

Assessment of Knowledge and Awareness of Cleft Lip and Palate Management among Adult Population in Chennai

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Abstract:-

➤ Aim

Cleft lip and palate (CL/P) is one of the most prevalent craniofacial congenital anomalies. This study aims to assess the knowledge and awareness of cleft lip and palate management among the adult population in Chennai.

➤ Materials and Methods

A cross-sectional study was conducted using a 8-item questionnaire, administered through both online and offline methods, targeting various segments of the population in Chennai.

➤ Results

A total of 317 participants completed the questionnaire. The knowledge rate regarding cleft lip and palate was notably higher among females, at 21.62%. Overall, only 19.24% of the sample was aware of the condition, with the majority of those informed primarily obtaining their knowledge from television. Just 2.21% of participants knew that the condition can be diagnosed before birth, and 3.15% were aware that individuals with clefts should seek medical assistance.

➤ Conclusion

The knowledge and awareness of cleft lip and palate (CL/P) among participants is minimal. To enhance awareness in the general population, informative seminars should be organized, and professional associations should ensure that reliable information is made available online.

Keywords:- Cleft Lip and Palate; Nasoalveolar Moulding; Newborn; Public Awareness; Feeding

I. INTRODUCTION

Clefts of the lip and palate represent a prevalent category of developmental anomalies observed across various human populations. These conditions may occur in isolation or in conjunction with broader developmental disorders, and they can lead to considerable morbidity in affected individuals, particularly during their formative years. This, in turn, has lasting implications for their overall quality of life throughout their lifespan([Cobourne](#)).

Orofacial clefts are the most prevalent congenital deformities, encompassing both cleft lip and cleft palate. These conditions arise from genetic mutations that disrupt the development of the lips and oral cavity during the fourth week of pregnancy. There are three primary types of these birth defects: cleft palate, cleft lip, and cleft lip with palate (CLP), commonly referred to as cleft lip (CL)(1) (2) (3) Orofacial clefts—comprising cleft lip (CL), cleft lip and palate (CLP), and isolated cleft palate (CP), as well as median, lateral (transversal), and oblique facial clefts—are among the most frequently occurring congenital anomalies. The incidence of orofacial clefts is estimated to be about 1 in every 500 to 550 live births. Prevalence rates vary based on ethnicity, country, and socioeconomic status (4)

The annual prevalence of clefts in India ranges from 27,000 to 33,000 cases(5).

The precise etiological factors that result in cleft lip and palate remain a subject of on going debate; however, several contributing factors have been identified. Among the most common causes associated with cleft lip and palate (CLP) are the use of teratogenic drugs by pregnant women, exposure to radiation, maternal diabetes, smoking during pregnancy, alcohol consumption, and a family history of the condition. (6)

Research has demonstrated that early intervention for children born with cleft lip and palate leads to normal growth and development, as well as typical speech, hearing, dental health, and feeding abilities. Conversely, the absence of timely treatment can adversely affect these functions to varying degrees, resulting in both physical and psychological consequences. Early surgical intervention for cleft lip and palate (CLP) is the most effective option for ensuring normal development and reducing the likelihood of long-term disabilities (7) (8). If a child does not receive surgical treatment, they may experience complications later in life. While treatment options are available for adults with untreated cleft lip and palate (CLP) from childhood, speech is often still affected, although other functions such as dental health, feeding, and hearing can show improvement with intervention (9). A cleft lip may hinder the formation of a proper seal around the nipple, but closure can typically still be achieved. In contrast, a cleft palate prevents the baby from generating the negative pressure required for effective feeding, which can also result in breathing difficulties during feeding. This situation significantly prolongs feeding times. Additionally, a cleft in the hard palate restricts the normal use of the tongue to compress the nipple(10). Feeding infants with clefts is a significant concern for parents, and research indicates that these children often experience growth delays compared to their peers without clefts. Lip repair is typically recommended between 3 and 6 months of age, while palate repair is advised between 9 and 12 months. To safely administer anesthesia for these procedures, the child must achieve adequate weight gain and remain free of health complications. Nutritional issues in individuals born with cleft lip and palate (CL/P) can be addressed using passive feeding plates. Additionally, by incorporating active regulators into these plates, it is possible to extend the columella and bring the cleft segments closer together, thereby enhancing facial aesthetics (11).

Knowledge and awareness of cleft lip and palate (CLP) are now considered critical concerns for parents due to its prevalence. CLP is a preventable and treatable condition that can significantly improve both the physical and psychological well-being of affected children. A lack of understanding about cleft lip and palate has been identified as a major factor contributing to neglect within the general population. Parental awareness plays a crucial role in fostering an attitude that encourages timely treatment for patients.

Furthermore, family support is instrumental in alleviating psychological stress and providing positive reinforcement regarding knowledge, awareness, and practices related to individuals with CLP (9). Modern advancements allow parents to detect certain developmental abnormalities before a child is born, with cleft lip and palate being one of them. While cleft lip and palate can be identified through antenatal screening, isolated cleft palate cannot be detected prior to birth. With accurate information, parents can prepare for the possibility of having a child with this condition and the additional support that may be required. Despite being a manageable anomaly, some parents may choose to terminate the pregnancy upon receiving an antenatal diagnosis of CLP, often due to inadequate understanding or lack of knowledge about the condition (12) (13) .

Given the significance of early treatment strategies for patients with cleft lip and palate (CL/P), this study aims to assess the level of knowledge and perceptions among adult population in Chennai.

II. MATERIALS AND METHODS

This study involved the creation of a questionnaire comprising 8 questions designed as a tool for data collection, aimed at assessing awareness of cleft lip and palate among individuals in Chennai. Three questions in the survey were designed to assess demographic characteristics such as gender, age, and occupation. The remaining 5 questions focused on gathering information about cleft lip and palate (CL/P) and the use of the nasal alveolar molding (NAM) or feeding plate. The questionnaire was administered both online and offline both Tamil and English. Participants were asked to confirm their voluntary participation in the survey forms. This study received approval from the Institutional Review Board ,Tamil Nadu Government Dental College and Hospital, Chennai with ethical clearance number (52/III/IERB/2024/TNGDCH). Data collection was done from February 2024 to May 2024.

The sample size was calculated using the G Power Software V.3.9.7. Considering the effect size to be measured at 0.3 for ' χ^2 tests - Goodness-of-fit tests: Contingency tables' with α err prob at 0.05 and degree of freedom at 16. The total sample size was estimated at 317 with a power of 95%. The questionnaires were distributed to 50 individuals via email using Google Forms, while the remaining forms were completed offline. An introductory section of the questionnaire included a brief informative letter outlining the study's purpose. No personal information that could identify participants was collected. Adult population above 18 years were included in the study and Cleft lip/palate patients were excluded from the study. The responses of 317 participants who completed the entire survey were analyzed.

III. STATISTICAL ANALYSIS

Statistical analysis of all data obtained in this study was performed using RStudio (R version 4.2.1 (2022-06-23 ucrt)). Descriptive statistics were calculated for all parameters. Pearson chi-square and Fisher's test were used to check the dependence between the variables in the study-knowledge of NAM/ feeding plates, age, gender, job, etc. Statistical significance was accepted at $p < 0.05$.

IV. RESULTS

A total of 317 participants completed the questionnaire, with a higher proportion of female respondents (58.35%) compared to male respondents (41.64%). We had participants from different profession like students, homemakers, dailywage workers, and people working in both private and government sectors. We could

include individuals from various age groups, with the majority of participants being between 18 and 30 years old. Out of the total sample, only 19.24% were aware of the condition, and among those who were informed, most gained their knowledge mainly from television (37.70%). Only 2.21% of the sample know that it is diagnosable before birth. 3.15 % of the sample are well aware that the cleft patients should seek medical help. Since the p-value (0.2596) is greater than the typical significance level of 0.05, there is no significant evidence to suggest a relationship between awareness of cleft lip and palate and gender in the sample data. Similarly, the p-value (0.2108) also exceeds the 0.05 threshold, indicating no significant association between age group and awareness of cleft lip and palate in the sample. Additionally, the p-value (0.677) is well above 0.05, suggesting that awareness of cleft lip and palate does not significantly differ based on a person's profession.

Table 1. Demographic Characteristics of Participants(n=317)

		N	%
GENDER	FEMALE	185	58.35%
	MALE	132	41.64%
JOB	HOME MAKER	35	11.04%
	PRIVATE JOB	111	35.02%
	GOVERNMENT JOB	33	10.41%
	IT	35	11.04%
	DAILY WAGE WORKER	24	7.57%
	STUDENT	75	23.66%
	TEACHER	4	1.26%
AGE(YEARS)	18 - 30	176	55.52%
	30 - 40	70	22.08%
	40 – 50	45	14.2%
	50 AND ABOVE	26	8.2%

Table 2 : Comparison of Individual Responses based on their Knowledge of Cleft Lip/Palate in Newborn

ANSWERS		YES	NO
GENDER	FEMALE	40	145
	MALE	21	111
AGE	18 - 30	28	148
	30 - 40	14	56
	40 - 50	11	34
	50 AND ABOVE	8	18
	H OME MAKER	9	26
JOB	PRIVATE JOB	20	91
	GOVERNMENT JOB	6	27
	IT	4	31
	DAILY WAGE WORKER	4	20
	STUDENT	18	57
	TEACHER	0	4
CAN IT BE SCREENED BEFORE BIRTH	YES	7	310
	NO		
DO YOU KNOW THEY CAN SEEK MEDICAL CARE	YES	10	307
	NO		
SOURCE OF INFORMATION	SOCIAL MEDIA	17	
	TV	23	
	FRIENDS	12	
	RELATIVE	9	
DO YOU KNOW ABOUT NASOALVEOLAR MOLDING/FEEDING	YES	4	313

PLATE	NO		
SHOULD SEEK MEDICAL ATTENTION FOR SPEECH PROBLEM	YES	7	310
	NO		

V. DISCUSSION

Cleft lip and/or palate (CL/P) are among the most prevalent congenital anomalies affecting the head and face. Therefore, it's crucial to guide newborns with CL/P to appropriate clinical services. In this study, we evaluated the general population's knowledge, awareness, and practices concerning cleft lip and palate (CL/P). To some extent, timely surgical intervention can help a child regain normalcy and a satisfactory quality of life (15). Therefore, having adequate knowledge, awareness, and practices related to CL/P is crucial. Additionally, fostering a positive perception of (CL/P) can significantly enhance the quality of life for affected children. A child born with cleft lip and palate (CL/P) may encounter challenges related to speech, hearing, feeding, and dental health, as well as experience psychosocial effects.

In India, many cleft patients struggle to follow care protocols due to inadequate feeding guidance, leading to feeding difficulties and poor nutrition, which delay primary surgeries. Parents face significant barriers, including lack of awareness and logistical challenges, as many families are uneducated and come from impoverished, remote areas. Additionally, the multidisciplinary approach in hospitals requires multiple consultations with various specialists, complicating adherence to treatment protocols(15). We observed that most people lacked awareness of the condition. Only 19.24% of the sample are aware of cleft lip/palate, which is consistent with findings from a previous study conducted in the Turkish population (16). Additionally, 30.77% of participants falling into the age group of 50 and above have more knowledge than the younger people. Majorly those with relatives or friends who had it were familiar with the protocol. Many individuals are unaware that cleft conditions can be diagnosed before birth through screening. Among those closely related to cleft patients, only a few were informed about the condition during screening; the majority learned of it only after the child was born. Previous study found that 36.5% of the 200 participants possessed adequate knowledge about prenatal screening tests (17). In our study only 2.21% of the sample knows that it is diagnosable before birth.

Many people are not aware that cleft lip and palate can be diagnosed prenatally and that managing the condition requires a multidisciplinary approach(18). Those who are aware of cleft lip and palate (CL/P) indicated that they learned about it through the Internet, social media, television, or healthcare professionals. Research has shown that the Internet serves as a significant source of information about CL/P; however, the quality of this information is often found to be low (16). In this study, we found that individuals primarily learned about cleft lip and palate through television (37.70%); however, many also received information from close relatives and other sources such as social media.

For patients presenting within the first few weeks after birth, lip taping and presurgical orthopedics, including nasoalveolar molding, are being implemented when necessary(15). Present study found that only (1.26%) of the population are aware about the feeding plate. Presurgical orthopedic treatment is a vital component of the multidisciplinary approach to managing cleft lip and palate (CL/P). It offers several key benefits, including aiding in feeding, narrowing the cleft width, and enhancing the outcomes of surgical repair for (CL/P)(19) (20). The limited awareness and logistical obstacles encountered by parents of children with cleft conditions constitute major impediments to following treatment protocols in India. A substantial number of these families are uneducated and financially constrained, often living in remote regions of the country (15). While many individuals are unaware that patients with cleft conditions should seek medical care, those who do recognize the need for care often lack knowledge about specific treatment options, such as the nasoalveolar molding plate and feeding plate. Among individuals closely associated with cleft patients, only those who have directly received these devices demonstrate awareness of them. Conversely, the majority of relatives and acquaintances of cleft patients remain uninformed about these treatment modalities. A significant proportion of individuals who have undergone surgical treatment for cleft conditions do not have a clear recollection of their surgical history. Abid et al. (17) conducted a study involving 145 mothers of children with unilateral or bilateral cleft lip and palate, where 70.57% of the mothers indicated that the use of NAM/Feeding plates was beneficial (20).

VI. BENEFITS OF THE STUDY

This study could provide insights into the population's awareness of cleft lip and palate, highlighting the need for foundational steps to enhance understanding of the condition, regardless of educational or socioeconomic status.

VII. CONCLUSION

- The knowledge and awareness of cleft lip and palate (CL/P) among participants is minimal. To enhance awareness in the general population, informative seminars should be organized, and professional associations should ensure that reliable information is made available online and offline.
- Awareness can be promoted through healthcare workers who have closer interactions with the community. The government can support such families by providing health schemes, encouraging them to seek timely assistance from the healthcare sector.

VIII. LIMITATIONS

This study involved 317 individuals from various occupational groups. Future research should be conducted with larger sample sizes and more participants.

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