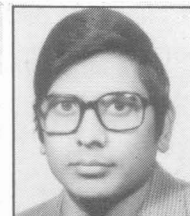


Pediatric Surgery in India A long way to go

D. K. Gupta, MCh



India is a vast country with different walks of people living together despite different social and cultural traditions. In India, about 23 million children are borne every year, and about 17 million survive. Infection, malnutrition, prematurity and diarrhea still remain the major causes of the high neonatal and infant mortality rates in our country. Despite of the keen interest shown by the Government and supported by the Non-Government agencies, it may still be an uphill task to improve upon the current infant mortality rate of 82/1000. The funds are limited and the health delivery system remains grossly inadequate to tackle the congenital and the acquired medical and surgical problems related to children below 14 years of age, constituting almost 37 percent of our 900 million population.

In the surgical horizon, pediatric surgery is comparatively a new subspecialty in India, only about 35 year old. In many developed nations the pediatric surgery is very well developed and recognized as an important subspecialty contributing to improve the child health delivery system and reducing the neonatal and infant mortality rates. There are number of children hospitals and centers which have recently celebrated their 175 year of establishment and progress in the western world. Infection, diarrhea and malnutrition are no more their problems. Congenital malformations, trauma and childhood cancers are their three major concerns requiring the focus of their attention.

Various subdivisions of pediatric surgery (pediatric urology, thoracic surgery, neuro surgery, GI surgery, plastic surgery, traumatology, oncology, neonatal surgery) have also been developed not only to provide an updated clinical service but gain expertise also. During the past two decades advances in research have also led to the development of new areas of interest like fetal therapy, organ transplantation, pediatric laparoscopy, endoscopy, laser therapy, gene therapy including attempts at cloning. The advances in the Biomedical Engineering (DNA flowcytometry, polymerase chain reactions, radio immuno-assay, tumor markers, genetic disorder identification) and radiological imaging (ultrasonography, CT, MRI, Spectroscopy and PET scans) have also contributed significantly to assist the clinicians in the early diagnosis of many congenital malformations, tumors and metabolic, enzymatic and hormonal defects and have also provided an opportunity to offer prevention in some situations.

Presently, of the 125 odd medical colleges in our country, there are only 22 centres providing facilities for teaching and training in Pediatric Surgery. At the moment, there are about 500 trained Pediatric Surgeons in the whole country, limited mostly to the institutions and urban practice. Needless to say, the large rural pediatric population still remain devoid of such facilities, least to talk about transferring the benefits of the advances of the modern medicine.

From the Department of Pediatric Surgery, All India Institute of Medical Sciences, New Delhi-110 029 (India).

Correspondence to : Dr. D. K. Gupta, Head, Department of Pediatric Surgery, All India Institute of Medical Sciences, New Delhi-110 029.

Congenital malformations

In a large sample survey conducted at AIIMS, less than 2 percent children were found to be born in India with various types of congenital malformations. Fortunately, only 10% of these require urgent attention. This, however, provides a huge pediatric surgical work-load to the few centers with meagre available facilities. Due to poor transportation and lack of available maternal and child health services, it is quite possible that a large number of new borns with congenital malformations, not compatible with life (cyanotic heart disease, respiratory distress, complex congenital anomalies, GI perforations and peritonitis) do not reach the hospital even. Neonatal emergencies with respiratory distress, intestinal obstruction and urinary obstructions, obvious congenital malformations on the body (spina bifida group, abdominal wall defects, hemangiomas) are quite compatible with life. Once suspected and referred early, by the medical or the para medical personnel, albeit the number may be small, have fair chances of success.

While air services are a phone call away to transport a newborn with serious malformation in most of the developed countries; in India it remains still a dream. A newborn might have to cover the short and long distances in cars, buses and trains (only very rarely by plane). Also, even a short journey of 200 km. may be quite hazardous due to inefficient mode of transportation and poor condition of the roads.

Though, prenatal ultrasonography has become quite popular, it is only in the urban areas that more and more cases with congenital malformations like hydronephrosis, hydrocephalus and intestinal obstructions are being detected antenatally for early guidance and referral. Fortunately, in our country the socio-cultural outlook is fast changing, specially in the middle class community, The recent observation is that the parents would like to accept a child irrespective of the sex, provided it is normal or a near normal baby,. This trend is laudable and should be accepted as a challenge by the medical community to properly counsel

the parents during the antenatal period on the possible outcome of the malformation. This needs adequate number of up to date neonatal surgical care units and trained pediatric surgical staff throughout the country to generate confidence in the minds of the public before accepting the Government norm of a small and healthy family.

Ethical issues

The subject of ethics in medicine is not new. Hippocrates is well known for laying down the ethical principles in medicine that still hold true for quite a few of these. As we are gaining the experience with our past practices and mistakes, the ethical considerations for a child born with various congenital malformations, trauma, cancer and many other congenital and metabolic disorders becomes quite different when compared to that in developed nations. These are influenced by poverty, the level of education and understanding of the parents, security of their jobs, number of existing healthy sibs, sex of the previous sibs, pressures of the society and their inclination to accept the child with a malformation. The past trend of a joint family setup is disappearing fast from the Indian scenario. A nuclear and educated family, is likely to take decision which might be contrary to that of elders in the joint family system in the past.

The parents get the first shock when they are confronted with the first disclosure of their child having an undetermined sex, a congenital malformation (overt or obvious) and mental retardation. While discussing the sensitive issue of ethical considerations, the parents should be explained about the extent and the likely outcome of the problem within the existing frame work of available experience and facilities in India. The advice may be totally different to the parents of a child who is born with a particular malformation in UK or USA. Usually, these are the obstetrician, pediatricians, neonatologists, general surgeons, family doctors, health workers and the pediatric surgeons who should be aware of the changes taking place from time to time in the current policies and practices while

managing these problems in relation to Indian conditions. Parents must be explained in detail about the extent of the problem, enabling them to make up their mind, preferably within next 24-48 hours. The attending doctor or a specialist has the equal responsibility while discussing the disease. Most of our parents still depend, respect and follow the advice of the medical personnel.

Problem becomes acute in cases with complex congenital anomalies which if not treated timely, certainly would lead to death and also if managed surgically, would possibly result in a life long liability to the parents. Each case is different in its plan of medical management and socio cultural background and should be considered accordingly. As the number of unemployed and enthusiastic lawyers is increasing, more and more cases are being filed under the consumer protection act to try adventurism rather than helping the parents or the medical profession. Despite, all advancements in the medical field and an ongoing success of the genome project (which involves an expenditure of a star war project), we do not know even 1% of the human body functions. This is likely to remain so at least for the next few decades. Presently, it is just impossible to offer the medical or the surgical treatment to each and every disease and disorder presenting to us.

The subject of euthanasia has been debated from time to time to permit the terminally ill patients to die in peace. However, in India so far euthanasia is not permitted by law and hence has not been practised. The doctors and the paramedical staff are required to help the patient with no license to kill.

The ethical considerations are required for the following subjects :

1. Child born with congenital malformations or its subsequent complications. (compatible and non compatible with life).
2. Child with trauma requiring prolonged life system support.

3. Child with advanced malignancy or the toxicity of the therapy.

Most of the indexed cases of congenital malformations like esophageal atresia with tracheo-esophageal fistula, intestinal atresia, anorectal malformations, abdominal wall defects and spina bifida have established surgical plan of management and a reasonably good outcome is expected. However, there are peculiar situations specific to our society, culture, practices, poverty, parity and the sex of the child. A newborn with esophageal atresia and other serious associated congenital malformations like tetralogy of Fallot may be considered for repair only if the parents can afford multiple surgeries including the cardiac one that involves a lot of expenditure. However, the same child belonging to a poor family that cannot even make both ends meet properly in our country, should not be encouraged to be treated vigorously. Similarly, the era is gone to treat all patients suffering from neural tube defect (NTD). A newborn with closed spina bifida without any neurological deficit to the bladder and bowel and who has a reasonably good power in the lower limbs, should be managed by the experts, not only to avoid nerve damage but also to manage the subsequently developing hydrocephalus and its complications. The real misery of a child with gross deficit, becomes obvious immediately after the stage of early childhood when the child is unable to sit or stand and attend to the toilets. There is a urinary and fecal smell all around. It becomes a living problem specially to the working parents. Also, only a few cases do well after the successful surgical and the medical management for hydrocephalus which develops in almost 80% of cases of NTD. A patient with an advanced hydrocephalus, grossly delayed milestones with a thin cerebral mantle and a raised intracranial tension, better be left alone. This would help the parents.

Abdominal wall defects of the newborn produce reasonably good results following primary or a staged repair. However, large omphaloceles with congenital



cardiac anomalies and other major malformations should better be advised against surgery for a family belonging to a poor socio-economic status, unable to afford the cardiac surgery. A reasonable cosmesis and the continence can also be expected following the staged reconstruction of the exstrophy-epispadias complex disorders. However, same cannot be true for a child coming from remote places like higher hills and with limited facilities for transportation and medical treatment. A colon conduit, though may sound unusual, may be the best alternative approach as one time surgery to provide urinary diversion to such children, making them free from smell. The severe forms of abdominal wall defects like vesico-intestinal fissure, though, can be tried for undertaking major reconstructive procedures, the results are less than optimal for Indian conditions in absence of a dependable and sustained support for their rehabilitation.

Intersex disorders form another rare but interesting group of patients requiring assignment of sex at an early age so as to reduce the uncertainty and the mental agony of the parents. Unlike, in the western world where sex of the child is immaterial for growth education and help to the family during the old age, there is a very strong gender bias in our society towards a male child. An infant with ambiguous genitalia with a small phallus and a reasonably sized vaginal pouch needs to be reared as a female. However, traditional families with problems of inheritance always prefer to have the sex of such a child assigned as male. Due to certain psychosocial compulsions of the parents, such a decision at times, may be justified despite being against the medical experience and the teachings.

Malignancy of the childhood is another area where the ignorance, late diagnosis, lack of resources and availability of only the limited expert facilities all hinder the optimal delivery of the care. In India, the children with solid tumors

like Wilms tumor, neuroblastoma, germ cell tumors and hepatoblastoma are already in advanced stage, quite often even with complications by the time they report to the specialized centers. While it is mandatory to investigate and treat all patients even with advanced malignancy, it is ethical to seek the opinion, confidence and support of the parents. The disease process and the institution of chemotherapy drugs may adversely affect the general health of the child requiring frequent hospitalizations. At one stage, the therapy becomes ineffective and the outcome obvious both to the treating doctors and the parents who by then might have felt exhausted of their stamina and the resources.

Though, the pattern of automobile accidents in India is different to that in the developed nations, majority of the children get medical attention albeit late. A few of them require a prolonged ICU care and the ventilatory support. This needs to be judged on merits in each case if the recovery is likely or not. Due to limited ICU facilities available in our country, a discontinuation of the artificial ventilation is fully justified in an otherwise brain dead child so as to offer the available facilities to a more deserving patients who has a high chance of recovery and contribution to the growth of the nation. Despite efforts by the Government, the organ donation has still not become popular even amongst the educated society, mainly due to the strong family opinion and sentiments.

In India, to promote the norm for a small, happy and healthy family and to check the population explosion further, the parents are fully justified in demanding to have a child who is normal or near normal in growth, development, schooling and feelings following the repair of the congenital malformations which is amenable to treatment ; medical or surgical.

Let us continue striving hard to achieve the goal and fulfill the expectations of the society at large.

