



Research Article

CLEFT LIP AND PALATE: AWARENESS ON INTERVENTION AMONG PARENTS IN RURAL AREAS OF KERALA

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ABSTRACT

Opening in upper lip or palate is referred to as a cleft lip and cleft palate. Congenital abnormalities (birth defects) are conditions that arise while a foetus is growing inside the uterus. Cleft lips and cleft palates are caused by the incomplete fusion of the tissues of the upper lip and roof of the mouth during foetal development. Children with cleft lip with or without cleft palate face a variety of challenges depending on the type and severity of their cleft. The most significant problem, as well as one of the most crucial worries, is the difficulties feeding following delivery. Also, child may develop difficulty in speaking. Understanding the problem and suitable therapy is crucial. As soon as the child receives early intervention, a speech-language pathologist must be consulted to treat with the child's speaking abilities and swallowing issues. The study aimed to analyse the awareness regarding the intervention of cleft lip and palate among parents in rural areas of Kerala. A group of 35 parents (aged 25 to 35 from Kannur district of Kerala) who had children in the age range of 0-7 years were given a list of 10 questions, and the results showed that parents have very low level of awareness.

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INTRODUCTION

Cleft lip and cleft palate are opening or crack in the upper lips, the palate, or both. When a developing baby's facial tissues don't fully seal, it can lead to cleft lip and cleft palate.

Cleft lip and palate are congenital structural malformation that are brought on by abnormal embryological development. Between the fourth and tenth weeks of the growing embryo or foetus, there is a disruption in embryologic growth that leads to cranial variations (Peterson-Falzone, Hardin-Jones, & Karnell, 2010).

Based on the cleft's severity and laterality (unilateral left, unilateral right, or bilateral).The structures involved (lip, alveolus, hard palate, soft palate) (width and extent of structures involved), clefts are classified into two types: combined clefts and isolated clefts (cleft lip or cleft palate only). They can be bilateral or unilateral, complete or insufficient.

The symptoms of cleft lip and palate include one or both sides of the face may be affected by a split in the lip and palate (roof of the mouth), A lip split that just looks like a tiny notch in the lip or that extends through the upper gum and palate and into the base of the nose, a gap in the roof of the mouth that has no impact on facial appearance.

Clefts in the palate can be visible or submucous. On intraoral inspection, an overt palatal cleft is discernible and open. The oral mucosa of a submucous cleft palate (SMCP) is still there, but the midline attachment of the underlying velar musculature

will be lost. On intraoral inspection, the cleft is frequently not noticeable and is not obviously open. The diagnosis of an occult (hidden) submucous cleft palate (OSMCP), a different kind of SMCP is only possible through direct observation during surgery or through magnetic resonance imaging (MRI). Cleft lip and palate can occur for a variety of reasons. The majority of cases are believed to be the result of multifactorial inheritance or the combination of a person's genes (genetic predisposition) with particular environmental variables (Beaty, 2011). Chromosome variations in people born with genetic disorders can also result in clefting. During the second and third trimester, the tissues that make up the lip and palate often fuse together. However, the fusion either happens or never happens partially in infants with cleft lip and cleft palate leaving a hole (cleft).

Clefting genes can be passed down from mother or father, either individually or as part of a genetic condition that features a cleft lip or cleft palate as one of its symptoms. Sometimes a baby inherits a gene that increases their risk of developing a cleft, but the cleft is really brought on by an environmental factor. Cleft babies are more likely to be born to parents who have a family history of cleft lip or cleft palate, exposure to specific chemicals. Pregnant women who have diabetes may have a higher risk of developing cleft lip and palate. Males are more likely to develop a cleft lip and females are more likely to have cleft palate without cleft lip.

Depending on the form and severity of the cleft, children with cleft lip with or without cleft palate encounter a number of

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difficulties. The most significant issue is the feeding difficulty after delivery, and is one of the most important concerns. While the majority of infants with cleft lips are able to breastfeed, a cleft palate may make sucking challenging.

The children may develop hearing loss and ear infections. Infants who have cleft palates are particularly susceptible to middle ear fluid accumulation and hearing loss. Also, the growth of the teeth may be impacted if the fissure penetrates the upper mouth. A cleft lip and palate can hinder the development of typical speech since the palate and lip is utilised to create sounds. Speech can come off as excessively nasal. Children with clefts may experience social, emotional, and behavioural issues.

One in every 700 live births experiences an oral cleft, whether it be a cleft lip, cleft lip and palate, or isolated cleft palate (World Health Organization [WHO], 2001). According to international estimates including cleft lip and palate, the rate ranges from 7.94 to 9.92 per 10,000 live births (International Perinatal Database of Typical Oral Clefts, 2011; Tanaka, Mahabir, Jupiter, & Menezes, 2012)

Orofacial clefts occur at varying rates depending on the demographic. Overall, Asians and American Indians have reported greater rates (one in 500 births), while people with African ancestry have reported lower rates (one in 2,500 births; Dixon, Marazita, Beaty, & Murray, 2011). The prevalence of isolated cleft palate is 2:1 more common in females than in males. In contrast, the ratio of men to women who have cleft lip, and also having cleft palate, is 2:1. (Mossey, Little, Munger, Dixon, & Shaw, 2009).

A multidisciplinary approach is used in the treatment of kids with cleft palate (with or without cleft lip) and related craniofacial or velopharyngeal disorders. A nurse or patient care coordinator is a member of the team who promotes teamwork and efficiency, helping families and organises care for individuals and families. A surgeon, an orthodontist and a speech language pathologist (SLP) must be the bare minimum of the cleft palate team's essential members.

Teams may also contain or have access to experts in other disciplines, including otolaryngology, paediatrics, psychiatry, general dentistry, genetics, nursing, audiology, and social work. Depending on the person's developmental, physical, and psychological requirements, there may be additional members. Speech-language pathologists (SLPs) plays crucial role in screening, evaluation, diagnosis and treatment of speech and language issues, as well as feeding and swallowing issues, related to cleft lip and palate. Clinical and educational services (diagnosis, assessment, planning, and treatment) like advocacy, prevention and education are some of the professional roles and tasks involved in speech-language pathology.

Cavalheiro, Lamonica & Maximano (2018) studied on child developmental skills and language in toddlers with cleft lip and palate and comparison of the performance in gross motor, adaptive fine motor, personal-social and language skills of children with non-syndromic CLP and typical children revealed statistically significant difference in gross motor, adaptive fine motor and language skills, both in receptive and expressive aspects.

Prathani & Pumnum (2016) investigated on 5-year speech and language outcomes in children with cleft lip/palate (CLP) and

found that articulation errors were the most common speech and language defects in children with clefts, followed by abnormal understandability, resonance abnormality, and voice disturbance.

Bessell (2013) did a systemic review on the topic speech therapy intervention for cleft lip and palate. The review found little evidence to support any specific intervention. Key uncertainties need to be identified and adequately powered, methodologically rigorous studies conducted to provide a secure evidence base for speech-language therapy practice in children with cleft palate with or without cleft lip.

Jones (2020) studied to examine practice patterns and opinions that speech-language pathologists (SLPs) have about speech-language intervention for children with cleft lip and palate. The findings of this study indicate a large degree of variability in opinions of SLP respondents regarding assessment and treatment of children with cleft lip and palate.

Sruthi, Sivakumar, Arvind, Pandian & Navaneethan (2018) analysed the knowledge awareness and attitude on cleft lip and palate management among dental students and found that they were aware of the condition but were not completely aware of the treatment procedure, treatment timing, the sequential timeline followed for each procedure and the role of each specialty in managing the cleft lip and palate.

Need For the Study

It's important to comprehend the condition and effective treatments of cleft lip and palate. A speech-language pathologist must be called to provide assistance for the child's speaking skills and swallowing problems as soon as the child receives early intervention. The current study aims to improve public understanding of cleft lip and palate intervention and to gauge that knowledge. The child's speech dysfluencies and feeding issues might be addressed as soon as feasible if others are made aware of the cleft lip and palate correction.

METHADODOLOGY

Aim

The aim of the present study was to analyse the awareness regarding the intervention of cleft lip and palate among people in rural area of Kerala.

The study was carried out in two phases.

Phase I: Preparation of Questionnaire

A set of 10 close ended (yes/no) questions were prepared keeping in mind the above literature review for the analysis of the parent's awareness towards the intervention of cleft lip and palate.

The prepared questions were validated by 10 speech language pathologists who are working in the field for more than 5 years. The corrections and suggestions advised by the speech language pathologists were incorporated and the final questionnaire was ready which is as below.

Appendix I

1. Have you heard about cleft lip and palate?
 - Yes
 - No

2. Do any of your family members have cleft lip or cleft palate?
 - Yes
 - No
3. Do you know that this condition should be surgically treated?
 - Yes
 - No
4. Do you know that this condition can be accompanied with feeding difficulty?
 - Yes
 - No
5. Are you aware that articulatory disorders could occur with them?
 - Yes
 - No
6. Do you know that there is a multidisciplinary team working together to treat cleft lip and palate?
 - Yes
 - No
7. Do you know who is a speech language pathologist?
 - Yes
 - No
8. Do you know that SLPs are a part of this multidisciplinary team?
 - Yes
 - No
9. Are you aware that speech therapy provides intervention for Cleft lip and palate?
 - Yes
 - No
10. Are you ready to convey the information to others?
 - Yes
 - No

of 25 to 35 and the results obtained from the study are discussed below

Table 1 showing the response of the parents regarding the awareness of cleft lip and palate intervention.

	Yes		No	
	Frequency	%	Frequency	%
Have you heard about cleft lip and palate?	30	85.7	5	14.3
Do any of your family members have cleft lip or cleft palate?	7	20	28	80
Do you know that this condition should be surgically treated?	27	77.1	8	22.9
Do you know that this condition can be accompanied with feeding difficulty?	16	45.7	19	54.3
Are you aware that articulatory disorders could occur with them?	14	40	21	60
Do you know that there is a multidisciplinary team working together to treat cleft lip and palate?	14	40	21	60
Do you know who is a speech language pathologist?	13	37.1	22	62.9
Do you know that SLPs are a part of this multidisciplinary team?	11	31.4	24	68.6
Are you aware that SLPs provides intervention for Cleft lip and palate?	11	31.4	24	68.6
Are you ready to convey the information to others?	35	100	0	0

The table 1 shows that around 85.7 percent of parents have heard about cleft lip and palate, and 20 percent of those parents themselves have a family history of cleft lip or cleft palate. The surgical correction of cleft lip and palate is known to around 77.1% of persons. The child's eating difficulties is poorly understood by about 45.71 percent of individuals. The findings also shows that just 40% of respondents are aware of the articulation problems they have. Only 40% of respondents know that a multidisciplinary team works together to treat cleft lip and palate. 37.1% of those surveyed were aware of what a speech-language pathologist is. According to 31.4% of respondents, Speech-language pathologists are a component of the multidisciplinary team. The knowledge that a speech-language pathologist offers treatment for Cleft lip and palate is known only by 31.4% of persons. The participants thought the current knowledge was incredibly fascinating, and they were more than delighted to be willing to share this knowledge with others.

Table 2 showing overall awareness on intervention aspects of cleft lip and palate in parents

		Frequency	%
Overall awareness	Yes	22	63.58
	No	13	36.42

Table 2 shows 63.58 percent of awareness and 36.42 percent of no awareness in parents for the intervention aspects in cleft lip and palate,

Table 3 showing the overall awareness among parents

	Frequency	%
Low (0 to 3)	14	40
Moderate (4 to 7)	13	37.1
High (8 to 10)	8	22.9

Phase II: Participants with Inclusive and Exclusive Criteria

A group of 35 parents (aged 25 to 35 from Kannur district of Kerala) who had children in the age range of 0-7 years and irrespective of male and female participated in the present study. Parents were free from any psychological illness, hearing disorders, neurological issues and speech language disorders

Stimulus Used

The prepared closed set of 10 questions was used for the collection of data.

Procedure

The validated list of questions was circulated among parents. The participant's task was to read and understand the questions carefully and mark the response

Analysis

The questionnaire which was administered on parents with their response was collected and a score of 1 was given for the response 'yes' and 0 for the response 'no'. the accumulated data was further subjected to statistical analysis and the results are discussed below.

RESULTS AND DISCUSSION

The aim of the study was to analyse the awareness regarding the intervention of cleft lip and palate among parents in the age range

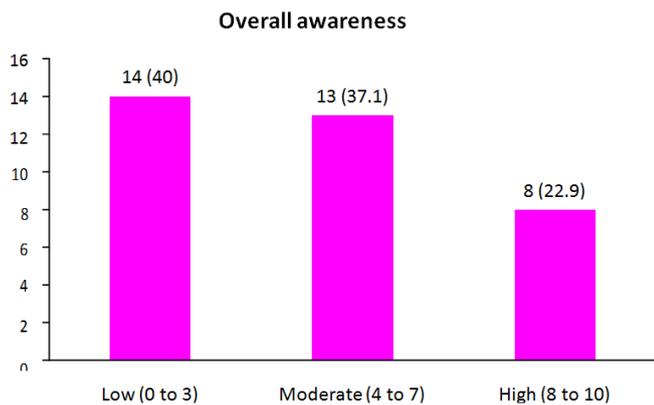


Figure 1 showing the graphical representation of over all awareness among parents

The above table3 and fig1 reveal that about 40% of the participants exhibited poor awareness, 37% of the participants showed moderate awareness, and 22.9 percentage showed high awareness

DISCUSSION

Cleft lip and cleft palate are the most common congenital defects which result from a baby's face tissues not completely sealing off during development that typically take the form of isolated birth defects but they are also associated with a number of inherited genetic disorders or syndromes.

The symptoms of cleft lip and palate include one or both sides of the face may be affected by a split in the lip and palate (roof of the mouth), A lip split that just looks like a tiny notch in the lip or that extends through the upper gum and palate and into the base of the nose, a gap in the roof of the mouth that has no impact on facial appearance. Less frequently, a cleft only affects the soft palate muscles (submucous cleft palate), which are in the back of the mouth and protected by the lining of the mouth. This kind of cleft is frequently undetected at birth and may not be identified until later when symptoms manifest. Submucous cleft palate symptoms and signs can include having trouble eating, swallowing issues that could cause food or fluids to leak out of the nose, speaking with a nasal tone, persistent ear infections

Various studies have showed the effect of cleft lip and palate in the child's speaking and swallowing issues. Results of a study conducted by Prathani and Pumnum (2016) on the 5-year speech and language outcomes in children with cleft lip/palate (CLP) revealed that articulation errors were the most prevalent speech and language issues in those with clefts, followed by abnormal understandability, resonance abnormality, and voice disturbance. So, it is crucial to be aware of the importance of speech and language intervention in each child's life.

The results reveals that there is a low awareness on intervention for cleft lip and palate which in turn shows that there is a need of intense courses or programmes to create knowledge among the people. People should be made aware of the significance of cleft lip and palate intervention, the role of SLPs in treating such clients, and the outlook for patients' futures.

Thus, based on the perspective of an SLP, this study may aid in our analysis of rural residents' knowledge of cleft lip and palate intervention. It also provides a means by which professionals who need to be aware of this issue can carry out various programmes to raise awareness of cleft lip and palate intervention.

CONCLUSION

Cleft lip and cleft palate are the opening in the upper lips or the palate. The purpose of the study was to find out the awareness among parents regarding intervention of cleft lip and palate. According to a meta-analysis of the studies that were looked at, 0.3 out of every 1000 live births are cleft lip cases (95 percent CI: 0.26-0.34). (Salari and Darvishi (2021)). Consequently, knowledge about the disorder and its intervention is essential. Thus, the present study was done to analyse the awareness regarding the intervention of cleft lip and palate and the result revealed a low awareness among parents in the rural areas of Kerala.

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