

Dilemmas in the management of neural tube defects

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Although the false incidence (children born with neural tube defects or NTD) and true incidence (foetuses with NTD) of spina bifida is on the decline in the developed world, the same cannot be said of spina bifida in developing countries. In a country like India, the socioeconomic consequences of this malformation are devastating. Because of their high incidence, problems related to antenatal diagnosis and abortion, the quality of life decisions involved, lack of social support structures, neglect of the girl child, lack of defined ethical guidelines and a paucity of multidisciplinary clinics, NTDs pose some of the greatest ethical challenges to the paediatric surgeon in India. Some years ago, I was shocked to know that the parents of my patient - a third girl child with meningocele - had officially named her "Nakoshi" which means "unwanted".

Prevention

For most congenital birth defects and especially for NTDs, the most ethical treatment would be prevention. Unfortunately, this aspect has been largely neglected in India. No proper epidemiological survey to determine the exact incidence of this anomaly has been carried out so far. In many leading hospitals with fully established obstetrics and gynaecology, paediatric surgery and radiology departments, co-ordinated efforts are not made to diagnose this anomaly antenatally. Estimation of maternal serum alpha-feto-protein is still not a routine screening test in every pregnancy, though it is not a very expensive test. And even if the mother of a child with spina bifida gets pregnant a second time, there is no guarantee that she will be offered this test. It is still not widely known that folic acid supplementation in the peri-conceptual period has been accepted as a preventive measure.

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Attitudes and approaches

Ethically or morally, two opposite positions have been adopted in relation to the treatment of such anomalies. On the one hand, the consumerist, individualist and capitalist world seems to defend the 'right to live', while on the other hand the non-consumerist, socialist societies are more ready to adopt a practical, statistical approach and a belief in 'death with dignity'.

Those who believe strongly in the right to live would not agree with 'selection of patients' for treatment. This group would probably also not agree on the abortion of foetuses having NTDs. The case of this lobby was amply supported by the famous 'Baby Doe regulations'. These regulations were laid down in 1985 in the USA and stated that withholding care from these babies constituted discrimination against the disabled and therefore was illegal. On the other hand, many socialistic and welfare societies have thought that not just life but quality of life is of greater importance, and judgements to that effect have been delivered in their courts of law.

Who decides what is best for the child? Should this be done by the doctor, social worker, parents, lawyer, nurse or the hospital ethics board? Many persons are concerned with the welfare of the child, but who decides what is best for the baby? In a country like India, ethically it is necessary that the decision be left to the parents because it is they alone who will have to bear the entire responsibility for the future needs of the child. In societies with advanced and established social support structures the decision making tends to shift from the parents into the hands of ethics boards and lawyers.

Family autonomy

We have said that in India it is perfectly ethical to leave critical treatment decisions to parents but respecting family autonomy does not mean leaving the parents alone in the decision-making process. They must be

properly guided. On many occasions these discussions with parents are done by the junior-most doctor in the department. This task should be performed by senior personnel.

Ethical issues to be considered before the birth of a child with spina bifida are: antenatal diagnosis, abortion and peri-conceptual vitamins. After birth, ethical questions such as selection criteria for treatment, the use of costly investigations, the question of euthanasia, and having a second child are important. We have already discussed antenatal diagnosis and the need for more efforts towards prevention.

Selection criteria

During the 1970s, clinicians who were more aggressive in attempting to treat infants born with anomalies began proposing selective treatment criteria. Dr. John Lorber was the first to use diagnostic indicators to propose guidelines about which infants with meningocele should be treated aggressively at birth. Although selection of patients for treatment is ethically acceptable, in many centres the manner in which this selection is done is unethical. To select patients without well defined and uniformly applied criteria is unethical. It is therefore an ethical requirement that each institution which handles children with meningocele debates and lays down proper guidelines for patient selection. The Indian Association of Pediatric Surgeons (IAPS) can play an important role in this context, by forming a working group to formulate these guidelines.

In order of priority my protocol gives importance to the following criteria in selecting patients for treatment.

Predicting ambulation: The single most important criterion is whether the child will be able to walk without help from anyone. This can be predicted by assessing power in the hip and knee joints. By and large, if the both hips are normal (even without power in the knees) then the child can walk with support (crutches). If the hips are



affected then the child will have to be confined to a wheelchair, and in India a wheelchair life is extremely difficult and the individual still has to depend on others.

Family support: Here, we must consider the parents' educational status, family income, and their degree of willingness to shoulder responsibility for the child's treatment and care.

Other disabilities: Spinal deformities, severe hydrocephalus, and other disabilities can influence the decision to select a child for aggressive treatment. In our protocol, we do not consider urinary or bowel incontinence to be a serious handicap because we now have the experience and expertise to successfully manage both these problems at least up to a level where they will not interfere with the patient's daily life.

Expensive investigations

Should they be done in all patients? In recent years CT scans and MRIs have become available in most cities in

India. However, they are still very expensive tests and are beyond the reach of many. In this context, it is again unethical to advise these tests in every case of meningocele that is treated. In deciding when and which imaging tests should be advised, it is ethically acceptable to apply the statistical approach to this problem. In our centre, based on previous statistics we have found that there is a high likelihood of having intraspinal lesions in cases of lipomeningoceles and thus I would get a MRI done in all these cases. Similarly in cases where there is almost total paraplegia the intraspinal findings are not going to have any significant or immediate effect on the ultimate outcome and thus expensive imaging techniques are not necessary.

Another approach that I have found very useful in difficult situations is: "Would I do it on my child?" Unfortunately, in today's scientific and positivist environment the ethical assumption frequently is that using existing technology in the hope of preserving biological life is always a

good worth pursuing.

Ethical care is comprehensive care

Lastly, no care which is incomplete and inadequate can be considered ethical. For most children born with this dreadful condition, the complete medical and social care that they require is rarely available. Very few centres (maybe just two in the entire country) run specialised spina bifida clinics. These clinics must be multidisciplinary in nature and must liaise with social support organisations and schools. Again, the IAPS can play an important role in guiding centres in establishing such clinics and working out the precise costs involved and the infrastructure required.

I have only highlighted in brief the important practical ethical issues that arise when we treat patients of NTDs in India. An enormous effort is required to change the future for these children but the socioeconomic gains of this effort will be equally enormous.

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