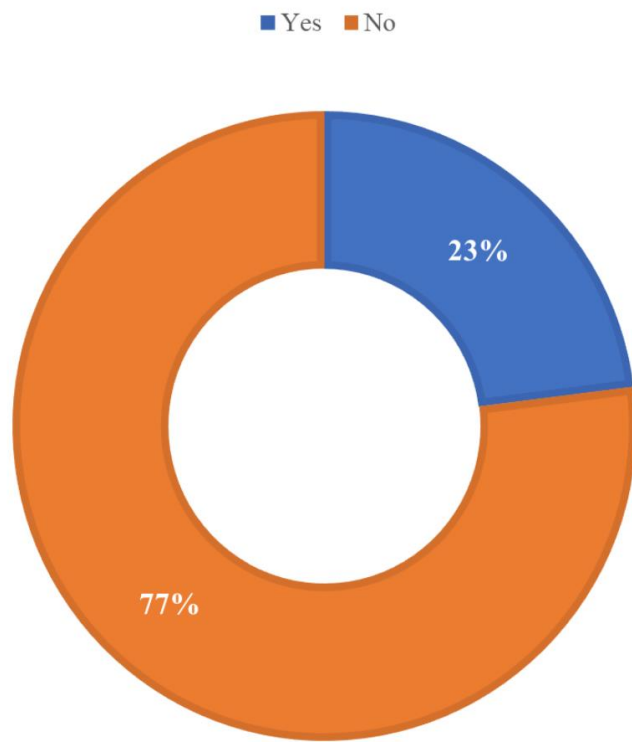
**Figure 2: Awareness regarding treatment modalities**



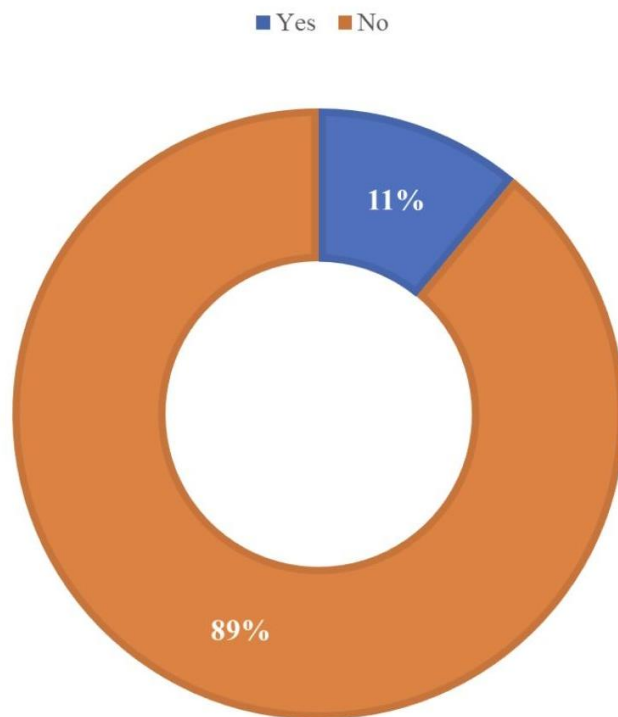
**Figure 3: Awareness about the age requirement for surgery**



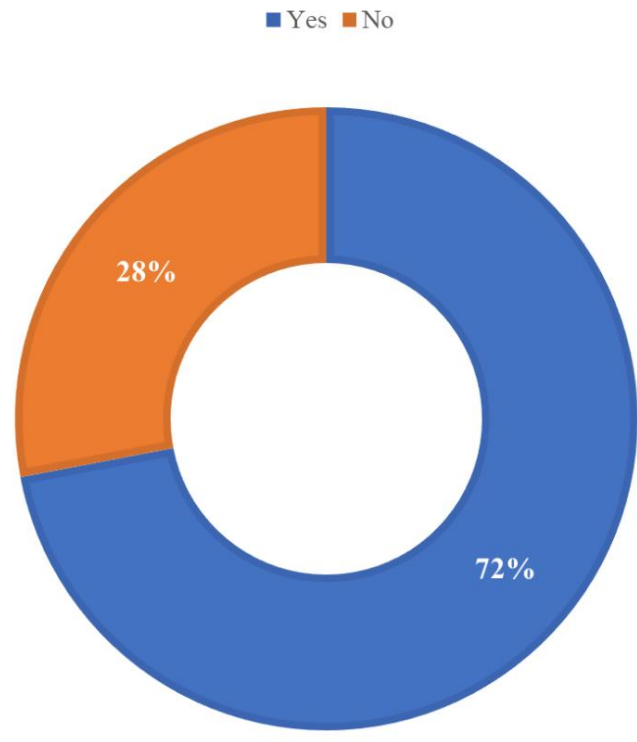




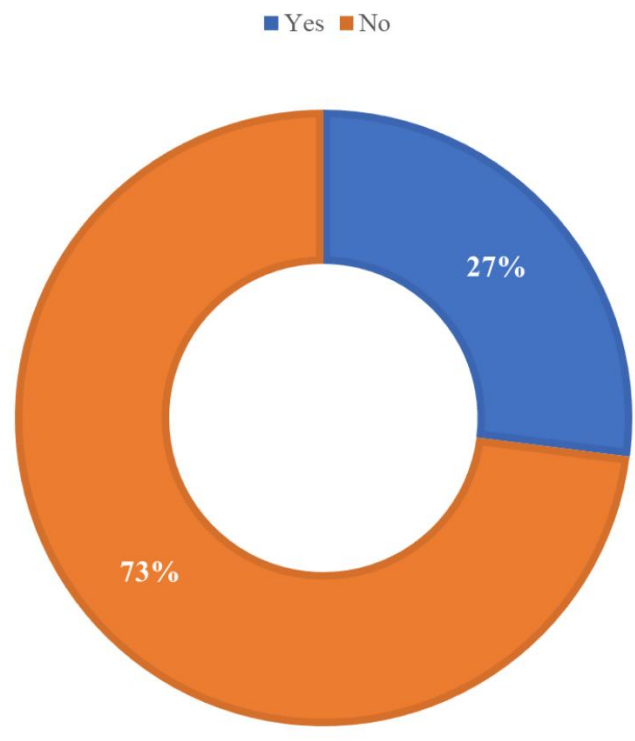
**Figure 4: Knowledge about the preventive measures during pregnancy**



**Figure 5: History of consanguineous marriage**

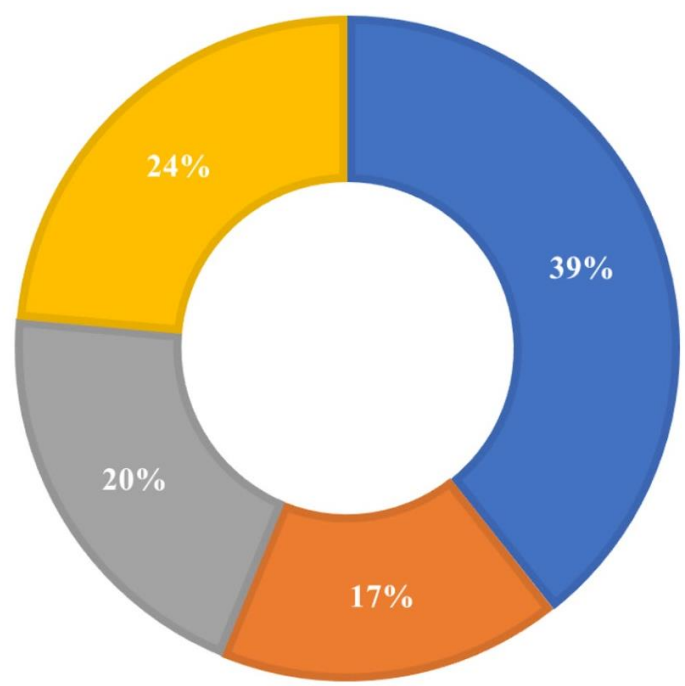


**Figure 6: Knowledge about medical problems related to consanguineous marriages**



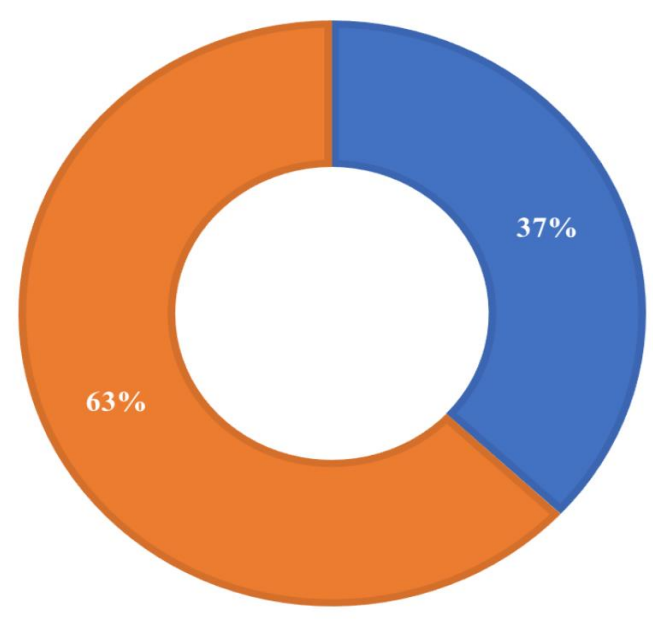
**Figure 7: Reasons that influenced the decision of treatment**

■ Aesthetic Correction ■ Functional Correction ■ Normal Upbringing ■ By Force of Others

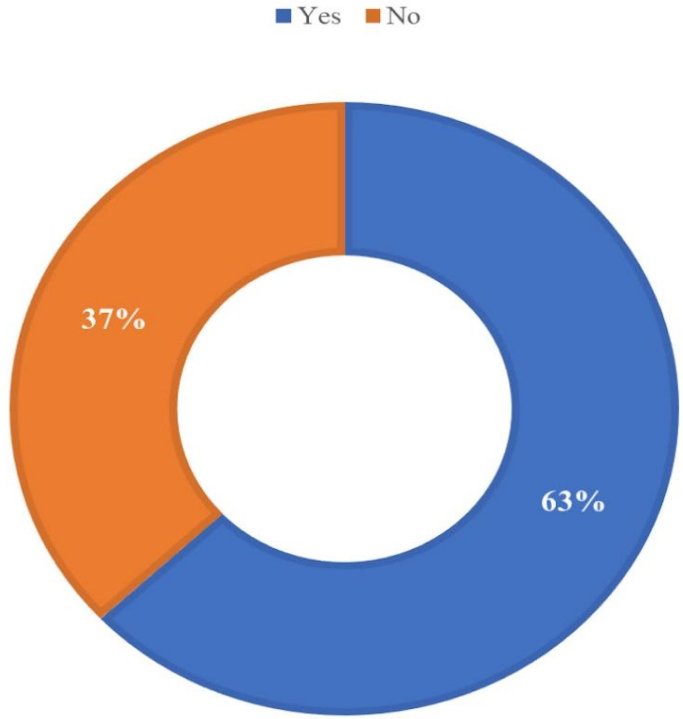


**Figure 8: Awareness and practice of proper feeding techniques**

■ Yes ■ No



**Figure 9: Positive attitude towards periodic follow up and completion of treatment**



**Figure 10: Belief that children will have better self confidence after surgery**

