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Speech understandability of repaired cleft palate patients pre and post caregiver training

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ABSTRACT

Background: Treating speech and language problems in repaired cleft palate patients in India is still an uphill task due to lack of facilities. This study attempted to use parents as team members for the speech management of cleft palate patients in Andhra Pradesh, India. Objectives: To investigate whether a positive change in speech understandability for individuals with cleft palate will result from a parent-administered intervention program. Materials and Methods: Twenty-eight parents had enrolled for the speech camp held in September 2004. The parent-training program at the speech camp ensured that parents were given adequate awareness. Out of the 28, 18 (64.28%) reported for one follow-up, referred to in this article as Group I. Ten (35.72%) out of the 28 came for two consecutive follow-ups, referred to in this article as Group II. Results: Pre and post training understandability scores obtained in the known context (reciting a familiar poem in the native language, counting 1 to 10) and unknown context (peer group names, family information, describing their journey from home to hospital) for Group I and Group II were evaluated. Results revealed that a higher percentage of cases showed significant improvement in understandability in the unknown context after treatment. Unknown context can be considered a measure to assess speech understandability after training. Further, it shows that parent training without practice at home may not show the desired results. Conclusion: This study reveals that parents can effect a positive change in the speech understandability of their children following training, provided the exercises are carried out regularly at home and the parents report for the follow-up assessments and guidance.

KEY WORDS

Corrective babbling, understandability

Cleft Lip and palate is a common condition referred to a speech and hearing clinic. We are all aware that children with cleft palate (CP) require surgical and dental management to establish a mechanism that is adequate for normal speech production. For some children, these treatments alone are sufficient and normal speech develops. A large percentage of children with cleft palate require speech-language intervention.

Children with craniofacial anomalies are at high risk for speech and language disorders. Keywords Evaluation of speech and language development provides information that is
needed by the team in planning speech management in addition to surgical and dental management. It also helps to assess treatment outcomes. For a speech-language pathologist, speech and language evaluation should occur often to ensure adequate documentation of each child’s progress and to develop ways of making appropriate recommendation for further intervention.

At least 50% of cleft palate children require the services of a speech-language pathologist. The children often require intervention to enhance their articulation or phonological development or general expressive language functioning. Some patients with cleft palate may have articulation and resonance problems associated with velopharyngeal inadequacy. This speech problem often impedes education, employment and becomes a social stigma lasting a lifetime. In the presence of velopharyngeal inadequacy, children often use compensatory articulatory patterns resulting in reduced speech intelligibility and acceptability. The inability to produce intelligible speech may result in reduced socio-communicative competence.

Children with cleft palate with borderline velopharyngeal valving problems do benefit from speech therapy. The effectiveness of a six-week summer residential speech program was studied in 13 children in the age group of six to 12 years with repaired cleft palate. Articulation therapy was provided for four hours daily for a period of 26 days. The pre-therapy and post-therapy video recording showed that all the subjects improved their articulation test performance during the therapy period. The same subjects were followed up nine months later and the assessment showed that the children had not made further significant progress and some showed regression. This was attributed to the poor speech therapy service delivery.

The incidence of Cleft lip and Palate in India is estimated approximately as one in 781 live births thus leaving a large population without adequate support of a speech pathologist. A multicentric survey conducted by the Tata Institute of Social Sciences, Mumbai, India with funding from Smile Train Inc. showed that only 25% of the cleft palate patients had undergone surgery and these were predominantly from districts with higher socioeconomic status.

A few researchers have examined the benefit of parent-directed intervention programs. Blakely and Brockman address this through a demonstration program as well as Scherer who demonstrated the success parent-directed intervention could have. D’Antonio and Nagarajan have developed programs that train community health workers. All of these efforts suggest that parents might well serve as a viable and useful resource for providing home-delivered speech intervention to their loved ones. The lack of availability of trained professionals in India led to an urgent need to look for alternative resources. The most appropriate resource could well be a parent or family member.

Parents form a powerful entity in the rehabilitation team. Routinely, they act as informants during history taking and assessment. They can also act as participants by following recommendations given by the professional with respect to speech teaching. However, parents rarely determine how to and how long to train without direct and continuing guidance by a speech pathologist. Any speech intervention done at home involves following a directed plan and periodic return checks to determine if the intervention is appropriate and the desired changes are being made.

The objective of the present study was to investigate whether a positive change in speech understandability for individuals with cleft palate could result from a parent-administered intervention given by parents who would be trained speech education mentors.

**MATERIALS AND METHODS**

**Subject/mentor selection**

For inclusion in the study all parents/mentors and subjects had to meet set criteria:

1. Subjects must have undergone CP repair with assessment by a plastic surgeon and two speech pathologists to determine that no structural velopharyngeal inadequacy remained. If a question existed, instrumental assessment was done.
2. Parent/Mentors were required to demonstrate literacy levels sufficient to read therapy materials or bring someone to camp who could read and write.
3. Subjects must have no other physical, behavioural or neurological problems.
4. Parents must agree to attend five-day speech training and return as requested for periodic reviews no more than six months apart. (These coincided with new
5. Parents must be Hindi or Telugu speakers.
6. Subjects must present with a myriad of cleft palate speech characteristics that included audible nasal emission, hypernasality and compensatory misarticulations. Subjects with only minimal articulation errors were not taken into the study.

Age of the parents was not a participant criterion; age and gender distribution of the subjects are shown in Table 1.

The 28 parent/subject dyads were enrolled in one, five-day speech camp in September 2004. Follow-up reviews were done in January and September 2005.

Of the 28-parent/subject dyads, 18 (64.28%) reported for one follow-up. These participants are referred to as Group I. The remaining 10 (35.72%) dyads returned for two consecutive follow-ups and are referred to as Group II.

Training trainers
Prior to beginning the parent/mentor training program, an association was formed among the Department of Plastic Surgery at Nizam’s Institute of Medical Science (NIMS) in Hyderabad, The Ali Yavar Jung National Institute for Hearing Handicap (NIHH) in Secunderabad, India and RSF-EARTHSPEAK, a United States-based, non-profit organization devoted to providing speech and related services for individuals with surgically corrected cleft palates. The goal of this triad was to develop a plan that would provide sustainable care to patients with cleft palate from surgery through speech correction [Table 2].

Lead participants from each organization included Dr. Mukunda Reddy, Head of the Plastic Surgery department at NIMS, Joan D’Mello, Head of NIHH and Dr. Richard and Andi Jobe, Medical and Speech Directors of RSF-EARTHSPEAK.

Three days before the parent speech training camp, speech interns from NIHH were trained in a workshop. The workshop provided information and practice on topics related to cleft palate, surgical repair, comprehensive speech evaluation, parent training and the theory and implementation of Corrective Babbling™. The workshop also involved intern observation and assisting workshop faculty in intake and review assessments. Continued training occurred during the parent weeklong speech camp. Morning and evening meetings were held to provide students with contextual instructions from the ongoing parent speech camp.

Assessment of potential speech camp students included comprehensive birth and developmental, surgical, medical and educational history, oral-motor examination and perceptual speech assessment using pre-set speech stimuli of syllables, words and sentences. The quality of speech was noted with respect to articulation, resonance, nasal emission and compensatory misarticulations.

Spontaneous speech was elicited with questions about family, friends and description of familiar animals. Utterances were rated using Peterson-Falzone, Trost-Cardamone, Karnell and Hardin-Jones[11] method. Its rating and description is shown below.

The parent speech training camp was held for one week, seven hours a day. Non-local participants were housed at NIMS.

All materials and a speech-training manual were provided to each parent/mentor. The manual was developed in English by Jobe A[16] of RSF-EARTHSPEAK and translated into Telugu by NIHH speech language pathologist Rao[17] and into Hindi by Kumar.[18] The manual was used as a resource in conjunction with the speech camp program and ensured that parents were given awareness about Cleft Palate, Causes, Surgical intervention, Associated Problems with Cleft Palate and the concepts of speech development and speech intervention using Corrective Babbling™. This method is clinician-developed over 18 years of experimentation and combines

<table>
<thead>
<tr>
<th>Rating scale</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>0</td>
<td>Speech is understandable all of the time</td>
</tr>
<tr>
<td>1</td>
<td>Speech is understandable almost all of the time</td>
</tr>
<tr>
<td>2</td>
<td>Speech is hard to understand some of the time</td>
</tr>
<tr>
<td>3</td>
<td>Speech is hard to understand most of all the time</td>
</tr>
</tbody>
</table>

Peterson-Falzone, et al., 2006, p.75

<p>| Table 1: Distribution of the subjects in terms of age and gender |
|-----------------|---------------|</p>
<table>
<thead>
<tr>
<th>Age group (in years)</th>
<th>Male</th>
<th>Female</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5</td>
<td>1</td>
<td>1</td>
<td>07.14</td>
</tr>
<tr>
<td>6-10</td>
<td>7</td>
<td>6</td>
<td>46.42</td>
</tr>
<tr>
<td>11-15</td>
<td>3</td>
<td>3</td>
<td>21.44</td>
</tr>
<tr>
<td>16-20</td>
<td>2</td>
<td>1</td>
<td>10.72</td>
</tr>
<tr>
<td>21-25</td>
<td>3</td>
<td>1</td>
<td>14.28</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>12</td>
<td>57.15%</td>
</tr>
<tr>
<td>Percentage</td>
<td>57.15%</td>
<td>42.85%</td>
<td></td>
</tr>
</tbody>
</table>
the principles of cerebral neuroplasticity with conventional speech therapy practices.

Parent/subject dyads were divided among the interns so that each intern had direct training and follow-up responsibility for up to four dyads. This afforded interns and parent/mentors the ability for smaller group instruction that supported lectures and gave opportunity for demonstration and supervision of parent practice. It also provided a more intimate environment within the larger camp body that promoted a safe learning environment.

On the first three days of the speech camp parent/child dyads worked together during lectures and practice times. On the later days parent/parent dyads formed to learn speech-training steps that were now beyond the current successful ability levels of the children in treatment. During these times children received audiological evaluation and were provided with supervised play. Daily homework was given and reviewed each morning through whole group demonstration.

Parents were taught steps of good teaching, how to elicit and stimulate sound production, modelling and reinforcement schedules, recording of progress using graphs and movement within the Corrective Babbling™ program as success for each sound taught was achieved.

On the last day of the camp, parent/mentors were tested in all areas of training given during the week. A pre-set test form in a one to one situation was used and we did assessment with the help of interns and supervising faculty. Parents responded verbally and through demonstration. Test results were rated on a scale of 1-4 with 1 being poor and 4 being excellent. Subjects were also assessed on progress in the Corrective Babbling™ sequence and parents told where in the program to begin. All subjects were either on pre-speech or early vocalization levels in the program at the time of camp termination.

Parent/mentors and their children were then directed to practice the Corrective Babbling™ program as taught, twice a day for 10 min each time. A record was kept of this schedule. They were directed to return for review at the next training camp in approximately five months. The timing of pre-treatment and follow-up sessions was approximately five months. The number of follow-ups to be made for each child was not determined at the pre-treatment stage; however, all the cases were asked to come for follow-up assessment so that those who had made optimal progress could be terminated from the intervention program. For those who did not make any progress an attempt was made to find out if the training was being conducted by the caregiver at home and help was provided to the caregiver in the skills that they lacked for continuation of the training at home. Follow-up review at periodic intervals was the only means to determine if caregiver training was taking place adequately and to provide further support to the caregiver.

RESULTS

When parents presented for review, they were seen one to one and asked about their practice times and feelings of progress. Graph books of recorded practice were reviewed when available. Parents were also asked how they felt the program was working and whether they were encountering any problems.

Speech pathologists and speech interns used prepared review sheets to individually test subjects on levels of progress within the Corrective Babbling™ program and spontaneous speech. Assessment of reported progress in the Corrective Babbling™ method confirmed if practice had taken place as reported. There was little variance in parent report and actual progress seen as reported. Most parents were truthful about their home experiences.

Spontaneous speech samples were evaluated by two independently assigned speech pathologists and one or more native-speaking speech interns from NIH. The evaluators varied across reviews. Inter- and intra-judge reliability among the speech pathologists and native-speaking speech interns was high.

Those cases that received an understandability of 0 in both known and unknown contexts were considered for termination of therapy and were not called for further follow-up.

It was observed that most of the cases received an understandability rating of 2 (i.e. speech is hard to understand some of the time) when first evaluated at the camp as a new case irrespective of the context. However, when the same case came for a follow-up after five months of training imparted by the caregiver using the Corrective Babbling™ manual, many of the cases received an understandability rating of 0 or 1 (i.e. speech is understandable all or almost all of the time) in the known
context. In the unknown context for the first follow-up, 11 cases were found to have an understandability rating of 0 or 1 (as compared to six cases at pre-training), which reveals the effectiveness of the training imparted through the caregivers. However, it should be noted that at the time of first follow-up, most of the cases were rated at 1 and 2 in the unknown context.

Most of the cases were rated to have an understandability rating of 1 (i.e. speech is understandable almost all of the time) on the first evaluation at the camp as a new case irrespective of the context and none of the cases were rated at 0 (i.e. speech is understandable all of the time).

When the same cases came for the first follow-up after three to four months of training imparted by the caregiver using the Corrective Babbling™ manual most of the cases rated an understandability of 1 (i.e. speech is understandable almost all of the time) in the known context. However, in the unknown context, five cases were found to have understandability rated at 2 (i.e. speech is hard to understand some of the time).

Again, the same cases reported for the second follow-up after three to four months of further training imparted by the caregiver using the Corrective Babbling™ manual. Improvements in most of the cases (five cases) were rated with an understandability of 1 (i.e. speech is understandable almost all of the time) in the known context as compared to the first follow-up of the case where the majority were rated at 2. A trend in the effectiveness of the treatment is revealed. In the known context for the second follow-up an equal number of cases (six cases) were found to have understandability rated at 0 (i.e. speech is understandable all of the time) and none of the cases were rated at 3, which reveals the effectiveness of the training imparted through the caregivers.

**DISCUSSION**

There were 28 cases and their caregivers who attended the speech camp in September 2004. All the parents were trained under the supervision of the speech-language pathologists from RSF EARTHSPEAK. Faculty from SRC AYJNIHH provided the English to Telugu translation. The caregivers were imparted training on the Corrective Babbling™ method and were given a manual to refer to and carry out the training/speech exercises at home. The same 28 cases and their caregivers were called back in January 2005. Eighteen (64.28%) out of 28 cases came only for one follow-up camp, referred to as Group I in this study. However, 10 (35.72%) out of 28 cases reported for the second follow-up, referred to as Group II in this study. When the gender difference was compared there was no particular trend observed preferring any gender.

The very fact that 35.72% of the caregivers (Group II) returned for the two subsequent follow-up sessions is an indicator that they see progress and they are willing to learn and teach their cleft child/patient with cleft palate. It is also assumed that those who may not have reported for the follow-up may not be carrying out the training/exercises at home. A Corrective Babbling™ result is dependent both on parent training and follow-up exercises at home.

There are several studies in the literature, which have highlighted the different methods used for assessing speech proficiency or intelligibility. Any studies related to cleft palate speech should include evaluation of speech intelligibility, using intelligibility measures that are shown to be not only reliable but also valid. Such measures include transcription tasks, multiple choice tasks (in which words differ by one phonetic contrast) and magnitude estimation tasks. However, in this study a rating scale of understandability was used to assess the progress of speech following the speech training by the caregivers.

The improvement tracked in the present study by reassessing the cases with repaired cleft palate on various parameters shows that the understandability rating in known and unknown contexts is a promising tool. The results show that there is a significant improvement in understandability from the first contact and at first follow-up for Group I subjects, especially in the unknown context assessment. Similar results are seen for Group II subjects.

This supports the observation that the training using the Corrective Babbling™ method has made an impact on the cases with repaired cleft when assessed using the speech understandability rating scale. It further supports that the Corrective Babbling™ method using child-parent teams seems to be working efficiently and may be a useful method of service delivery in India and the subcontinent.
Comparing the scores obtained in the unknown and known context, it was consistently observed that the scores were significantly better in the known context than unknown context. These findings were consistent with the earlier reports.

A few authors have cited their concern about reduced socio-communicative competence in children with cleft palate, which is attributed to their inability to produce intelligible speech.[4,5] With this method of training an overt change in the communication style and confidence was observed in the cases attending the camp. This method may indirectly contribute to improving the socio-communicative competence.

Limitations of the study
The study provides only a small window into what might be an effective way to get help to the many unserved children with cleft palate speech needs in India. Result cannot be generalized as the number of subjects is too small. Also, reasons why some parents did not return need to be more fully explored. Results of this study might look very different if all participants had been reviewed. Reasons for non-return were known for some but not for all. Factors of communication, mobility of the poor who cannot be relocated and inability to leave needed work or ill family members at the time of the review recall accounted for some non-returns. But others remain unknown.

Also, it would have been good to know more about the overall speech characteristics of the subjects. Cursory exploration of their speech characteristics was made, but this was not assessed or recorded well enough to say what related to what. Certainly, there is good evidence that understandability changed for many, but the full reasons for why this happened are not delineated in this study.

Further, more controlled research must be done before Corrective Babbling™ can be said to be an effective speech intervention agent in the hands of a trained parent. However, this initial study warrants that further research should be done. The understandability scores show promise of parent-delivered speech intervention using Corrective Babbling™ and that promise offers hope to the many who wait without speech correction in India.

CONCLUSION
Through this work we are confident to say that the parents can act as informants, carry out recommendations given by professionals in a language that they can understand well and are powerful decision-makers to improve the quality of life for the child/adult with cleft palate. This study to some extent supports the belief that the parents can act as speech facilitators for their wards with repaired cleft palate. Its effectiveness for universal practice in India needs to be further explored.

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3. Peterson-Falzone SJ, Trost-Cardamone J, Karnell MP, Hardin-


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