BRIEF REPORTS

PROVIDING INTERVENTION SERVICES FOR COMMUNICATION DEFICITS ASSOCIATED WITH CLEFT LIP AND / OR PALATE - A RETROSPECTIVE ANALYSIS

Sunitha Raman,* Monica Jacob, Manju Sara Jacob, Roopa Nagarajan

ABSTRACT

The incidence of cleft lip and palate in India is enormous: one in 781 live births. Early identification and early intervention programmes are the most effective tools to counter the long-term detrimental effects on speech and language in this population. The current institutional based rehabilitation programmes follow a 3-tier strategy of regular therapy, demonstration therapy and parent guidance programmes. The efficacy of this programme is greatly hampered by factors such as socio economic status, distance travelled to avail of services and other health considerations. To overcome these setbacks and evolve more effective intervention plans, the focus needs to be directed towards outreach and community based rehabilitation.

INTRODUCTION

The management of cleft lip and /or palate is a complex and life long issue. The staggering magnitude of the need for intervention is indicated by the results of a recent study conducted by the Tata Institute of Sciences (1).

The salient features are:

- The incidence of cleft lip/palate in India is estimated at one in 781 live births, with a male to female ratio of 2:1.

- An estimated 35,000 children are born with cleft lip/palate every year.

- Most report a family income of Rs.1, 000/- a month.

- Approximately 46% had made no effort to correct the defect. Others reported that they may have consulted a doctor, but no surgery was done due to economic reasons, ill health of the child or fear of surgery.

- Care takers / individuals with cleft lip/palate reported problems ranging from speech defects to social acceptance and feeding.

These results focused on the fact that, early identification and early intervention is the need of the hour. Early identification of the cleft is not an imposing problem as very often, it is a visible deformity. In India early forms of surgical intervention are also becoming a reality, consequent to the efforts by non-profit organisations such as the Smile Train.

Ever since their partnership with agencies in India, around 3,500 surgeries were performed in 2000 approximately 640 surgeries were performed at Sri Ramachandra Hospital duirng 2003.

As an integral part of the team dedicated to improve the quality of life of individuals with cleft lip/palate, the speech pathologists were called upon to provide the following services:

- Assist in decision-making regarding surgical / prosthodontic / orthodontic management.
- Evaluate and provide diagnostic therapy pre-operatively.
- Deliver speech therapeutic services post operatively.
- Heighten awareness of speech defects and rehabilitation measures among families and professionals.
- Train allied health workers to provide greater assistance in speech services covering cleft care.

To achieve these objectives, the data reviewed revealed the necessity to address various concerns such as the need to draw a profile of the average patient at the cleft clinic, evaluation of current models of service delivery and inclusion of necessary modifications and to develop additional / alternative methods of rehabilitation.

The present study attempted to address these concerns.

METHODOLOGY

Data Collection

Sample size: 488 individuals.

Criteria for subject selection:

- All individuals with oral cleft (unilateral/bilateral, complete/incomplete, lip and /or palate, repaired/un repaired).
- All subjects who reported at the Sri Ramachandra Cleft Care Centre and were registered under the Smile Train Programme between 13th November 2000 to 15th December 2001 (2).
- All subjects included under the study were evaluated at least once, by a speech pathologist from the Department of Speech, Language and Hearing Sciences, SRMC and RI (DU).

Procedure

The parameters considered for data collection were: type of cleft, gender distribution, age at first consultation, distance travelled to avail of services, economic status and type of intervention procedure.

Each sample was slotted into different categories under each parameter, in accordance with the data enlisted in the case records that were compiled at the time of the patient's first visit. The collected data were then statistically analysed.
One hundred children in the age group between 0 and 3 years, were also analysed for their language levels using the Language Assessment Tool.

Data Analysis

Frequency distribution (in percentage) according to the pre-determined class intervals was calculated. The mean and the standard deviation were calculated for "age of first consultation", "economic status" and "distance traveled to avail of the services". Test of significance (two sample mean tests) was applied to statistically determine the significance of the relationship between intervention procedures and the enlisted parameters as stated earlier.

RESULTS AND DISCUSSION

A typical profile of the average client who visits the Sri Ramachandra Cleft Care Centre was drawn out on the basis of the statistical analysis.

Gender Distribution

At first consultation, the male to female percentage ratio was found to be 3:2, with the distribution of 290 males (59.53%) and 198 females (40.57%). At the therapy clinic, Department of Speech, Language and Hearing Sciences, Sri Ramachandra Hospital, the gender distribution was 40 males (54.05%) and 34 females (45.95%) with the percentage ratio of 1.2:1.

Figure 1. Gender distribution at first evaluation

	Male	Female
☐ First Evaluation	290	198
▦ Therapy	40	34
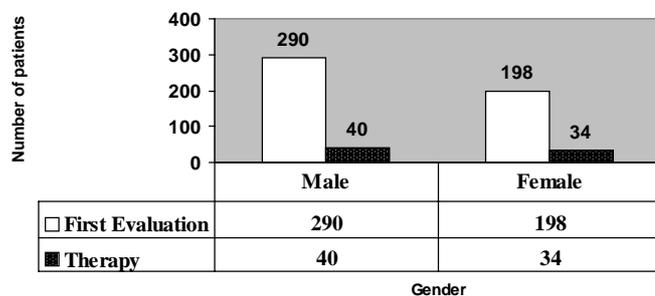
Age of First Consultation

Most subjects (56.11%) were found to have a cleft of lip and palate as against 19.24% reporting with a cleft palate alone and 24.65% reporting only with a cleft of lip. The earliest age of first consultation (mean) is 4 years with 333 (68.23%) children receiving medical help within the first 3 years of birth. 56 children (11.48%) between the ages of 3.1 and 6 years and 33 children (6.76%) between the ages of 6.1 and 9 years, reported for medical consultation for the first time. 4.93% of the total subjects (24 children) in the age group of 9.1 to 12 years and 2.25% (11 children) in the age group of 12.1 to 15 years, had had their first evaluation for medical services. 6.35% (31 individuals) over the age of 15 years sought medical assistance for the first time.

Figure 2. Age of first consultation (in years)

Age, in years →
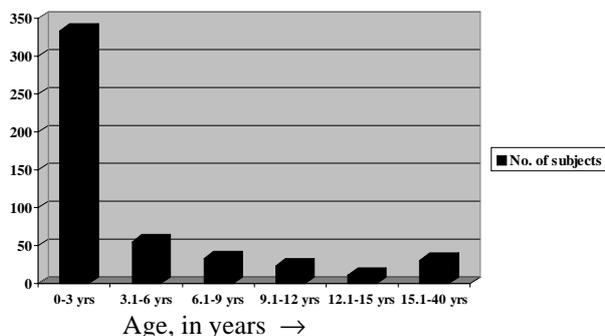
Economic Status

The results showed that the vast majority of patients (81.35%) who reported at the clinic numbering 397 subjects, lived below the poverty line (less than Rs.1750 per month). 61 subjects (12.50%) reported of annual incomes between Rs.21,000 and Rs.40,000 per annum. While 18 individuals (3.69%) indicated an annual income between Rs.41,000 and Rs.60,000, 2.46% of the subjects reported an income greater than Rs.60,000 (up to Rs.5 lakhs per year).

Figure 3. Economic status (Annual Income in Rupees)

Annual income, in Rupees →
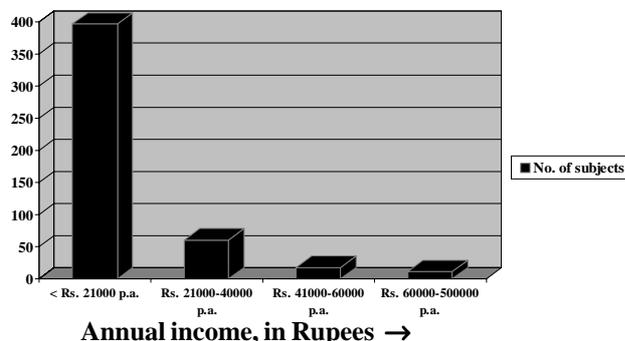
Distance traveled to avail of services

About 26.8% of the subjects reported having travelled 20 km to avail of the services.17.6% reported having travelled distances between 21 and 50 km, while 14% reported traveling between 51 to 100 km. Hometowns of 31.2% of the individuals were located at distances between 101 and 400 km, while hometowns of 10.2% were located at distances between 401 to 2000 km. Only 0.2% reported traveling more than 2000 km to receive the necessary medical attention.

Figure 4. Distance travelled to avail of services
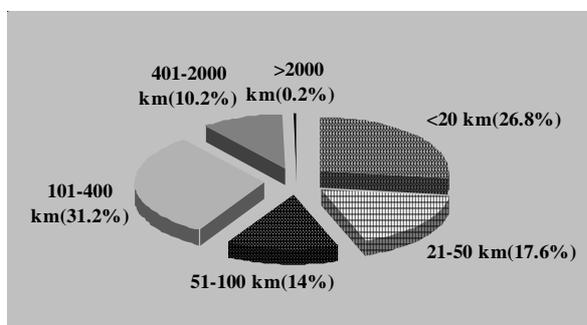
Results of the analysis show that most patients (55.6%) travel distances upto 50 km to avail of the services. Significantly, a large majority (81.35%) fall below the poverty line and hence, can neither afford extensive travel, nor the services. Tests of significance (two sample mean tests) applied between type of intervention procedure and "distance travelled to avail of services", "age of first consultation" and economic status" showed statistical significance of each of these factors.

Due to these limitations imposed by the socio economic status, extensive distances and other health considerations, most patients are unable to access the benefits of a regular intensive speech and language therapy programme.

The current intervention programmes at the Sri Ramachandra Hospital Speech Clinic include a three-tier strategy:

Regular therapy

Intensive language, articulation (phoneme specific goal), voice and prosodic therapy are offered at the Speech clinic of Sri Ramachandra Hospital at schedules of one, two, three or five sessions per week as per the patient's convenience. However, even this extent of flexibility is unable to accommodate the constraints of school / office timings of most clients. This thereby limits the choice to one, or a maximum of two sessions per week.
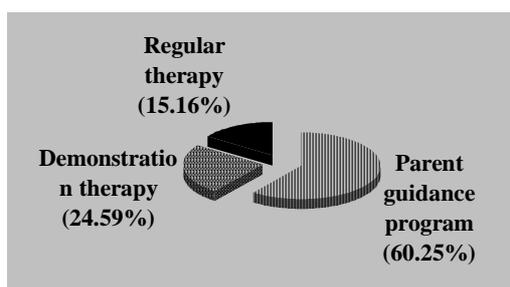
Demonstration therapy

This plan was developed to accommodate the needs of the large majority who can neither afford the time nor money for a regular therapy schedule. Lasting between one week and one month, it includes a complete demonstration of all techniques and activities included in the home plan. This programme is individually tailored to suit the needs and responses of the client with a suggested review and follow up after two to three months.

A review of the current trend of the age of first consultation revealed that the figure was shifting towards the age range of 0 to 1.6 years. Subsequently, an analysis of the language deficits of 100 toddlers between the ages of 0 and 3, indicated that 68% had delayed / inadequate expressive language and 32% had speech and language within normal limits. However, even this number of 32% of children were considered to be at a high risk for developing further communication deficits. A probe into the speech disorders among older children (who were intervened later in life) revealed developmental errors of articulation (including compensatory patterns), hyper nasality, reduced intelligibility and errors in prosody. To prevent / minimise these detrimental long-term effects, an effective early intervention plan, that can be implemented even prior to demonstration therapy, needs to be developed. Therefore there arises a need for parent guidance programmes.

Parent - guidance programmes

This package includes (i) measures to sensitise the family to the communication deficits in the child, (ii) hand-outs to monitor the child's developmental milestones and (iii) activities to promote speech and language development. This individually tailored plan is given to the caregiver after a detailed explanation of its contents. This briefing is done during the ward visits, post surgically. The efficacy of this measure is yet to be validated.

Figure 5. Distribution of intervention procedures

To monitor the progress of the client and increase efficiency in services, alternative methods of rehabilitation are also suggested. The benefits of home training programmes and

demonstration therapy, need to be augmented to match the greater benefits of regular therapy. Models of out-reach and community based rehabilitation, would serve to bridge the chasm between the need of the community and the services provided.

- **Out reach programmes** include camps, screening and counselling and the SLP's visits to the community for periodic follow up.
- **CBR** can be a powerful service delivery model, to directly provide services at the community level. It involves skill transfer and systematic monitoring of progress of the child / client. Sensitising surgeons and other medical professionals at primary health centres and rehabilitation centres, also forms a core objective. CBR also necessitates development of training material / curriculum / programmes to empower local authorities and health workers. This is the ideal solution to counter the stumbling blocks of non-availability of adequate number of professionals and requirement of working with individuals who are illiterate and monolingual.

CONCLUSION

The results of the present study indicate that the homogeneous model of institutional based rehabilitation currently followed, does not fully meet the therapeutic needs of persons with cleft lip/and or palate. Early intervention programmes incorporating out-reach and community based rehabilitation schemes, would ensure a higher success criterion. Therefore, it can be concluded, that despite the great diversity of needs which is reflective of the nation's population at large, it is the most unified efforts of the community, with the service providing institutions. that will bring about sustainable efficiency in intervention measures.

*Department of Speech, Language and Hearing Sciences
College of Allied Health Sciences
S.R.M.C.&R.I. (D.U.)
No.1, Ramachandra Nagar
Porur, Chennai-600 116

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2)   Hussain SA. ***Fellowship in Cleft Lip and Palate Surgery.*** Unpublished Dissertation submitted to Sri Ramachandra Medical College and Research Institute (Deemed University), 2001.