

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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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.¹ Congenital facial defects in India are associated with considerable superstition, social rejection, and failure to integrate into society. In managing such defects, the goals of the treatment include the management of the human psyche and the patient's acceptance to the society.

Approximately 15,000 children are born with clefts per hour worldwide. A child is born with a cleft somewhere in the world every 2 minutes.² In India, cleft lip/palate occurs in nearly 1 in 500 live births, and most of these defects are not surgically corrected.³ The congenital facial defects are a pressing problem in India owing to the limited resources. The burden of care for the child with cleft affects the entire family units. It is not unusual to see patients with untreated cleft lip for the entirety of their life. The complete rehabilitation of these patients involves speech therapy and orthodontics; secondary corrections are inconsistent at best and often times unavailable.

India is the second most populated country in the world⁴ with a population of 1,147,677,000. The annual per capita income of India as of February 28, 2008, is Indian Rupee 29,786 (US \$660).⁵ Andhra Pradesh state, where the GSR Craniofacial Institute is situated, is located in the southern part of India. Andhra Pradesh⁴ is spread over an area of 275,000 km² with a population of 81,315,000. The annual per capita income of Andhra Pradesh is Indian Rupee 33,970 (US \$755).⁶ The state is divided into 23 administrative districts with Hyderabad city as its capital. Each district is further divided into mandals. There are 1123 mandals in the state, which are further divided into villages, towns, and cities. There are 26,586 villages in the state. Any place that has more than 0.5 million residents is classified as a town and has a municipal administration. Any town that has a population more than 1.5 million is classified as a city. There are 264 towns and cities in Andhra Pradesh.

The health care delivery system in India and Andhra Pradesh in particular is by 2 pathways: the government-funded hospitals and the private or corporate hospitals.

Government-funded general hospitals are situated in every district capital. Subunits of general hospital are usually located in 2 or 3 large towns in the district and are known as area hospitals. Smaller referral primary health centers or community health centers are located on an average, 1 for every 3 villages. This system of health care delivery is government-funded, and the care provided is free of cost to the patient. These hospitals see more than 2 million patients as outpatients and more than 160,000 patients as inpatients.⁷ The budget allocation for health care by the government of Andhra Pradesh for the financial year 2007 to 2008 was Indian Rupee 13,150 million (US \$292 million).⁶ The per capita allocation of funds for health care is less than US \$4 per person in the state. This also means that government hospitals are understaffed and have poor infrastructure.

The private or corporate hospitals are usually located in larger towns and cities. These hospitals have better facilities and cater to patients who can afford health insurance or can directly pay for the health care services. The average cost of each surgery for simple

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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 established⁸ 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 developed⁸ 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 surgeon 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.

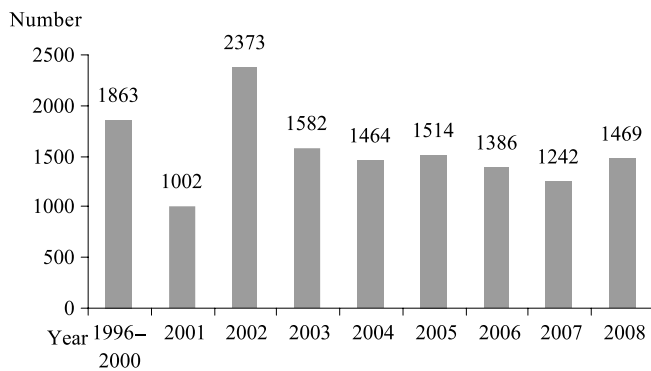


FIGURE 2. Number of patients treated surgically at the GSR Institute of Craniofacial Surgery from 1996 to 2008.

universities and hospitals and develop various basic science and clinical science research projects.

IMPLEMENTATION AND STANDARDIZATION

From August 1996 to September 2000, the primary author was the sole administrator and surgeon. He visited various districts on rotation twice a week to organize surgical treatment for patients with cleft and craniofacial disorders. This helped educate the various primary care physicians and also bring awareness about the cleft deformities and their management.

This experience helped the primary author realize the value of centralization to a single institute to provide comprehensive and cohesive care. The logical place to set up the institute was in Hyderabad, which is the capital of the state of Andhra Pradesh. This city is easily accessible to the surrounding states of Tamil Nadu, Karnataka, Maharashtra, Madhya Pradesh, and Orissa.

Setting up a complete stand-alone institution would initially have required large financial support. The primary author started this project in an existing hospital. He recruited other consultants and formed a team that included a pediatrician, an otolaryngologist, a neurosurgeon, a speech therapist, an orthodontist, and a general dentist. A core group of nurses were trained in managing infants and children with facial defects.

In November 2000, with the entry of external funding agencies into India, the team shifted its base to a larger but lesser used hospital in June 2001. However, the primary author faced procedural and administrative hurdles, and the costs for providing similar care increased with no improvement in delivery of care. In

November 2003, the authors decided that, to have a sustainable module for organizing a center for cleft and craniofacial defects, a stand-alone institution is required. This is found to be the best option that would ensure optimal use of external funding.

The Hyderabad Cleft Society (HCS), which was established as a not-for-profit society in 1996, was now used as the instrument to raise funds. The HCS set up the GSR Institute of Craniofacial Surgery, a 50-bedded hospital, as its operating arm to deliver comprehensive treatment to patients with cleft and craniofacial defects.

Screening and awareness campaigns were launched statewide in all districts within and outside the state in a 1000-km radius of the hospital. At such campaigns, patients with congenital facial defects are screened for treatment at the institute. Patient's education and awareness are increased about consanguinity and its effects on birth of children with congenital defects and dispel superstitions such as clefts being associated with the eclipse of the sun and moon.

In India, children 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.⁹ In India, 17% of children younger than 5 years are mild to moderately undernourished and 6% of children are severely malnourished.¹⁰ 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

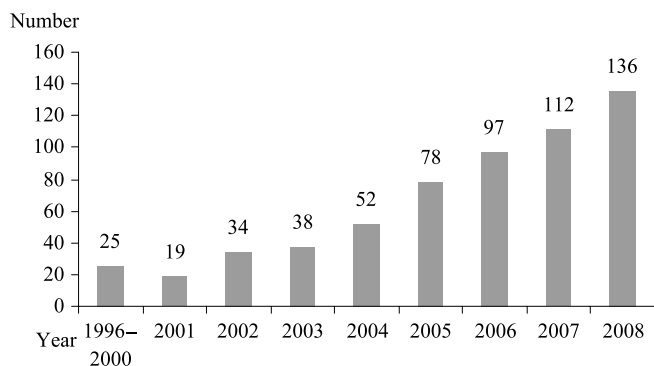


FIGURE 3. Number of patients treated with orthodontics at the GSR Institute of Craniofacial Surgery from 1996 to 2008.

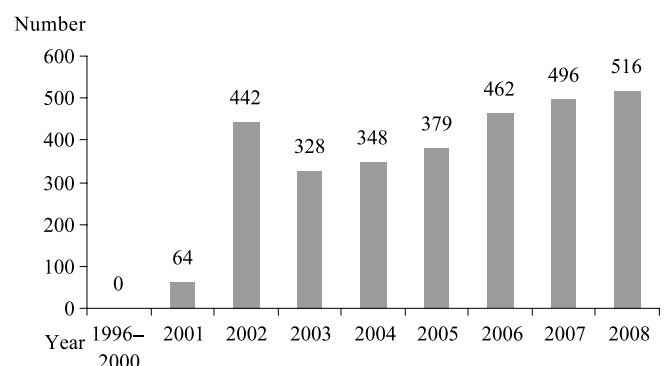


FIGURE 4. Number of patients treated with speech therapy at the GSR Institute of Craniofacial Surgery from 1996 to 2008.

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

1. Sperber GH. Craniofacial development. In: *Early Orofacial Development*. Canada: BC Decker Inc, 2001:30–49
2. Shaw W. Global strategies to reduce the health care burden of craniofacial anomalies. Report of WHO meetings on International Collaborative Research on Craniofacial Anomalies. *Cleft Palate Craniofac J* 2001;41:238–243
3. Ankola AV, Nagesh L, Hedge P, et al. Primary dentition status and treatment needs of children with cleft lip and/or palate. *J Indian Soc Pedod Prev Dent* 2005;23:80–82
4. Registrar General & Census Commissioner of India (Census of India Web site). *Projected Population by Sex as on 1st March 2008*. Available at: http://www.censusindia.gov.in/Census_Data_2001/Projected_Population/Projected_population.aspx#2008. Accessed June 5, 2008.
5. Ministry of Finance, Government of India. *State of Economy 2008*. 1:3 Table 1.2. 2008. Finance Ministry, Government of India.
6. K. Rosaiah, Minister for Finance, Government of Andhra Pradesh State. *Annual Budget Speech for the Financial Year 2008 to 2009* (Andhra Pradesh Government Web site). Available at: <http://www.apfinance.gov.in/html/fin-min-speech-2008-main.htm>. Accessed June 5, 2008.
7. Department of Health and Family Welfare, Government of Andhra Pradesh (Andhra Pradesh Government Web site). Available at: <http://www.aponline.gov.in/apportal/departments/departments.asp?dep=16&org=91&category=Performance>. Accessed June 5, 2008.
8. Adenwalla HS, Narayanan PV, Rajshree CJ. The history and evolution of cleft surgery in India. *Indian J Plast Surg* 2005;38:188–191
9. Sanghvi U, Thankappan KR, Sarma PS, et al. Assessing potential risk factors for child malnutrition in rural Kerala, India. *J Trop Pediatr* 2001;47:350–355
10. International Institute for Population Sciences and Macro International. *National Family Health Survey (NFHS-3), 2005–2006. Demographics and Health Surveys*, 2007;1:223–226. Mumbai, India: International Institute for Population Sciences.