



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

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