Cleft and Craniofacial anomalies

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Over the last 20 years or so, there has been a noticeable increase in interest in cleft lip and palate, and to a lesser extent, craniofacial anomalies in India, where with the advent of significant funding streams, there has been a massive increase in service provision.

It had been widely perceived that standards of care, in many areas, were unacceptable, being either inequitable or having poor outcomes. Much of this aware-

ness has been driven by globalization which has resulted in rapid economic integration between countries by removing obstacles to the global movement of capital and the production of goods and services. This has been facilitated by improved IT and communication. Driven by unprecedented levels of wealth and the creation of many jobs, the sub-continent being no exception, poverty levels have reduced in certain sectors of society, though there is an ever-widening gap between the rich and poor countries and between the rich and the poor people.

In India, cleft lip is still regarded as a cosmetic problem by many. Clefts represent a major impact on appearance, speech and hearing, psychological well-being and communal integration. The deformity also represents long-term consequences both for the affected individual of an emotional and cultural nature as well as a burden of care for the family and the state, where the tensions of the economic status of a particular region are often at odds with cultural beliefs. Despite poverty, the rise in accessible communications has produced a society increasingly obsessed by appearance, an obsession that represents a challenge for the disfigured, in particular for those with compromised facial appearance, and demands for solutions that will meet ever increasingly higher expectations of a culture driven by opportunities for wealth and success. There is an increasing desire for patients and their families, not unreasonably, to continue their search, for treatments that will eradicate all stigma of the craniofacial anomalies.

With an estimated population of 1.2 billion in India and an estimated 24 million births per year, there are roughly

30,000 children born with clefts each year. Inequalities of access to care and quality of cleft care with distinct differences in urban versus rural areas and accumulation over the years of unrepaired clefts make this a significant health care problem in India. Serious acknowledgement by such organizations as the World Health Organization and work by many NGOs and charitable organizations must be supported, whilst interest amongst local politicians and the wealthy is not only required but must be stimulated and sustained.

The development of cleft surgery in India in the 20th century was initiated by Ruck in 1955 and saw the involvement of Gillies and Peet (Adenwalla et al).¹ A little later, Tessier began his innovative work on finding ways to perform osteotomies and approaches to the craniofacial region in what was to become the speciality of craniofacial surgery. Smile Train became involved in cleft care in India in 2000, creating not only interest but also tremendous enthusiasm for comprehensive cleft care. The quality of work improved all over the country, driven by the establishment of a robust safety protocol. As funds became more readily available, more centres were established. Other organizations have also been involved in establishing fully funded and resourced centres in India, in particular, Cleft Children International (CCI), which also started in 2000, and has supported the development of several cleft and craniofacial centres. Maxillofacial surgeons, with few exceptions, previously only doing alveolar bone grafts and orthognathic work on clefts, have begun to follow their colleagues in Western Europe in acquiring dual medical and dental qualification, and have, therefore, become increasingly involved in the totality of cleft and craniofacial surgery. Another landmark was the establishment of the multidisciplinary Indian Society of Cleft Lip, Palate and Craniofacial Anomalies in March 2002 by Dr. Suresh Tambwekar in Bombay in March 2002, although the idea of founding such a society was first suggested by Dr. Guna-seelan of the Ragas Institute, Madras, 8 years previously.

The major issues that currently face those involved in the management of cleft and craniofacial anomalies, whether in Western industrialized nations or in the less well developed countries are the same. They include the ability to plan and provide local, effective, accessible and equitable care, and

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<http://dx.doi.org/10.1016/j.jobcr.2012.06.002>

to determine and address the burden of care for the affected individual, their families and their employers within the context of the individual culture, not forgetting the potential socio-economic burden for the State. Gap between the costs of providing a service, and developing increasingly effective management strategies, whether medical or organizational, are to be bridged. Whilst surgical services, for example, might be funded, it is the responsibility of the donor organization to ensure that those funds are used effectively and the responsibility of the users, for example and in the context of this discussion, the surgeon, to adopt a method of surgery that will produce the best outcomes with minimal need for costly further revisionary or secondary surgical procedures should the initial technique be wanting. The identification of surgical methods that are effective is essential.

Proper surgical training is an absolute requirement, as is continued research not only to determine the nature and extent of the problem but also the best methods for dealing with it. This research needs to be co-ordinated and the work of the International Collaboration on Craniofacial Anomalies sponsored by the World Health Organization (2000) is of great importance. Epidemiological information gathered through birth defects surveillance is an important adjunct to carrying out clinical and aetiological research. Information on the incidence in the population, causative risk factors and providing baseline data prior to intervention are all important elements. It was agreed that a global registry and database on craniofacial anomalies should be created and this, the International Database on Craniofacial Anomalies (ICDFA) was designed to gather information on craniofacial abnormalities from existing birth defects registries and databases around the world to become a resource underpinning research. It is only by consistency of association between different populations with different gene pools and maternal exposures, lifestyles, nutrition etc. that conclusive evidence regarding causality will be found. It is therefore essential, and a major objective of the WHO that international multi-centre collaborative studies established to gather the appropriate evidence and improve knowledge and the cause of birth defects in general and orofacial clefts in particular.

At the same time, there need to be coordinated educational programmes. Education needs to be focused on basic health matters within the individual culture and prevention of disease, which with improved diagnostic facilities and treatment, will ultimately impact on craniofacial disease. There have been a large number of studies regarding nutrition and malnutrition. Over the years major studies, perhaps not all meeting the gold standard of randomized double blind controlled studies, but nevertheless collectively adding to our understanding of the problem, have been undertaken. These include studies to determine aetio-pathogenetic factors of craniofacial anomalies such as hypervitaminosis A, high dosage cortisone, radiation,

the effect of anti-epileptic drugs and maternal alcoholism on craniofacial embryogenesis, the effect of dietary supplements such as folic acid, which is now considered to be protective, the effects of smoking, obesity and malnourishment. Educating a local population on these matters should be relatively easy, but of course is dependent on initial up to date and reliable evidence, best disseminated by the educated professionals who provide the local regional services. Above all else, there also need to be educational programmes regarding practices that are particular to individual cultures.

The Millennium Development Goals (2000) defined a series of challenges for all who are committed to improving the health of people in low and middle income countries. Current evidence supports the notion that improvements in the health of women and children promote social and economic stability within society. Yet, in many parts of the world, the human rights of women and children are consistently ignored or subjugated to other political and social imperatives. The Goals represent human needs and basic rights that every individual around the world should be able to enjoy and world leaders pledged to forge a wide-ranging global partnership for development to achieve these universal objectives. In agreeing the Millennium Development Goals, the WHO recognized that non-communicable diseases, including birth defects cause significant infant mortality and childhood morbidity and so, in 2008, included cleft lip and palate in their Global Burden of Disease initiative. This will fuel the interest of India in birth defects registration and international efforts aimed at improving quality of care and ultimately prevention of non-syndromic clefts of the lip and palate.

So finally, in order to effectively advance care there needs to be agreement amongst all the specialties involved, maxillofacial, plastic, ORL, neurosurgery, on ways to develop and build centres of excellence guided by agreed parameters of care based on, for example, those developed by the American Cleft Palate Association, for clefts and for craniofacial anomalies, incorporating educational programmes for professionals as well as the wider population, and appropriate research. In this way, a greater awareness of the problems will develop and perhaps influence the national decision makers and attract much needed funding from the wealthier citizens, which would allow, through the creation of endowment funds, the necessary capitalisation of comprehensive centres of excellence and research. India has much to offer and nowhere more so than in the management of craniofacial anomalies.

REFERENCE

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