Introduction

Development of communication, particularly speech and language, in children has been an area of interest for researchers from disciplines such as psycholinguistics, speech language pathology and developmental psychology. It has been documented that while normal children exposed to conducive linguistic environment acquire speech and language skills typically, atypical children of one type or the other have limitations in acquiring speech and language or any of its sub systems. Children with Cleft Lip and Palate (CLP) are such atypical population who have been found to have defective speech due to inability to acquire the sound systems of the language. Speech Language Pathologist (SLP) is one of the team members, involved in the rehabilitation of children with CLP.

In developed countries, a multidisciplinary team is involved in the rehabilitation process and a timeline for treatment is followed. But in most developing countries, there is a shortage of qualified professionals to provide comprehensive management for children with CLP, hence resulting in delayed intervention or no intervention (Magee, VanderBurg, & Hatcher, 2010). This brings about a need for alternate models of service delivery. This thesis will focus on evaluation of community-based model of service delivery for speech intervention in children with repaired CLP. In this and the following chapters an attempt is made to explain the communication disorders in children with CLP, need for intervention, models of intervention and the challenges in delivery of speech intervention for children with CLP.

CLP is an anomaly of the lip, palate or both that may appear in different degrees of severity and configuration. The incidence of CLP is known to vary widely across geographical areas, with higher rates seen in Asian population and lower rates in African population (Vanderas, 1987). In India, the incidence of CLP is 1 in 781 live births with a male to female ratio of 2:1. It was also reported that about 35,000 children are born with cleft lip or palate every year (Raju, 2000). In a survey conducted in Tamil Nadu, India, incidence of CLP was reported to be 1 in 1976 live births (Sridhar, 2009). The frequency of occurrence of CLP in India indicates a requirement for larger number of speech pathologists to be involved in cleft care and be part of a multidisciplinary team.
Individuals with CLP often demonstrate multiple problems such as early feeding difficulties, nutritional issues, developmental delays, abnormal speech and/or resonance, dento-facial and orthodontic abnormalities, hearing loss, and possibly psychosocial issues (American Cleft Palate-Craniofacial Association, 2009). Abnormal speech patterns exhibited by individuals with CLP include hypernasality, audible nasal air emission, weak pressure consonants, and compensatory articulation pattern (Peterson-Falzone, Hardin-Jones, & Karnell, 2009). Several factors such as type and severity of cleft, age and time of palate repair, efficacy of repair, unrepaired residual cleft, presence of fistula, status of velopharyngeal function, hearing status, socioeconomic and linguistic status can possibly have an impact on communication in children with cleft lip and palate (D’Antonio & Scherer, 2008).

Prior to surgical correction of palate, these children are bound to exhibit difficulty in articulating high pressure consonants such as [t], [ʈ] and [k] besides the presence of nasality. Post palatal repair, these children have been found to have the potential to produce normal speech with appropriate therapeutic intervention (Hardin-Jones & Chapman, 2008; Jones, Chapman, & Hardin-Jones, 2003; Hardin- Jones & Jones, 2005). It has been reported that at least 80% of children born with non-syndromic cleft palate, who undergo palate repair by 18 months of age, do not require direct speech therapy at all (Peterson-Falzone, 1990). However, in India, it has been reported that the earliest age of reporting for surgery is much higher than 18 months (Raman, Jacob, Jacob, & Nagarajan, 2004).

Post palatal repair, some children develop normal speech but many exhibit speech delays into the preschool years and beyond (Lohmander & Persson, 2008). A wide variety of speech sound errors are noticed in these individuals. The pressure consonants (stops, fricatives & affricates) are more affected than the other sound categories. Atypical articulation patterns observed in individuals with CLP are broadly classified as obligatory and compensatory errors (Kummer, 2008). Obligatory errors are observed only in the presence of any structural abnormalities. These errors patterns cannot be corrected through speech therapy unless the underlying structural deficit is corrected. Compensatory errors are errors that occur due to mislearnt articulatory placements by children during their period of development. Compensatory errors observed in
individuals with CLP include, glottal stops, mid dorsum palatal stops, pharyngeal fricatives, pharyngeal stops and nasal snorts (Kummer, 2008) The most common compensatory error pattern reported in individuals with CLP is the glottal stop. Abnormal nasal resonance is another characteristic feature in most individuals with CLP. Approximately 20% to 32% of children continue to exhibit air leaks into the nose and have a hypernasal speech after primary surgery of the palate, either because of residual fistulae or velopharyngeal inadequacy (Sharp, Dailey & Moon 2003). Nagarajan, Subramaniyan, Sendhil Nathan and George (2008) reported that more than 60% of children with CLP enrolled in a community-based project exhibited errors in articulation and resonance that would require services of an SLP.

The role of SLP begins as early as the neonatal period for addressing issues related to feeding. During infancy, an SLP counsels caregivers about normal speech and language development and teaches parents ways to correct abnormal consonant productions such as compensatory speech errors (Golding-Kushner, 2001). Later, the SLP is involved in assessment and management of speech errors in individuals with cleft.

Management of speech in individuals with CLP in India faces unique challenges when compared to developed countries. One such challenge is the lack of availability of trained professionals in India, particularly in rural areas. The timeline for speech therapy poses its own set of challenges (D’Antonio & Nagarajan, 2003). These necessitate the need to consider alternative models of service delivery for speech.

**Models of delivering speech services**

**Institutional Based Rehabilitation:** Services of SLP are required to assess and provide intervention if any deviancy is noted in language, articulation, phonology or speech development. Individuals with CLP receive therapy services in a hospital/institution often as part of a team care. In this model, services are offered to those individuals who can travel to the hospital or centre to receive services. Such a system of service delivery is available only in few University clinics, hospitals, special schools and rehabilitation centres for individuals with CLP. However, such a model of service delivery is not feasible in many developing countries where
the needs are many, but the resources are few. Institutional rehabilitation provides services to the individual which is often available only for a small number at a higher cost.

**Camp Model:** Providing speech services via camps is a model adopted in many countries such as Nepal (Rai et al., 2013), Mexico (Pamplona, Ysunza, Patiño, Ramírez, Drucker, & Mazón, 2005). These camps are especially useful in identifying the needs of individuals with CLP and in increasing awareness about the condition and available services. Through these camps, simple speech correction techniques can be provided to the families along with instructions for follow-up in consecutive camps.

**Training Paraprofessionals:** In countries where the profession of speech language pathology does not exist or is limited, but has a strong commitment to cleft care, it is possible to train other allied professionals the principles of speech language pathology. In Sri Lanka, Sri Lankan Cleft Lip and Palate Project developed a program for training SLP assistants (Wirt, Wyatt, Sell, Grunwell, & Mars, 1990; Wirt, Wyatt, Sell, Mars, Grunwell, & Lamaabadsuriya, 1990).

With the increasing availability of surgical care for individuals with CLP, there has been an emphasis on the development of team care and early repair of clefts in India. Though there has been a growing recognition that both diagnostic and rehabilitative services must be made available, only few speech pathologists and centres in India are specialized in cleft care and such centres are not enough to meet the needs, even in local areas. D’Antonio and Nagarajan (2003) suggested the need to develop different models of service delivery for regions where the demands are high, and resources are limited. Models of service delivery in the developed countries may not be suitable universally, especially in developing countries. Several organisations such as Earth Speak, Smile Train, Transforming Faces, etc. have initiated speech services through different models of service delivery in developing countries. These models have either exclusively addressed speech or have incorporated speech as a component of more multidisciplinary services. Sell, Nagarajan, and Wickenden (2011) have outlined the different models of delivery of speech services that have been adopted/adapted worldwide. Some examples of the projects which provide exclusive speech services include Earth Speak in Nepal.
and Bangladesh. On the other hand, projects that provide multidisciplinary services include Sri Lanka cleft lip and palate project, Sri Ramachandra University- Transforming Faces (SRU-TF) project in India, and Bhutan cleft care project.

In Sri Lanka, Sri Lankan cleft lip and palate project was initiated in 1982 by the team from Great Ormond Street Hospital (GOSH) UK. The project included surgeon, speech pathologist and orthodontist and more than 60 members extending its services to three centres with 3 multidisciplinary teams within Sri Lanka. In the first stage, individuals with CLP were identified, treatment plans conceived, and long-term goals were established for the project. The second phase constituted a training phase which provided knowledge and skill to local assistants and identified priorities in delivery of services. The final phase of the project aimed to promote effective research and initiation of a diploma and undergraduate based speech and language training course.

The community based model of service delivery for individuals with CLP has been explored in different dimensions in different parts of the world, including Thailand (Prathanee, Dechongkit, & Manochiopinig, 2006) and Sri Lanka (Wirt, Wyatt, Sell, Grunwell, & Mars, 1990). These models focused on the delivery of services for feeding difficulties and speech therapy. Community Based Rehabilitation (CBR) model was promoted by the World Health Organization (WHO) and other United Nations (UN) agencies in the early eighties, as an alternative service option for the rehabilitation of people with disabilities in developing countries, who had no access to service. In CBR, intervention is shifted from institutions to the homes and communities of people with disabilities, and carried out by minimally trained people, such as families and other community member/volunteers, thereby providing service and reducing the financial costs (Thomas & Thomas, 2002). D’Antonio and Nagarajan (2003) conducted a consensus workshop to address the question “How can speech services be developed for children with cleft in India?” Following their recommendations, a community based program for individuals with CLP was initiated by Sri Ramachandra University (SRU) in 2005 in Tamilnadu, a state in South India. This project, known as the SRU-TF project, was funded by Transforming Faces, a Canadian charity, formerly known as Transforming Faces Worldwide (TFW).
This model focuses on the community being involved in rehabilitation of differently-abled individuals delivered by grass root workers in the community. CBR workers, also referred as community based workers (CBW) play an important role in the implementation of CBR. They are usually the main persons in contact with the family and serve as liaison between the service provider and the beneficiary. CBR model involves the beneficiaries themselves, their families and communities, and the appropriate health, education, vocational and social service providers. CBR models are designed to operate at the local level and within the context of local conditions. This model encourages the use of simple methods and techniques that are acceptable, affordable, and relevant to the community. Currently, there have been various efforts by World Health Organization (WHO) in promoting “Community Based Rehabilitation” model of service delivery. Community based rehabilitation can be defined as a strategy within the community for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities (WHO, 2004).

This ongoing community based project, SRU-TF (Sri Ramachandra University-Transforming Faces) was initiated to integrate hospital based services with community based initiatives and to enable multidisciplinary care in cleft. The project was initiated in Thiruvannamalai district in 2005 and replicated in Cuddalore district in 2011. Both are rural districts located in the state of Tamilnadu in India. This project has, so far enrolled about 500 individuals with CLP. Through this project, surgical services, VPD evaluation and advanced orthognathic services are provided at the hospital, whereas other support services such as identification and referral, counselling, speech screening and assessment, dental services and speech correction services are provided at the level of the community. Over 200 CBWs in both districts have received training in identifying and referring individuals with cleft. One hundred and twenty-five workers received training and were involved in screening of communication disorders. Twenty workers received training in providing speech intervention services.

completed by CBR workers and SLPs independently showed good agreement for identifying articulation and resonance disorders, but a poorer agreement for rating of speech intelligibility. In 2007, a needs assessment study was carried out and 129 individuals between 3 and 15 years participated in the study. The results of the study revealed that 43% exhibited abnormalities in articulation and resonance, 12% had issues only in articulation, and 3% had abnormalities in resonance. Another 3% of these individuals exhibited delays in language development (George, 2007). Information obtained from the needs assessment was valuable to develop a program for delivery of speech correction services. This has resulted in over 70 children with CLP who have received speech correction services by trained CBWs under the supervision of an SLP.

**Need for the study**

Surgical repair of a cleft normalizes a child’s appearance and decreases social stigma; however, poor resonance and faulty articulation might still exist. One of the major goals of cleft repair is to normalize speech. Nagarajan et al. (2006) emphasized that speech therapy services for individuals with CLP requires frequent visits for a longer time than surgical services. More so, institution based speech therapy services are limited to only major towns and cities in India. Most individuals living in rural area are unable to access the benefits of a regular intensive speech therapy program (Raman et al., 2004). It has been documented that most individuals seeking services are from a low economic stratum and live very far from centres where team care is available (Raju, 2000; Raman et al., 2004).

Management for speech in individuals with CLP in India face unique challenges when compared to western countries. One such challenge is the non-availability of trained professionals in India. There are very few SLPs who have expertise in areas of CLP at urban centres and almost do not exist in rural areas. This is further complicated by non-availability of generalist SLPs in rural areas of India. The major barriers to the development of services for individuals with CLP described by D’Antonio and Nagarajan (2003) are listed below in Table 1.

**Table 1**

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<th>Barriers to the development of speech pathology services</th>
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<td>- No profession of speech language pathology or less speech language</td>
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Effectiveness of community based worker implemented speech correction program for children with repaired cleft lip and palate in rural districts of Tamil Nadu
Effectiveness of community based worker implemented speech correction program for children with repaired cleft lip and palate in rural districts of Tamil Nadu

Introduction

pathologists

- Service availability restricted to urban and tertiary care medical centres
- Diversity in language and culture
- Socioeconomic & education status of family/caregivers
- Families living in rural/remote areas
- Primary focus on surgical correction by visiting surgical teams and less importance on interdisciplinary care
- Myths and misconceptions relating to the condition CLP and its impact on seeking intervention

In such cases, CBR as a service delivery model could be an ideal solution to counter challenges of non-availability of professionals and requirement of monolingual individuals. In India, there exists a system of community based service delivery for health and rehabilitation. It has been established that CBWs could identify and screen individuals with cleft (Nagarajan et al., 2006; Nagarajan et al., 2008). As the next step, the efficacy of using CBWs to deliver speech correction service to children with CLP would have to be assessed. The proposed study aims to develop a community based model of speech correction program and evaluate the effectiveness of CBW and SLP delivered speech correction program at the community.
Aim: To evaluate the effectiveness of community based model of speech correction program in two districts of Tamil Nadu.

Objectives of the Study
1. To develop and evaluate the effectiveness of training program for Community Based Workers (CBW) on delivering speech correction program
2. Implementation and evaluation of effectiveness of the community based workers implemented speech correction program of pressure consonants in children with CLP with respect to:
   2.1. Caregivers’ views on speech and language status and need for intervention in children with CLP.
   2.2. Outcomes of CBW implemented speech correction program and Speech Language Pathologist (SLP) implemented speech correction program.
   2.3. Caregiver’s views of speech correction program delivered in the community through CBWs.