



Caregivers' perception of speech and language status and related needs in children with cleft lip and palate



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ABSTRACT

Background and Purpose: Comprehensive management for communication disorders in individuals with CLP was provided in a community based program in two rural districts in Tamilnadu, India. This program provides services at the community to empower the families about CLP and treatment options.

Objective: To document the caregiver perceptions' of communication status and needs in children with repaired CLP.

Method: Six Focus Group Discussions were conducted in Thiruvannamalai and Cuddalore districts in Tamil Nadu, India. Participants were 55 Caregivers of children (5–12 years of age) with repaired CLP.

Results: Most participants were concerned about their child's communication and few expressed concerns about specific errors in speech observed in their children. The caregivers recognized the need for and were willing to avail speech correction services. The focus group discussions highlighted some factors that need to be considered while planning a service delivery program for speech correction. The caregivers' expressed inability to independently carryout home training programs attributing it the lack of cooperation from their children. However they were open to receiving services if it was logistically convenient.

Conclusion: This study provided the caregiver perceptions' of needs relating to communication in children with CLP. These need to be incorporated in the existing program to develop a model for speech intervention that would be feasible, sustainable and have good compliance.

1. Introduction

In India, the incidence of Cleft Lip/Palate (CLP) is reported to be 1 in 781 live births with a male to female ratio of 2:1. It is estimated that 35,000 children are born with cleft lip or palate every year [1]. In a survey conducted in Tamilnadu, India, incidence of CLP was reported to be 1 in 1976 live births [2]. A majority live in areas far removed from the tertiary care centres where surgical repair might have been performed.

The limited access to intervention and guidance for parents of children with CLP about comprehensive long term care including speech intervention is a major challenge [3]. To address the barriers in providing comprehensive management for children with CLP living in rural districts, a community based rehabilitation program in two rural districts in South India was conceptualized and implemented. This program was initiated in Thiruvannamalai in the year (2005), and extended to Cuddalore in the year (2011) both rural districts in

Tamilnadu, India. The area of Thiruvannamalai district is 6,192sqkm and Cuddalore district is 3678 sqkm. Both districts are located at 200 Kms and a minimum of 4 h travel by road to the tertiary care hospital. This program has enrolled more than 500 individuals with CLP and provides services, such as identification, referral, counselling, speech screening and information about dental care at the community through trained Community Based Rehabilitation Workers (CBRW). The beneficiaries visit the hospital only when surgery, dental treatment and nasoendoscopy assessment is warranted. The services that could be delivered in the communities were determined by the needs assessment studies. At two points during the 12 years of existence of this program [4] & [5], needs assessments was conducted in Thiruvannamalai district in Tamilnadu. These were primarily a top down approach, where Speech Language Pathologist (SLP) profiled speech and language problems in individuals with CLP across age groups.

Community based programs are best executed when stakeholders and beneficiaries are involved in planning. In this community based

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program, Focus Groups Discussion (FGD) have been used to obtain caregiver views about their experiences and concerns relating to children between birth and five years of age born with CLP [6] & [7]. These studies highlighted the need for an information delivery system at the community through grass root level workers and the importance of repeated family counselling. These children are monitored for speech and language development by CBRW at the community. Since screening for speech, speech recordings, and assessment are integrated, there were several requests for a speech correction program that could also be provided at the community.

There was no available SLP trained in cleft at the community. It was therefore proposed that existing CBRW associated with the project could be trained to deliver a speech correction program under the supervision of an SLP. Two major aspects needed to be addressed before designing such a program. The first, what is the typical speech profile (i.e. most common type of speech errors seen in children with repaired CLP in the age group of 06–14; 11 years of age)? This information would be used to develop training material, and resource material to train the CBRW.

The other question pertained to the barriers and challenges that exist at the community for the delivery of such a program [8]. Compliance for community based programs are determined by the motivation and involvement of caregivers. The perception of caregivers regarding the need for services, who should provide the service, where should the service be provided, had to be explored before the program could be rolled out.

To study the perception of a group on a specific topic, qualitative method is preferred as it is more flexible in nature [9]. Perception of group of individuals or perception of community can be elicited using a Focus Group discussion (FGD) [10]. This allows the participants to respond at ease and also collects meaningful responses which can be compared across participants. The focus group discussion approach allows group participation and develops a consensus which is vital for projects where caregivers' involvement is important. Focus group discussion approach have been utilized to document parent's perception about knowledge and beliefs of the mother in the rural community regarding ear and hearing health care [11] and perception of mothers of beneficiaries regarding a rural community based neonatal hearing screening program provided by village health workers [12]. Therefore this approach was undertaken in this study to obtain perception of caregivers relating to the communication needs of children with repaired CLP.

2. Method

This study was carried out after obtaining approval from the Institutional Ethics Committee. The reference number is IEC-N1/10/DEC/20/42.

2.1. Procedure

2.1.1. Developing focus group guides

Guides were developed to conduct FGD, under the broad domains a) knowledge about speech and language development, b) effect of cleft on communication, c) awareness about speech and language intervention, and d) the intent to provide speech and language intervention. Guides were developed following a detailed review of literature and outcomes of previous focused group discussions [6] & [7].

2.1.2. Conducting focus group discussion

Setting: Focus group discussions (FGD) were conducted in Thiruvannamalai and Cuddalore districts in Tamil Nadu at a block resource centre and hospital respectively. The participants of this study had easy access to these facilities.

Participants: Fifty five caregivers of children with repaired CLP (UCLP = 39; BCLP = 16) residing in Thiruvannamalai (n = 27),

Table 1
Summary of participant's details.

Participants	Thiruvannamalai	Cuddalore
N	27	28
Mother	16	15
Father	09	10
Others ^a	02	03
Education status		
Primary School	07	03
Secondary School	06	07
Graduate	00	00
Uneducated	14	18
Occupation		
Daily wage worker	14	20
Farmer	11	08
Business	02	00
Annual Income		
< Rs 50,000	10	09
Rs 51,000–1,00,000	15	15
> Rs1,00,000	02	03

^a Grandparents/Uncle.

Cuddalore (n = 28) districts served as participants. The characteristics of participants are described in (Table 1).

In this geographical region it is not uncommon to have extended families in one residence. Grandparents, aunts, uncles, elder siblings could be involved significantly in the care of children with CLP. They accompany the child to camps, and to the hospital etc. In this study the term “caregiver” refers to a member of the family who was involved in enabling cleft care.

Participants were caregivers of children with repaired cleft and were recruited based on the characteristics of their children. The data base was used to identify children who met the following criteria, (i) were children between 5 & 12 who had undergone speech evaluation in the 6 months preceding this study, (ii) had undergone two flap cleft repair technique with intravelar veloplasty by an experienced cleft surgeon for palate repair at/before 36 month of age. The 36 month cut off age for cleft repair was selected as most children in our project have repair completed before age three, (iii) with no residual cleft post palate repair, (iv) were enrolled in school, (v) their clinical records indicated no other sensory and cognitive issues in the previous evaluations, (vi) demonstrated normal language development and (vii) exhibited one or more of the following: abnormal backing of oral consonants to glottal, mid-dorsum palatal and velar, weak oral pressure consonants, intermittent or frequent audible nasal air emission, presence of hypernasal resonance indicating velopharyngeal defect validated by a nasoendoscopy assessment requiring surgical correction. Speech assessment was completed by an experience Speech Language Pathologist (SLP) trained in cleft. Nasoendoscopy procedure was carried out by a plastic surgeon and the speech pathologist at the tertiary care hospital.

2.2. Execution of FGD sessions

Each FGD session included (a) a moderator (principal investigator) to initiate and guide the discussion, (b) a facilitator (SLP) to assist the moderator in the discussion, (c) an observer, (an intern in Bachelors in Audiology and Speech, Language Pathology) to take notes on the discussion and (d) caregivers as participants. Six focus group discussion sessions (03 in Thiruvannamalai & 03 in Cuddalore) were conducted over eight weeks period. Each FGD invited participants from a specific geographical area. It was ensured that number of participants per FGD was restricted to a maximum of 10.

2.3. Conduct of FGD sessions

Participants (identified by number cards at their seat) were seated in a circular seating style. Two digital voice recorders (Sony recorder ICD

series) were placed in the centre to ensure good quality voice recording. The discussion commenced with moderator welcoming participants. This was followed by a brief self-introduction by the participants. The study purpose and significance of participant's contribution were explained. Equal opportunity was provided to all participants to express their opinions. Each session lasted 45 min.

2.4. Data analysis

The recorded samples were transcribed verbatim in the local language (Tamil) and used for analysis. The transcriptions were cross checked with the discussion notes of the observer by an independent SLP, to ensure that there was no loss of information. Thematic analysis was carried out and results are presented descriptively under the domains that evolved from the discussions.

3. Results

There were 110 children with CLP in the community who met the above criteria. Caregivers of these children were contacted through the 08 CBRWs (Community Based Rehabilitation Workers) involved in the project activities. They were informed about the study purpose and date/venue of the FGD. Some parents were unable to report on the specific days. It is also possible that some parents were not concerned about their child's speech and therefore did not report for the focus group discussion sessions.

Various themes that emerged during the discussions are reported under four broad domains (1) Parental perception at the time of birth of the child on the possible effect of cleft on speech and language development (2) Communication disorders in children with CLP, (3) Awareness about speech and language intervention, (4) The intent to provide speech and language intervention.

1. Parental perception at the time of birth of the child on the effect of cleft on speech and language development

Forty one participants reported that when their child was born they believed that their child speech would be affected. Two participants reported that it never occurred to them that CLP could be impact speech and language development.

2. Communication disorders in children with CLP,

There was consensus that the speech of children with CLP differed from speech of typically developing children in their community. Forty five participants reported, community based workers drew their attention towards the effect of cleft on communication. When asked specifically if they had received counselling from professionals regarding the need for speech therapy, forty nine participants reported that one or more professionals of the multidisciplinary team had provided information. Two participants reported that the school teachers sensitized them about the unclear speech in their children.

There was consensus that adequate speech/communication was important for social acceptance. When importance of speech/communication, was explored further, thirty three participants reported that speech was important for education. Thirty six participants reported that success in learning and schooling is related to the ability to speak well. Twenty eight participants reported that they desired their child to speak well, to gain respect and be treated well in society. One care giver expressed his opinion that unless a child could speak clearly, he cannot communicate his whereabouts or address to strangers in an emergency. Some other aspects reported by the caregivers included teasing in school, delay in enrolment at school and demand for medical fitness and certificate that child was not cognitively impaired at the time admission at school.

3.1. Current concerns related to speech and language

Forty participants stated that their children's speech was unclear. When specifics regarding the types of speech errors was probed, twenty seven participants stated that their child had difficulty in producing sounds/k/,/t/,/y/,/l/,/r/. Ten participants reported nasalized speech in their children. Twenty five participants responded that their child sounded different when compared to other children but his/her speech could be understood.

3.2. Awareness about speech and language intervention

Forty four participants reported that they were informed about the possible need for speech therapy at the time of palate repair. Most participants reported that prior to the visit to hospital for palate repair, they were unaware about the existence of speech pathologists. Thirty participants had been counselled by speech therapist during their visit to hospital. When questioned if their children had an immediate requirement for speech therapy, Forty four participants reported in the affirmative.

3.3. Caregivers criteria for considering speech as normal

Caregivers used different criteria for categorizing speech as normal. Thirty six participants responded that speech could be considered as normal if 80% is understood. Twenty participants responded that strangers should be able to understand speech for it to be considered normal. Two participants said understanding speech while talking over phone was a criteria for normal speech.

3.4. The intent to provide speech and language intervention

Forty seven participants were willing to access speech therapy if the services was available in their town/village. Fifty participants reported logistic challenges in availing speech therapy. One participant responded that he/she could execute a home based program if practice modules are recorded and given in a mobile phone. Twenty seven participants responded that they had no time to execute the exercises at home. Twenty nine participants responded that their children would not cooperate at home and they preferred an external person to provide the speech exercises.

4. Discussion

The focus groups provided some insights for future planning. The responses were testimony to the penetration of the project within the rural communities and the expectations of caregivers. It is noteworthy that caregivers were able to describe types of speech deficits and clarity of speech. Specifically, they were able to identify nasality, and difficulty in production of sounds. This level of sensitivity towards speech disorders could have been facilitated by the CBRWs linked with the child. These perceptions can be compared with the study carried out in Thailand [13]. In that study parents expressed concerns about speech problems in their children with CLP and wished to know if their children could speak or not, or if the child could speak clearly or not. Caregivers demonstrated basic knowledge and awareness about issues related to speech in children with CLP. This suggests that instructions and repeated counselling by professionals, reiterated by community based rehabilitation workers was useful.

In our study, caregivers opined that child's acceptance in the community was determined by their speech. In another study in Thailand, care givers of children with CLP who did not enroll in the community speech therapy camps expressed concerns that unclear speech would impact acceptance in their community [14]. The availability of SSA (Sarva Shiksha Abhiyan) scheme "Education for All" implemented by Government of India [15] in rural districts of India, could have ensured

enrolment of these children in school. Though caregivers reported of teasing in school and low self-esteem in their children, no drop outs from school were reported. Acceptance in the community and their performance in school was attributed to the effect of cleft on communication. The findings of this study are in consonance with results of another study from India, where parental expectation was all about speech, self-confidence, and better acceptance by peers [16].

When probed about their intent to avail speech services, the barriers and challenges become evident. The reasons for not being able to visit the nearest speech therapy clinic was attributed to the remote living environment, caregiver's occupation and schooling issues. These are similar to the challenges reported in other parts of the developing world [17].

The suggestion of home training program to be carried out by caregivers was rejected almost universally. Participants cited lack of time and poor cooperation of the children. The geographical spread of children over the two districts also makes it difficult to identify a central point in the district where speech services could be provided. Further scheduling a mutually convenient time for speech therapy was a challenge. In these rural districts in our program, the logistics related challenges have not changed over 12 years. Therefore this factor is most important to ensure compliance for any model of speech correction program that may be developed.

This study was limited to caregivers who volunteered to participate and it can be assumed that all had concerns about their children's communication. Themes of the FGDs in this study being general and exploratory in nature, did not bring out patterns of responses that could be grouped. More in-depth themes could be explored going forward.

5. Conclusion

This study provided the insights into the caregiver's perception of speech and language status in their children with CLP. The results of the study suggests that the participants in this study were aware of their children needs related to speech and shows willingness to avail the services. The network created by the project connecting the child with the hospital using CBRWS was the strength of the program. The rudiments of service delivery model emerged after the FGDs. The SLP would coordinate the child specific program based on his/her speech profile delivered by CBRW at a venue as close to the child residence as possible.

Conflicts of interest

There are no conflict of Interests.

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