Developing and Standardizing a Center to Treat Cleft and Craniofacial Anomalies in a Developing Country Like India

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Abstract: The range of facial deformities is enormous. All produce some degree of disfigurement and result in the impairment of function to some degree, sometimes even to the point of incompatibility with life. Congenital facial defects in India are associated with considerable superstition, social rejection, and failure to integrate into society.

In India, cleft defects occur in 1 in 500 births. Congenital facial defects are a pressing problem in India owing to the limited resources to treat such patients. Poverty is a major factor for parents of such children to get appropriate treatment.

Setting up an institute to treat children with cleft and craniofacial deformities in India presents problems with financing treatment for poor patients, procuring the right infrastructure, and employing well-trained human resources.

The authors have set up such an institute in Hyderabad in the southern state of Andhra Pradesh in India. The logistics of setting up such a facility in a developing country and the future of funding for cleft treatment are important factors to consider while establishing a center for patients with cleft and craniofacial anomalies.

The aim of setting up such centers was to provide quality comprehensive treatment for patients from all sections of society with cleft and craniofacial anomalies.

Key Words: Cleft lip, cleft palate, craniofacial anomalies, developing and standardizing, institute, cleft surgery, speech therapy, orthodontics

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cleft defects at such hospitals will be between Indian Rupee 25,000 (US $500) and 50,000 (US $1000).

With an annual per capita income of US $755, most people in the state cannot afford health insurance. Less than 10% of the population has health insurance in Andhra Pradesh, India. Hence, access to care at these hospitals is limited to a minority of population.

HISTORY

The history of treatment of patients with cleft and craniofacial deformities in India started with Sir Benjamin Rank from the University of Melbourne coming to India in 1955 to train Indian surgeons in plastic surgery. Dr. C. Balakrishnan established a major plastic surgical department at the Postgraduate Institute at Chandigarh in the 1950s. Dr. Behman Davar, Dr. Charles Pinto, Dr. Arthur De Sa, and Dr. Rustom Irani developed cleft centers in the 1960s. Since then, some dedicated surgeons such as Dr. Adenwala in Trichur, Kerala, Drs. K. S. Goleria, Suresh Tambwekar, and Ravin Thatte in Mumbai and many others around the country have been treating patients with cleft defects.

The cleft and craniofacial deformities are looked upon in India as cosmetic deformities rather than functional deformities by many treating physicians. The focus has been on the surgery of the soft tissue defect alone of the face, that is, cleft lip or nose and palate.

Total rehabilitation of the patient involves patient’s education, genetic counseling, and speech management; secondary corrections are not considered by most physicians and cleft centers. These surgeons were unable to create teams that included the comprehensive management of the cleft and craniofacial defects. This is due to the large volume of patient populations, few well-trained personnel, and lack of financial resources.

This changed in the year 2000 when an American funding agency set up a base in India to fund cleft treatment. These funds helped surgeons treat patients who could not afford the care. This encouraged more surgeons to provide care and propagated additional funding agencies to participate in cleft management since 2001. However, the local hospitals and surgeons did not have proper mechanisms in place to make optimal use of the funding. This led to some hospitals and surgeon stop work, citing low returns on investment.

OBJECTIVES AND PLAN

The primary author developed basic plan to start a Cleft and Craniofacial Center in October 2000. The primary objective was to provide comprehensive care to patients with cleft and craniofacial defects, who cannot afford the costs of their treatment. The other objectives included patient recruitment and access to care, long-term financial self-sustainability, standardized record keeping, delivery of multispecialty care, and develop outcome studies from the gathered data.

Because most patients could not afford treatment, raising funds for treatment is the only option. To maximize the care with minimal resources, the treatment focus was on congenital facial deformities only. This was also conducive to build an administrative system for a hospital treating only 1 part of the body where employment of staff and costs can be kept to an essential minimum. In addition, the authors thought that this could be best established by an independent institute without bureaucratic hurdles that are faced in a developing country. Infrastructural and administrative expenses would be used solely for the work that is funded. The desired goal for the facility is to handle 1200 cleft and craniofacial surgeries with 500 cleft speech therapies and 200 cleft orthodontic therapies every year.

This facility would cater to the population of approximately 100 million people living in an area in a 1000-km radius from Hyderabad, which includes the adjacent districts and states. All employees and physicians served on a full-time basis. This improved efficiency. This was also a means to provide employment opportunities for the local population.

The Cleft and Craniofacial Institute is to be managed under 4 categories: treatment, infrastructure and equipment, human resources, and research (Fig. 1).

Funds are to be raised for each aspect separately even if 1 person or institution was funding multiple areas of care. The needs of the patient are to be addressed starting with transporting the patient from their district or mandal headquarter, delivering treatment in the form of surgery, orthodontics and speech therapy, providing free medicines, and transporting the patient back to their districts.

Education and awareness of the parents and patients with cleft and facial deformities, treatment facilities, and options available are by partnering individuals, nongovernment agencies, and the local government bodies. In addition, the institute needs to aggressively procure the necessary infrastructure by donations and fund-raising from different resources.

The research is planned to be carried out by starting partnerships with various institutions around the world. The large volume of cleft and craniofacial surgeries, would help in providing the outcomes research. This would help in collaborating with other

FIGURE 1. Four headings under which funds are raised by the HCS.
In India, 17% of children born with cleft and craniofacial defects experience malnutrition. Approximately 42% to 57% of all child deaths in developing countries are due to the potentiating effects of malnutrition on infectious disease, of which more than three quarters can be attributed to mild to moderate malnutrition. In India, 17% of children younger than 5 years are mildly to moderately undernourished and 6% of children are severely malnourished. In Andhra Pradesh, the figures are 11.4% and 3.8%, respectively. Children born with cleft and craniofacial defects are prone to higher malnutrition because of feeding problems associated with their defects. Feeding advice in the form of audiovisual tools is given to all parents of children with cleft and craniofacial defects, who bring their children for consultation.

The institute has treated 13,835 patients as of November 30, 2008. These patients are provided transportation to the hospital, surgical care at appropriate times, and other treatments such as orthodontics and speech therapy and are transported back. Most care and transportation are provided free of cost. The fees paid by few patients who can afford go into the corpus of HCS.

The HCS continues to build a corpus from external and domestic funding agencies to ensure long-term sustenance. The HCS currently supports a team of 7 surgeons, 3 pediatricians, a geneticist, a couple of speech therapists, and orthodontists.

The institute consists of 2 fully functional operating rooms, an intensive care unit with pediatric ventilators, radiographic machines, orthodontic/dental equipment, and speech therapy equipment. The infrastructure includes a 50-bed hospital facility that includes a 6-bed postoperative facility, a dental clinic, and a speech therapy clinic. Most of the records are computerized; these include patients’ photographs, staging of surgery, postoperative follow-up, and recall dates for long-term follow-up. The long-term
follow-up of patients has risen from a meager 8% in 2000 to 46% in 2008.

The authors run the charity as a nonprofit corporate entity, by maximizing the number of patients getting standard care, and continue to retain well-trained personnel. The numbers of patients treated by the institute are mentioned in Figures 2 to 4.

For the past 8 years, the management of cleft and craniofacial deformities has changed. There is increasing importance given to speech therapy and orthodontics and secondary surgical corrections. The fund-raising is done by surgeons on behalf of all the departments involved. There is streamlining of the charity given and accepted by various institutions. The authors believe that the complete rehabilitation of a patient happens only with the total integration into society by appropriate education and self-sustainability. Currently, there is still poor acceptance of patients with facial deformities in India especially in rural areas. This is improving with education. Meanwhile, the HCS is facilitating in establishing a residential school to educate children with clefts so that they could seek meaningful employment.

The surgeons, institute, and other personnel are encouraged to interact and collaborate with organizations for their administrative and technical expertise. The GSR Institute of Craniofacial Surgery continues to forge partnerships with universities and funding organizations in countries such as Belgium, Canada, Germany, Italy, the Netherlands, South Korea, Sweden, Switzerland, United States of America, United Kingdom, and the Indian Subcontinent. This helps in the constant improvement of the quality of work done at the institute. In addition, the regular exchange programs advance fund-raising capacities with strategic alliances with well-established funding agencies.

The financial quality control and management is conducted internally by nongovernment third-party audits and legally by the Ministry of Home, Government of India, under the Foreign Contributions Regulation Act 1976. The health outcomes of the medical and technical aspects of the institute is overseen by an international medical advisory board made up of health care professionals from all disciplines including surgery, orthodontics, and speech therapy.

REFERENCES