

Practical problems and challenges in managing birth defects during pregnancy: A debate for all!

The solution of the birth defects during pregnancy in theory appears to be very simple however, there are many practical problems or rather challenges for us in this regards. In India there are wide variation in the economic status thus affordability, in educational status thus attitude, in availability of diagnostic and therapeutic facilities in their town and the attitude of policy makers in our country towards the priority in managing birth defects. The debate revolves round the various groups or agencies that are related with this. Some of them are given below.

1. **The Public:** the awareness for early detection of the birth defects in pregnancy is mainly confined to the high and upper middle class only. However, this group constitutes only 10-15% of our population while majority of abnormalities especially the major one are more common in lower classes. Thus a significant number of babies with incompatible anomalies are born without undergoing any antenatal screening test or just to suffer themselves, pose financial and emotional burden to the couple and to cause an unnecessary increase our Neonatal Mortality Rate[NMR] for that we at present are not able to do any thing. Thus one can realize that a proper antenatal testing for the birth defects can reduce the neonatal mortality and morbidity in the following ways: [A] By providing improved prenatal and postnatal surgical and medical care, an improvement in the survival rate of newborns with correctable birth defects is expected. [B] By providing therapeutic abortion to incompatible or uncorrectable anomalies the incidence of deliveries/stillbirths of neonates having such anomalies will be reduced.

2. **The Doctors:** What to talk about the public even majority of general practitioners do not know about what to do next if some anomaly is detected. In India still many GPs are not aware of the advancements in the fields of pediatric surgery and believe that there is no cure for majority of congenital anomalies. The fact is that with the advancement in the neonatal intensive care and pediatric anesthesia, most of the congenital anomalies are correctable. Babies suffering from such problems can now look forward to a normal life and often they do far better than their physicians expect initially. It is also seen that many times even the treating obstetricians do not guide properly to such couples who can afford and are willing to undergo any test or treatment. This may cause a delay in detection of some uncorrectable anomalies during pregnancy, by that time the couple probably loses the option to get an MTP done.

[1] **The Law:** As far as the MTP after 24 weeks is concerned; the court can give permission in special cases. In these special cases only the safety of the mother in relation to the detected anomaly is considered. In other words the permission is given only in cases where there is a threat to the mother due to this anomaly. In case if the anomaly is not causing the danger to the life, how so ever major or uncorrectable anomaly it could be, law doe not allow for the MTP! This is very strange attitude.

Will Law provide funds for the treatment to such cases? Considering the fact that 80% of population in this country earns less than 80 rupees/day and the facilities for such cases virtually non existent. If some how it make arrangement for a few cases, then who is going to manage to rest of the cases delivered every year In India it is estimated that 4,95,100 newborns with major malformations are delivered every year and out of this a significant number belongs to uncorrectable one.

After the birth of such baby, as the time passes, the emotional bond between parents and the severely malformed baby get stronger and now the same parents who were strong enough before pregnancy to get the baby aborted due to uncorrectable defect, become so much attached to the same baby that they don't like even to hear any negative comment for their baby. Thus this uncorrectable anomaly gives a great mental trauma to them after birth. Besides, they have to bear the treatment cost by their own pocket and that also consumes lot of their own time and in effects the relations between the husband and wife also. What the law can do for this?

Emotions dominates when you see the problems from a distance or if occurring in others family. Ask to those who face it in their family.

[4] **The parents:** They are the most emotionally attached and the best well wisher of the baby on the earth and certainly more as compared to government and society or even law makers. Ultimately they are the one who are going face the problem. Neither the court nor the govt nor the society would come to bear the heavy expenses. This we are considering for the severe complex problems where the facilities are available only in big cities. Had it been the question of only finances, than at least the couple has the feeling that after that much cost the baby is going to lead a normal life. What about the babies who in spite of costly treatment do not lead a normal life and remains dependent on their patents. It is a bitter truth that it is very exceptional to find that after the death of parents the other close relatives do the care for such crippled patients similar to its parents.

[2] The Government: At present there is no screening programme for the management of birth defects during pregnancy in India. There is no proper arrangements for the treatment of such babies. There are only few or 40-50 centres to manage such cases that are very much inadequate for these babies. While every year about 4,95,100 newborns with major malformations are delivered. I don't want to discuss this in details as everyone of us know the status of health facilities in government hospitals.

The NGOs: Various Government and Nongovernmental organizations have done extremely well in preventive pediatrics for infective diseases. However, the problem of birth defects has still not gained much attention from these organizations. They feel it is the infective causes in the neonates that have to be targeted or controlled first before embarking on to the other causes. The attitude of the various health agencies towards the neonatal diseases is that those problems that are more common should get the priority in attention and funds. No one is going to contradict this. However, in this way sometime the issue of some significant problems [how vast or prevalent it may be] gets diluted if we go by the criteria of figures.

The neonates born with the defects are waiting and waiting from the last several decades for their chance to come that may probably come once the polio, tetanus or diarrhea, etc. get controlled. I would call it a clear cut discrimination to spend several thousand crore to infective diseases in newborns and not a single Rupees to non infective causes like birth defects.

[3] The Indian society: It is true that our Indian society is now no longer very supportive to geriatric people but certainly comes forwards for the pediatric or for babies who have just landed in the world. A single financial support is sufficient to cure most of the major anomalies. However, for the anomaly that requires repeated expenses may be difficult to get help always from society.

It is true that there is no dearth of donors in India. At present the rich of the country are busy in donating and construction of the temples. There is an extremely rich class that never hesitates in donating bags or tons of gold and jewellery for temple construction. It would be much better if this class also make some donation for the construction hospitals for babies born with some birth defects as the building of the hospital is in no way less than sponsoring a temple. It would be much better if you earn the blessings of god through serving the little gods that have just arrived in the world.

I feel that there is a tremendous scope for various charitable social organizations in India. Instead of waiting for the government to think and rethink and then implement any firm policy as there are so many ifs and buts, it is expected that we ourselves come forward to help/start such medical services in our country.

[5] The insurance companies: There is clear cut discrimination by these companies for the babies who are born with some cases of birth defects. A healthy out come of the pregnancy can only be called if both the mother and the baby are discharged in a sound state of health from the hospital. However, the insurance companies reimburse only for those expenses that are made towards the mother and they refuse for any expense that is made for treating the baby having any congenital anomaly. Are the babies born with some congenital anomalies not human beings? Don't they have any human rights?