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Use of a Consensus Building Approach to Plan Speech Services for Children with Cleft Palate in India

Linda L. D'Antonio[a] Roopa Nagarajan[b]

[a]Department of Surgery, Loma Linda University and Loma Linda Children's Hospital, Loma Linda, Calif., USA; [b]Department of Speech-Language and Hearing Sciences, Sri Ramachandra Medical College and Research Institute (DU), Chennai, India

Key Words

Speech-language pathology · Cleft palate · Community-based rehabilitation · India · Consensus · Institute of Cultural Affairs

Abstract

Cleft lip and palate (CLP) is a common birth defect worldwide. While surgical repair can normalize appearance, debilitating speech disorders frequently persist. Speech-language pathology (SLP) services are needed to address these disorders. However in many regions of the world, there is no discipline of SLP or inadequate numbers of trained clinicians. New models for service delivery must be explored to address the needs of children with CLP. Community-based rehabilitation (CBR) programs represent one model that has been successful in the delivery of other rehabilitation services. This paper presents the outcome of a consensus workshop held in India that explored the application of the CBR model to address the need for SLP services for children with CLP when traditional SLP services are limited or not available.

Introduction

Cleft lip and palate (CLP) is one of the most common birth defects worldwide. Surgical repair of a cleft lip normalizes a child's appearance and decreases social stigma. A major goal of cleft repair is to normalize speech. However, in many cases, severe communication disorders often occur. The frequency and severity of these disorders is increased by late surgical repair that often occurs in countries where there is inaccessibility to surgical services. These communication

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Linda L. D'Antonio, PhD, Loma Linda University
Surgery Medical Group, 11370 Anderson Street, Suite 2100
Loma Linda, CA 92354 (USA)
Tel. +1 909 558 2344, Fax +1 909 799 1452
E-Mail LDAntonio@ahs.llumc.edu

impairments can be so severe that they limit the individual's social and educational options.

Speech therapy is necessary to prevent or eliminate these communication disorders. In most industrialized countries speech-language pathology (SLP) services are available from infancy through adolescence. In some countries, the discipline of SLP does not exist or is in its infancy. Therefore, many children with disabling speech disorders associated with CLP remain isolated because of their inability to communicate. This paper discusses a variety of models for providing SLP services for children with CLP and describes a consensus building approach that was utilized in India to develop specific strategies for providing services within the child's community.

Barriers to SLP Services

While surgical services for CLP are increasing, there has been a lag in the availability of speech services. There are many factors that may contribute to this. First, in many poorer countries where health care resources are limited, a significant amount of surgery for CLP is provided by volunteer surgical teams. Historically, these teams generally have spent short periods of time in host countries and have addressed surgical issues primarily with little emphasis on the interdisciplinary approach to cleft care [1]. In a position statement on international care programs, the American Cleft Palate-Craniofacial Association recommended that an interdisciplinary team approach be fostered as part of international volunteer cleft care programs [2]. However, many health care professionals who might support interdisciplinary care in their home environment, often have difficulty envisioning how speech services can be made available as part of volunteer cleft programs [3].

Even when medical and economic conditions allow for an increase in the availability of surgery, barriers to the delivery of speech services often remain. The greatest and most obvious barrier is that in many countries there is no profession of SLP or too few speech-language pathologists. When services are available, it is often only in urban, tertiary medical centers. Services are often complicated further by the presence of many languages or dialects that make SLP a challenge.

In addition to these professional challenges there are many social problems that limit the success of existing models of service delivery. In a recent report [4] the Tata Institute documented some of the major challenges in India that are common in many other countries. For example, the study found that many families and patients have misconceptions regarding the cause of clefting and the availability of treatment that contribute to the failure to seek treatment. Additionally, families are often extremely poor and uneducated and many individuals with CLP live in remote areas where there is little way to access speech services.

From this discussion, it is clear that the traditional models for delivery of SLP services for children with CLP are not adequate to reach the increasing numbers of children in need in many countries. To make significant accomplishments in fostering SLP for children with cleft palate, we must consider creative models of service delivery.

Possible Solutions

There are a variety of solutions for providing SLP services for children with CLP. The solutions that are most likely to work in the immediate future are those that require little funding and take advantage of existing resources and build on newer models of rehabilitation.

Institutionally Based Rehabilitation

The most obvious solutions to the need for SLP services are also the most costly and require the greatest commitment of time and resources. These include the development of the profession in countries where it has not existed previously and an increase in the number of training programs where there are too few speech-language pathologists. Historically, as the profession of SLP develops within a country and numbers of clinicians increase, there is an increase in the accessibility of professionally staffed institutionally based treatment programs.

Outreach Programs

When SLP services are limited in availability, outreach programs such as treatment 'camps' have been successful for allowing children to take advantage of limited services. These programs are particularly useful for identifying children who are in need and for providing education regarding the availability of services. In the case of ongoing programs or recurring camps, some basic therapy materials can be given to families with instructions for follow-up at the next camp where the process can be continued.

Training Allied Professionals

In countries where there is no profession of SLP but there is a strong commitment to cleft care, it is possible to train other professionals in the principles of SLP. Most notably, the Sri Lankan Cleft Lip and Palate Project developed a program for training SLP assistants [5, 6]. Similarly, through a grant from The Smile Train [www.smiletrain.org], 200 oral-maxillofacial surgeons and nurses have been trained in China to deliver SLP services for children with CLP [7].

Community-Based Programs

A historical review of rehabilitation models shows radical change since the 1970s. In the early models, services were provided in special institutions that segregated the individual. A later model focused on outreach rehabilitation where isolated activities were directed at individuals by trained rehabilitation workers. The more current model calls for community responsibility for rehabilitation and emphasizes social integration. Community-based rehabilitation (CBR) is the model that has been promoted as the vehicle to meet these objectives [8].

It is important to note, while the aim of CBR is for communities to take responsibility for rehabilitation, this cannot be done in isolation from the other strategies that have been discussed. As Mendis [8, p. 537] points out: 'CBR calls for, and encompasses the participation of all other available sectors and services within that society, that could contribute to the community's efforts. Services provided by institutions are vital supportive components of CBR.'

A formal definition of CBR can be found in a joint position statement published by WHO, ILO and UNESCO [9]: 'Community-based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. Community-based rehabilitation is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services.'

Two of the most widely disseminated resources for CBR programs are D. Werner's [10] book *Disabled Village Children* and the World Health Organization's [11] publication *Training in the Community for People with Disabilities*. Both publications address communication issues on a limited basis. A manual for

CBR workers focused specifically on communication disorders was published by Wirz and Winyard [12]. Subsequently the World Health Organization published a *Handbook for People Working with Children with Communication Difficulties* [13]. The handbook was originally developed for use in Zimbabwe and describes practical strategies for assisting anyone who may want to work with children with communication impairment. In the preface, the then Minister of Health for Zimbabwe notes that it is necessary to look beyond the materials and models from Europe and America and to develop training and materials relevant to the needs of the local people. The handbook is comprised of a series of manuals on basic communication and communication therapies for specific disabilities. Over the years the concept of community-based speech services has continued to evolve and gain more acceptance and has become common in many countries. For example, Fair and Louw [14] illustrate a successful example of early communication intervention within a community-based intervention model in South Africa. In spite of the increasing recognition of the value of conducting communication therapy within a CBR model the communication needs of children with CLP have not been addressed in similar publications. In light of the increasing recognition of CBR as a service delivery model for many forms of communication impairment, it would be logical to explore the use of CBR models to address the communication needs of children with CLP.

One Solution: Suggestions from a Consensus Workshop in India

The Need

India has a population of more than one billion people and a common figure suggests that there are more than 35,000 children born with each year with CLP. A recent study reported that 33% of individuals with clefts in India are below the age of 10 years and nearly half of individuals with CLP have never attempted to access surgical repair. Those who have undergone repair tend to be from the higher socioeconomic communities [4].

India has a well-established profession of SLP. Graduates are certified in both SLP and audiology jointly. Over the past 35 years, over 2,000 speech-language pathologists/audiologists have been trained in India. While there are 14 training programs, it is estimated that less than 15–20 new graduates per year go into hospital settings where cleft care currently is provided. As these figures would suggest, the ratio of speech-language pathologists to the number of children with CLP is highly unfavorable.

CBR in India

India has a multitiered health care network in which community-based health care is provided in both a health network and a rehabilitation network. CLP is both a health and rehabilitation problem and therefore is accessible through both networks. India has a successful history of utilizing CBR programs for children with several areas of disability including some forms of communication impairment.

The application of a CBR model for providing SLP services for children with CLP has high face validity. The usefulness of the approach has been demonstrated for educating parents and rural health workers in Nepal regarding feeding techniques, otologic issues and surgical options for children with CLP [15, 16]. However, there are no reports of utilizing this model on any significant scale for children with CLP. India has a unique constellation of features that make it an ideal location for establishing and testing such a model. There is a high need for cleft-related SLP services; there is a well-established disci-

pline of SLP, and an established and successful CBR network. Therefore, India was chosen as a site to explore the application of the CBR approach to SLP services for children with CLP.

The Need for Participation and Consensus Building

While the literature and previous experiences suggested to the authors that a CBR model could be an efficient service delivery system for children with CLP, it seemed critical that this observation be confirmed and elaborated on by a group of individuals with first-hand experience of the problem and/or those who would be in positions to design and implement such programs.

The modern literature on community development and social change suggests that group decision making employing participatory values is the optimal means for solving difficult problems. As one author notes [8, p. 537]:

'"Social change cannot be imposed from outside." The experience of other development activities has shown that a positive attitude change is encouraged when people participate actively in the processes calling for change. Attitude change must come from within, people need to be aware of the change called for and take responsibility for that change, participating in the processes relating to the change, if it is to be effective and lasting. The emphasis that *social change must come from within the families and communities in which people with disabilities live* has been one of the underlying principles of CBR.'

Therefore, the first step necessary in exploring a community-based approach to the delivery of speech services for children with CLP was to gather a group of experts from India who could develop a consensus regarding the key elements of such a community-based model. An international symposium on speech disorders associated with CLP was held in Chennai, India in October, 2002. The timing of this meeting was used as a convenient time and place to hold a 'consensus meeting'. Twelve professionals were identified and agreed to address the problem. Eleven of the participants were from India and one was from Bangladesh. Participants were invited because of their recognized expertise in one of three areas: speech-language pathologists' expert in CLP, speech-language pathologists' expert in CBR programs and experts in India's CBR delivery system.

The Consensus Workshop Method

A consensus workshop was held employing methods developed by The Institute of Cultural Affairs (ICA). ICA is a worldwide, nonprofit organization committed to social change [www.icaworld.org, May 2003]: 'Its primary objective is to promote positive change in communities, organizations and individual lives... by helping people find their own solutions to problems and the means to implement those solutions... The ICA uses highly participatory techniques to foster creative thinking, consensus-based decision making and team building. Its methods generate ownership, create clear goals, open lines of communication, broaden perspectives and motivate people to adapt to their changing environment while honoring the cultural traditions and diversity of all involved' [www.ica-usa.org, May 2003].

From its origins in the 1960s, ICA has developed and refined a package of methods for achieving these goals. Together, the methods are known as the Technology of Participation (ToP, trademarked in 1994) and include: the Discussion method, the Workshop method, the Action Planning method and the Participatory Strategic Planning Process [17]. The ToP methods have been used globally in

remote villages, neighborhoods, cities, and Fortune 500 companies. When significant change is needed as would be the case when exploring dramatically new models for the delivery of SLP services for children with CLP, then a method is necessary that will take into account many views and arrive at creative solutions. As suggested previously, sustainable change is most likely to occur when the core values of full participation, mutual understanding, inclusive solutions and shared responsibility have been honored [18].

One useful method that meets these criteria is the ICA Consensus Workshop method. With the assistance of a trained facilitator this method allows a group to 'think together', 'to plan' and 'to work' together as teams. Broadly speaking, the consensus workshop method is used for actively involving all members of a group in *planning*: weaving everyone's input into a practical plan; *problem solving*: developing solutions; *individual or group research*: channeling input into a research topic, and *decision making*, in order to: (1) gather their ideas, (2) discern the larger patterns through dialogue, and (3) summarize the group's insights, and come to consensus on a resolution [19, p. 6].

The underlying core values or assumptions of the method as described by Stanfield [19, p. 54] are: (1) Everyone has wisdom. (2) Everyone's wisdom is needed for the wisest result. (3) There are no wrong answers. (4) The whole is greater than the sum of its parts. (5) Everyone will have this opportunity to hear and be heard.

The Consensus

The 12 participants of the India consensus workshop and the ICA trained facilitator addressed the question: How can we provide speech-language services for children with cleft palate in their communities?

The consensus workshop begins with a 'context setting' during which the facilitator provides information about the issue to be addressed so that all members of the group have some common background. This was especially important in this group since the participants came from diverse backgrounds and differing levels of experience with CLP. At the conclusion of the workshop members of the group who had not been aware of the magnitude of the problems associated with CLP commented that the context setting had led them to personal commitments to include a variety of rehabilitation services for children with CLP in their own CBR projects and/or to educate others on this topic.

The members were invited to brainstorm individually and next as teams to develop as many solutions as possible to the question. The ideas were then clustered into strategies for how to work toward the goal of providing speech services for children with CLP in their communities. Next, the group engaged in in-depth dialogue about the strategies in order to discern the consensus and to develop ownership of the strategies. The group developed consensus around seven strategies as follows:

Develop a three-tiered training program that would include speech-language pathologists, allied health professionals (doctors/nurses etc.) and community workers (village health workers, school teachers, special educators, and successful individuals with CLP). The content, duration and level of training would depend on the focus group.

Develop materials for information, education and communication that might include simple sensitization and awareness materials for medical/allied and community level health care workers, preparation of books, audio/video material on step-by-step therapy procedures, and handouts for parents etc.

Influence government policies through advocacy using print and electronic media. One

example of a policy could be the recommendation of compulsory exposure to CLP and rural posting as part of the student's clinical experience.

Create awareness at different levels and use different media to educate doctors, parents, CBR workers and personnel at primary health centers regarding CLP in general and the communication needs of children with CLP in particular. Information should include the role of surgery, the availability of surgical and rehabilitation services and referral resources. This education process should focus on information dissemination, acceptance of the need for SLP services and attitudinal change at the community level.

Promote the formation of community and professional pressure groups to serve as core/support groups at the grass root level.

Network with existing development projects so that there is a convergence of resources.

Focus on the rural community with special emphasis on the 'girl child' and the poor. Involve people with CLP from planning to implementation.

Finally, the group committed to a series of 'next steps' including: establishing a listserve to enable continued dialogue among group members; sensitizing primary health care doctors and village health nurses through workshops on care of children with CLP; use of television and radio to spread the message that help is available for CLP and how to access services; establishment of a parent education program conducted during the child's hospital stay to explain how normal development can be impacted by CLP and basic information regarding speech-language stimulation; and seeking funding to coordinate with one CBR program to develop and evaluate a pilot speech program for children with CLP. At the conclusion of the workshop the participants reported significant satisfaction with the process and the product.

Conclusion

SLP services are necessary for preventing and treating speech disorders associated with CLP. Existing models of service delivery cannot meet the needs of this population in many regions of the world. A consensus building approach was employed to develop strategies for increasing the availability of speech services for children with CLP in India with an emphasis on the use CBR programs. While the strategies developed emphasized poorer regions of the world, there are clear applications of these approaches for countries where SLP services have traditionally been plentiful but are becoming increasingly scarce with changes in health care funding.

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