

AWARENESS OF PARENTS ON THE NATURE OF CLEFT LIP AND PALATE (CLP): AN EXPLORATORY STUDY

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Abstract

Cleft lip and palate (CLP) is a congenital anomaly which requires a multidimensional medical care by multidisciplinary team of professionals. Extensive information and appropriate knowledge is required for the parents of Child with CLP. This study is an endeavor to assess the parental awareness of the condition of cleft lip and palate. The present study is aimed to assess the parental awareness on nature of CLP on various aspects such as cause, associated problems, assessment and treatment of CLP. 30 parents of children with CLP who visited the unit of structural orofacial anomalies (USOFA), All India Institute of Speech and Hearing (AIISH), Mysore served as participants of the study. A Questionnaire was developed with five subdivisions on seven domains which consisted of five myths and five facts. The participants were asked to mark YES or NO for correct or incorrect statements respectively. On exploring the responses, the results revealed that the parents having a child with CLP believe more in the myths about the causes rather than facts and the awareness on treatment schedule and the role of team members are limited. The results also indicate better awareness on the associated problems and also showed a greater need to sensitize the parents on assessment and treatment of CLP. The results obtained could be attributed to the facts that the medical guidance provided for the parents having child with CLP was limited or in spite of having the child with CLP, the efforts taken to understand the condition is not adequate. The results of the present study warrant developing more systematic programs towards creating awareness on CLP among parents and various health care professionals.

Key words: *Cleft lip and palate, parental knowledge, parental awareness*

Cleft lip and palate (CLP) is one of the most commonly seen congenital anomalies after congenital cardiac anomalies (Wyszynski, 2002). The exact incidence of CLP is not available in India, because of the lack of an established registry for craniofacial deformities. The last dedicated multicenter study involving three cities in India and 94,906 births was conducted between 1994 and 1996 (World Health Organization, 2001). The present incidence of cleft deformities however is around 1 in 650 live births in India, which translates to around 30,000 new patients every year (Raju, 2000).

CLP is a heterogeneous condition resulting in varieties of associated problems. These irregularities vary greatly in terms of extent of the cleft and other characteristics (Sinko, Jagsch, R., Prechtel, V., Watzinger, F., Hollmann, K., & Baumann, A. 2005). CLP deformities are completely correctable and provide the client a chance to get back into normalcy with predictable quality of life. Depending on the severity and the variability of the cleft, the families need to cope with speech therapy, ear infections, learning disabilities, and other associated problems and treatment

CLP requires a multidimensional medical care by multidisciplinary team of professionals. The management team not only consists of professionals, but also consists of non

professional members (family members/parents). An integrated system of delivery of care enables the individuals within the team to function in an interdisciplinary way so that all aspects of health care for the cleft condition can be delivered. Counseling by all professionals play a very important role in shaping the beliefs, attitudes, and concerns of the parents. These teams of professionals should demonstrate a belief in the child's ability to cope with the challenges of cleft lip and palate. Being a part of the team extensive information and appropriate knowledge is required for the parents of child with CLP. The incidence of CLP has remained the same and the associated benefits too have not been utilized solely due to the lack of awareness among the parents or the various health care providers themselves.

Parents of children with disabilities or chronic illnesses, including orofacial clefts, have been surveyed to determine their needs, concerns, and sources of stress. Results from the survey on parents of children with cleft lip and/or cleft palate and other diagnoses by Horner, M., Bartsch, A., Trimbach, G., Zobel, I., & Witt, E. (1987) indicated that rehabilitation program service should include help with the financial burden of having a child with a birth defect, recreation for the child, child care, and counseling options for the family and parents. It

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suggests that the professionals should give parents adequate information early in the course of treatment and in multiple sessions which increase parental retention of information and to promote the process of coping (Broder & Trier, 1985; Hafner, M. M., Rawlins, P., & Giles, K. 1997).

The family environment is an important factor in the rehabilitation of a child with a facial cleft. The attitudes, expectations and degree of support shown by parents are likely to have an enormous influence on a child's perception of their cleft impairment (Bull & Rumsey, 1988; Lansdown, R., Lloyd, J., & Hunter, J. 1991). Pannbacker and Scheuerle (1993) evaluated parental attitudes towards the treatment of their child's cleft palate. They found that 36% of parents wished for more participation in their children's treatment decisions, and a large percentage (65%) thought that their help was only slightly effective or ineffective.

Young (2001) examined the type of information required by the parents and desire when being informed after delivery that their newborn has a cleft. The results showed that parents wanted the informer to be sure to cover topics such as feeding methods and home management. They also reported that information on subjects such as etiology and repair of the cleft can be reported until follow-up visits.

Byrnes, A. L., Berk, N. W., Cooper, M. E., & Marazita, M. L. (2003) reported that parents wanted health care providers to "Be in greater control of the informing conversation, to show more caring and confidence, to show more of their own feelings, to give parents more of an opportunity to talk and show feelings, to make a greater effort to comfort parents, to provide more information, to initiate more of a discussion about the association between clefts and mental retardation/ learning disabilities, and to provide more referrals to other parents during the informing interview."

White, Eiserman, Beddoe, and Vanderberg (2006) studied the perceptions, expectations, and reactions to cleft lip and palate surgery in native populations as a pilot study in rural India. 52 families were given a 15-item questionnaire designed to elicit from parents general knowledge concerning cleft lip and palate, beliefs regarding its causation, and expectations of what surgery would accomplish. Shorter second and third questionnaires were administered after the screening process and after surgery. The results revealed that 64% of parents did not limit their child's social interaction and were not ashamed to be seen in public. 26% exercised some constraints, and 10% kept their

children totally isolated, not permitting them to leave the house or attend school. Regarding causation, the vast majority (84%) ascribed the cleft to "God's will" and 10% to sins committed in past lives. Only one parent had acknowledged the influence of genetics, although several had a positive family history. Environmental factors were not considered as an issue. Most families expected their child's life to be better when the facial deformity was corrected. Marriage prospects were the main concern, more so for girls than boys. Educational opportunity was a second strong theme. Authors concluded that a greater understanding of the beliefs and expectations was gained by means of the study.

Latta, L. C., Dick, R., Parry, C., & Tamura, G. S. (2008) carried out a qualitative study on parental responses to involvement in interdisciplinary teaching sessions and found that parents valued participation with the team in decision making about their child's care, as well as being able to communicate with the practitioners and understand the plan of care. Professionals have noted the benefits of parental involvement and, in fact, are encouraged by the American Cleft Palate Association (2008) to "Ensure the family/caregiver and patient have opportunities to play an active role in the treatment process". To further involve parents in the treatment process and to increase satisfaction, it is important to assess the level of understanding by the parents on the nature of CLP condition.

This study is an endeavor to assess the parental awareness of the condition of cleft lip and palate. Awareness is the state or ability to perceive, to feel, or to be conscious of events, objects or sensory patterns. It is important for the parents to understand the facts and myths about the causes, associated problems, about diagnosis and treatment issues of CLP. Thus, there is a need to carry out explorative study on the awareness of Indian parents about the child with CLP. The present study is carried out to sensitize the parents of child with CLP on nature of CLP, various issues related to the information on facts and myths with respect to various domains, in order to focus during counseling, which thus ultimately improves the treatment outcomes.

Objective

To assess the parental awareness on nature of CLP on various aspects such as causes associated problems, assessment and treatment of CLP.

Method

Participants

The present study included 30 parents of children with CLP who visited the unit of structural orofacial anomalies (USOFA), All India Institute

of Speech and Hearing (AIISH), Mysore. The children of participants included in the study were in the age range of 2 to 15 years. Among them 5 children had unrepaired CLP and 25 of them had undergone surgery for cleft lip/ cleft palate. Consent was obtained from the participants to take part in the study.

Questionnaire

The questionnaire was developed with five subdivisions on seven domains such as causes, associated problems, evaluations, treatment (General, surgery, and speech therapy), and general nature of CLP. Each domain had ten statements which consisted of five myths and five facts. The response for each of the question was close ended and binary choice of 'YES or NO' was provided.

Procedure

The parents were given the prepared questionnaire and were briefed about each statement. Parents were also given information to ask for clarification if any. The questionnaire was filled by each participant. The parents were asked to mark YES or NO for correct or incorrect statements respectively. After the survey, parents were educated regarding the nature of CLP and they were provided with keys containing the correct answers.

The data from 30 participants was analyzed using SPSS software (version 16). The percentage of correct and incorrect responses for each domain was calculated. Comparison across domains was made with the help of repeated measure ANOVA. The values were then tabulated and depicted through the graphical representation.

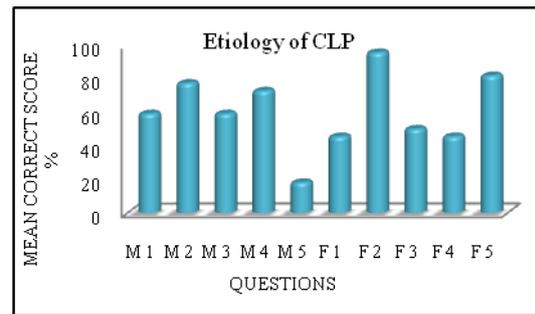
Results and Discussion

a) *To estimate the awareness of parents within the various domains on nature of CLP (various aspects such as causes, associated problems, assessment and treatment of CLP).*

i. Etiology

Questions in this domain were intended to assess the knowledge of the parents regarding the etiology for CLP. The results revealed that the parents believed more in the myths than the facts causing CLP. On frequency analysis, it was found that among the statements related to the facts, 95.5% of parents believed that insufficient intake of Vitamin A and Folic acid could lead to CLP followed by 81.8% of parents reported that fall of mother during pregnancy may be the cause of CLP. 50% of the parents believed CLP could occur due to previous miscarriages and abortions and only 45.5% of parents believed that CLP is due to heredity and also believed that

if the mother's age is more than 30 years during pregnancy then it could also lead to CLP.

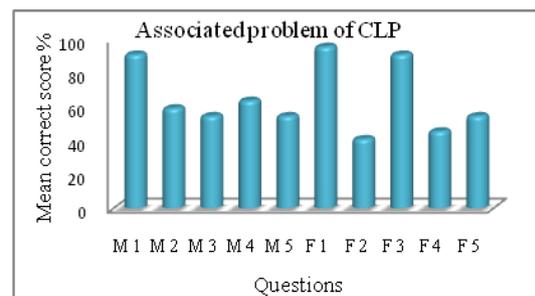


Graph 1: *The mean percentage distribution of the participant's response on etiology of CLP*

Many parents felt the myths to be the actual cause for CLP. 77.3% parents had responded to ultra sound scanning at 5 month of gestational period could lead to CLP and 72.7% of parents felt that the cause of the cleft is due to past sin in life. The present results support the findings by White, Eiserman, Beddoe, and Vanderberg (2006) who reported that 84% of parents in their study reported God's will and 10% reported the past sins had caused CLP in the child. 59.1% of parents felt that eclipse and excessive vomiting might have been the cause for CLP. 18.2% of parents felt that mother's smoking and drinking habits had no effect in leading to CLP as shown in above graph 1. These results indicated that the parents need to be oriented regarding the etiological factors that could cause CLP in children.

ii. Associated Problems

Domain on the associated problems focused on assessing the parental knowledge on the associated problems in the child with CLP. On frequency analysis, it was found that 95.5% of parents reported that their child had difficulty in sucking and drinking milk. Parents also felt that 90.9% of the time the child could have problems in pronouncing certain sounds and 54.5% of parents responded that the child with CLP may develop inferiority complex. 45.5% of parents reported that their child speaks through the nose.

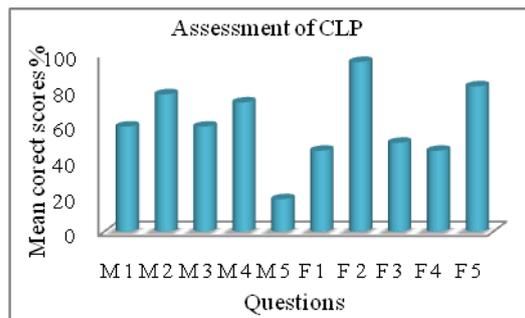


Graph 2: *The mean % distribution of the participant's response on associated problems of CLP*

The responses for the myth statements showed that good percent of parents (90.9%) felt that their child could have difficulty in attending and concentrating towards work, 63.6% of parents reported that child with CLP will not have dental problems and 59.1% parents felt that the child with CLP will have problems to perform up to the age matched peer group. 54.5% of parents said the children with CLP could have problem in walking and running and will not develop difficulty in speaking. The results of the present study shows that there is a need to educate the parents about the problems which child with CLP may face as it grows so the parents can provide a strong psychological and overall frame to the child.

iii. Assessment

On this domain, the parental knowledge on the assessment of child with CLP was explored. The percentages of correct responses marked by the parents showed that a good percentage (95.5%) of parents reported that the speech and language assessment was very important for child with CLP. 81.8% of parents reported that the family support could be extended through counseling and 50.5% of parents reported that psychological assessment was required for child with CLP. 45.5% of parents reported that regular dental check up and hearing screening is required for the child with CLP.



Graph 3: The mean percentage distribution of the parent's response on assessment of CLP

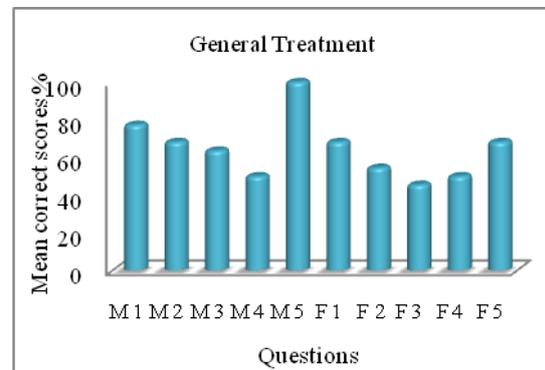
The responses given by parents for the incorrect statements indicated that 77.3% of parents believed that the testing of CLP is done only once a year and 72.7% of them believed that the social worker will help in correcting the feeding problems in children with CLP. 59.1% of parents felt that child with CLP will be assessed by only one doctor and they also believed that plastic surgeon would help in correcting the dental problems. 18.2% of parents felt that testing for reading and writing in CLP was very important (shown in graph 3). The finding of the present study supports the findings by young (2002); Broder and Trier (1985); Hafner et al. (1997); Pannbacker and Scheuerle (1993), and Latta et

al. (2008). These results revealed that the parents have to be more educated regarding the assessment and treatment of child with CLP.

iv. General Treatment

The domain on general treatment covers the questions pertaining to the general issues pertaining to treatment of CLP. The results of this study indicated that the parents of children with CLP are not sensitized about the general treatment procedures for child with CLP.

In accordance with the graph 4, it is seen that 68.2% of the parents reported that the feeding problems can be corrected by providing feeding aids and surgery helps to reduce the food particles coming out from the nose (nasal regurgitation). 54.5% of the participants reported that dental treatment can be initiated by 2 years of age. 45.5% of parents believed that prosthesis can be used if the surgery performed was not successful. 50% of them reported that modified feeding bottles can be used to feed the baby with CLP.

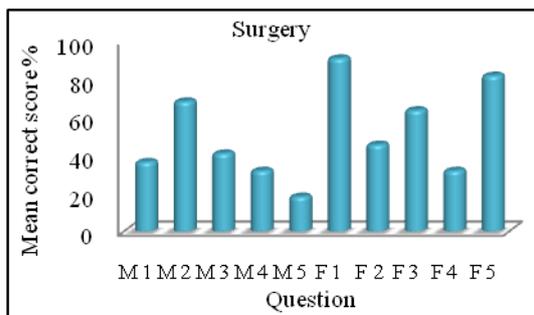


Graph 4: The mean % distribution of the participant's response on general treatment of CLP

From the section pertaining to the myth related to CLP, it is seen that 100% of parents had believed that attending speech therapy regularly improves speech and 77.3% of parents felt that family members help is not required while providing therapy for child with CLP. 68.2% of parents felt that training the child with CLP at home is not required and 63.6% of them said that academic performances will not improve after psychological treatment. 50% of parents believed that attending speech therapy and prosthesis fitting was not very much important. These results revealed that the parents have to be oriented towards the long term treatment related to CLP. The result of the present study is supported by the findings of young (2002); Broder and Trier (1985); Hafner et al. (1997); Pannbacker and Scheuerle (1993), and Latta et al. (2008).

v. Surgery

Questions on surgical details were formulated to explore the knowledge among parents. It was shown that 90.9% of the parents reported that surgery is important for normal speech and language development and 81.8% reported that the surgery of the palate can be done when the child is 6 months old. 63.85 % of parents reported that the child has to be hospitalized for a week approximately after surgery and 45.5% reported that surgery of the palate is not always successful and 31.8% surgery of palate always does not lead to normal speech.



Graph 5: The mean percentage distribution of the participant's response on surgery of CLP

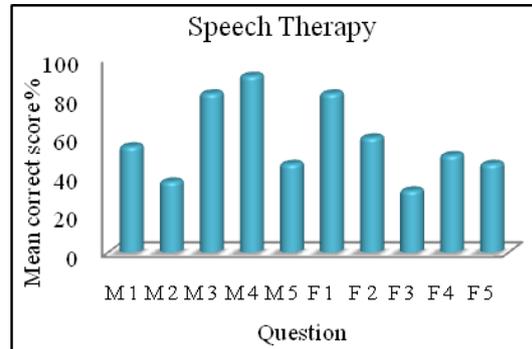
The section related to myths on surgery indicated that 68.2% of the parents reported that surgery for the palate can be done as many times as possible and 40.9% of parents felt that Hb count and weight is not an important issue for surgery. 36.4% of parents reported that surgery of lips is done after one year and 31.8% of parents reported that fistula always leads to speaking difficulty. 18.2% of parents reported that surgery is free of cost in all government hospitals (as shown in graph 5).

vi. Speech Therapy

This domain assessed the knowledge of parents related to speech therapy. Among the statements related to facts 81.8% of the parents reported that speech therapy is always required after surgery. 59.1% of parents felt that speech therapy will reduce the air flow through the nose and 50% reported that tablets and medicines will not help to get better speech. 45.5% of parents reported that speech problems cannot be corrected by plastic surgeons and 31.8% felt that speech problems cannot be corrected through black magic.

Among the subjects 90.9% of parents reported that speech problems can be corrected within six days and 81.8% parents stated that pronunciation problems can be corrected only through surgery. 54.5% of population thought that speech therapy can be started only after 5 years of child's age and 45.5% of parents believed that speech

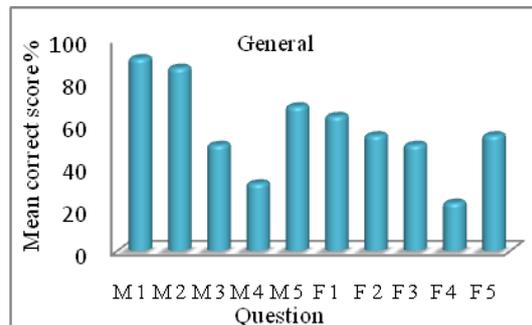
therapy will help to close fistula. 36.4% of parents believed that speech therapy can be given by teachers as shown in the above graph 6. These results revealed that there is a greater need for the parents to be oriented towards the importance of various aspects about speech therapy.



Graph 6: The mean % distribution of the participant's response on speech therapy of CLP

vii. General

This domain had questions regarding general information on CLP. The results show that the parents believed less in facts when compared to myths. 63.6% of the parents reported that pediatrician is one of the team members of CLP, 54.5% felt dentists are also members of CLP and engineers have no role to play in CLP team. 50% of parents stated that general physician's consultation is also required for a child with CLP. 22.7% of parents stated that social workers also have to play in a CLP team.

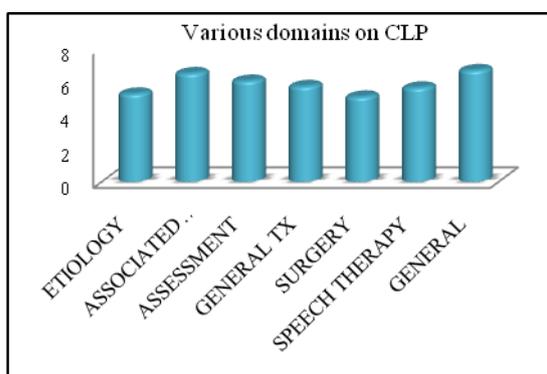


Graph 7: The mean percentage distribution of the parent's response on general aspects of CLP

As shown in graph 7, the percentage of correct responses on myth statements obtained were that 90.9% of parents reported that skin doctor's advice is required for child with CLP and 86.4% of them reported that fortune tellers also have a role in CLP rehabilitation team. 68.2% of parents reported that prostodontist are not CLP team members and 50% of parents reported that nurses are not team members of CLP. 31.8% parents reported that family members do not have a role in CLP team.

B) *To estimate the awareness of parents across the domains on nature of CLP (various aspects such as causes, associated problems, assessment and treatment of CLP).*

30 parents of children with CLP were administered questionnaire consisting of ten questions on seven domains. Comparison across the domains was done using repeated measures ANOVA, and there was significant difference ($p < 0.005$) seen between domain in surgery and general information. On comparing the average scores across the domains, average of 5 to 6 scores were obtained as shown in below table 8 suggesting that there is a need for the parents to be educated across all the domains. The mean values are shown in the below graph 8, it can be noticed that the parents had a better knowledge on domains about associated problems, assessment, and general information when compared to rest of the domains.



Graph 8: *The mean % of response on nature of CLP on various aspects of CLP*

The results of the present study add to the established results of the previous studies carried out by Broder and Trier (1985), Horner *et al.* (1987), Pannbacker and Scheuerle (1993), Hafner *et al.*, (1997), Young (2001), White, Eiserman, Beddoe, and Vanderberg (2006), Latta *et al.*, (2008) that there is a greater need for the parents to know the facts on various domains on CLP. The percentage of parents reporting the myths to be correct statements shows that there is need to educate the parents on various facts on nature of CLP.

Overall results from the present study show that there is a greater need for the parents to know the facts on various domains on CLP. The results obtained could be attributed to the facts that the medical guidance provided for the parents having child with CLP was limited or in spite of having the child with CLP, the efforts taken to understand the condition is not adequate. This shows that there is a need for education of the health care professionals. The results are in concordance with findings from the study by

Johansson and Ringsberg (2004) as well as that of Grow and Lehman (2001). As these authors state, the findings from the studies such as these can serve as part of the education for multidisciplinary health professionals that is currently lacking.

Thus it can be concluded that the findings from the study warrant the SLP to develop more systematic programs towards creating awareness on CLP in various culture and communities. It is also important for speech language pathologists to have knowledge on the parent's awareness on CLP as parents play an important role in identification and management of CLP. Also to further address this issue, birth and treatment hospitals should implement standard education and training regarding the care of patients with orofacial clefts. Perhaps, as participants mentioned, information should be created or provided about an existing online resource that addresses the etiology of clefting, surgeries, postsurgical care, feeding limitations and tips, and other crucial information.

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Appendix I

QUESTIONNAIRE: Awareness on Issues Related to Cleft Lip and Palate

Name: _____ **Date:** _____
Age: _____ **Education:** _____
Profession: _____ **Phone no:** _____
Email Id: _____

I. The following session has the list of few conditions which may or may not be the cause for the cleft lip and palate (CLP). Please tick the appropriate one.

Cleft lip and palate occurs due to....

Sl. No	Causes	Yes	No
1	CLP is due to the heredity (runs in the family)		
2	If the Vitamin A and Folic acid is taken less during pregnancy it increases the possibility of CLP		
3	Eclipse during pregnancy		

- 4 Ultrasound scanning during 5th month
- 5 Previous miscarriage / abortions
- 6 Excessive vomiting during pregnancy
- 7 Mothers age more than 30 years during pregnancy
- 8 Fall during pregnancy
- 9 Past life's sin or curses
- 10 Mother smoking and drinking alcohol habits have no effect

II. Child born with CLP may or may not have the following problem. Please tick the appropriate one.

The child born with CLP will always have problems such as.....

Sl. No	Associated problems	Yes	No
1	Difficulty to drink milk		
2	Dental problem		
3	Difficulty in walking and running		
4	Problem in pronouncing some sounds/words		
5	Will have cold and cough		
6	Can have inferiority complex		
7	Difficulty to perform up to their age level(low IQ... low menatal ability)		
8	Will have difficulty in attending and concentrating		
9	Will speak up to their age level		
10	CLP child speaks through nose even after surgery		

III. Testing the child with CLP is very much important for treatment. Please tick the appropriate one.

Do you feel that

Sl. No	Assessment	Yes	No
1	Child with CLP will be examined by only one doctor		
2	Testing is done only once in a year		
3	Regular dental checkup is required		
4	Speech and language testing is very important		
5	The plastic surgeon will correct the dental problem		
6	Social worker will help in feeding problem		
7	Psychological assessment is required in CLP		
8	Hearing screening is required in CLP		
9	Family support is extended through counseling		
10	Testing reading and writing problem is important		

**IV. Treatment is required the child with CLP.
Please tick the appropriate one.**

Do you feel that

Sl. No	General	Yes	No
1	Feeding problem can be corrected by providing feeding aids		
2	Family member`s help in therapy is not required		
3	Dental treatment can be initiated by 2 years		
4	Prosthesis can be used if the surgery is not successful		
5	Training the child at home is not required		
6	Academic performance will not improve after psychological treatment		
7	Modified feeding bottles can be used to feed the baby with CLP		
8	Attending speech therapy after surgery or prosthesis fitting is not important		
9	Surgery helps to reduce the food particles coming from the nose		
10	Attending regular therapy will not be beneficial for the child		

V. Surgery

Sl. No	Surgery	Yes	No
1	Surgery for lips is done after one year		
2	Surgery is important for normal speech and language development		
3	Surgery of the palate is not always successful		
4	Palate surgery can be done as many times as possible		
5	Hb count and weight is not important consideration during surgery		
6	Surgery is free of cost in all the government hospitals		
7	After surgery child will be hospitalized for one week		
8	Surgery of the palate leads to normal speech		
9	The fistula always does not lead to speaking difficulty		
10	Surgery of the palate can be done as soon as infant is born		

VI. Speech therapy

Sl. No	Speech therapy	Yes	No
1	Speech therapy can be started after 5 years		
2	Speech therapy is always required after surgery		
3	Speech therapy will help to close the fistula/cleft		
4	Speech therapy will reduce the flow of air through the nose		
5	Pronunciation problem can be corrected only through surgery		
6	Speech can be corrected by black magic		
7	Speech problem cannot be corrected by plastic surgeon		
8	Tables/ tonics cannot help to get better speech		
9	Speech problems can be corrected in 6 days		
10	Therapy is given by a school teacher		

I. General

1. Did you know about the disorder before the child was born?- Yes/No
2. Do you feel you don't have enough information about CLP?- Yes/No
3. Who all can provide useful information about CLP?

Sl.No	Yes	No
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

Signature