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EDITORIAL

PRENATAL DIAGNOSIS - ETHICAL & MEDICOLEGAL CONSIDERATIONS

Prenatal diagnosis is not new. Prenatal diagnosis of fetal malformations like hydrocephalus and anencephalus based on clinical examination is in vogue since many centuries. In the earlier decades of this century radiology aided such diagnosis and termination of pregnancy - albeit late - for gross fetal malformation was an accepted clinical practice. Recent decades have seen tremendous technological advances. Ultrasonography, biochemical evaluation, radioimmunoassays and chromosonal analysis of maternal blood, amniotic fluid, chorionic villi, fetal blood and biopsy specimens of fetal tissues have enabled us to diagnose- even predict pre-conceptionally - fetal anatomical, functional and metabolic malformations. Besides there are growing expectations from our patients that as far as possible we see to it that only healthy and normal babies are born. It has now become our professional responsibility to identify those couples - based on personal and family history - who are at risk of

conceiving abnormal fetuses and to counsel them on the availability of modern techniques of prenatal diagnosis. Failure to do so would be tantamount to professional negligence and can invite action under Consumer Protection Act (CPA). Failure to give proper advice could invite legal action similar to giving wrong advice.

The aim of prenatal diagnosis is to confirm or exclude fetal abnormality and if confirmed to take necessary appropriate action like termination of pregnancy, intrauterine treatment, early delivery for immediate neonatal treatment, arrangement for early neonatal treatment after spontaneous delivery and lastly, preparing the couple and their family to accept the handicapped child in certain situations. To counsel the couples on all these aspects, to help and guide them in prenatal diagnosis, to refer them to specialised centres for prenatal diagnosis and if necessary for genetic and other counselling, to take appropriate action after unfavourable report following prenatal diagnosis and to refer to specialised centres for such action, when necessary, is our moral, ethical and professional responsibility. Failure to fulfil this responsibility is negligence liable for action under CPA. It must be emphasised that doing sonography for fetal malformation needs great skill, experience and expertise and hence should be entrusted to those competent to do it.

Many ethical and legal issues are involved in prenatal diagnosis. Laws of different countries decide on legal issues. The ethical perspectives also vary in different communities, cultures, religions and societies. Should prenatal diagnosis, especially by invasive methods, be undertaken without any definite purpose e.g. when there is no indication or when the couple is not willing to take any logical followup action like termination? Limited availability of such facilities and risk of complications of invasive procedures - however small it may be - should decide against this. Should prenatal diagnosis be made compulsory? This is a highly complex issue but the concept of individual's freedom and practical limitations of resources would weigh against such compulsion. Incidentally, in China, a couple with an abnormal child is permitted to have a second pregnancy only on consenting to undergo prenatal diagnosis while in Cyprus, the refusal of the Greek Orthodox church to marry couples without carrier testing for thalassaemia has almost eliminated thalassaemia major. Lastly, if a pregnant woman having an affected child not only wants to know whether the foetus is affected but also wants to know whether it would later be a compaptible donor for bone marrow transplant for the living affected child and intends to abort if not so compatible, is it ethical for us to do HLA typing of the feuts for this purpose?

No invasive procedures for prenatal diagnosis should ever be carried out without an informed, written and valid consent. Such a consent can only follow proper and adequate counselling including information about various choices (e.g. choice between chorionic villus sampling and amniocentesis) and their advantages, disadvantages and risks of complications. In

our country, since fetal sexing is legally prohibited for fear of selective female feticide, no report of prenatal diagnosis should ever indicate fetal sex unless a sex-linked disorder is under consideration. After prenatal diagnosis, it is our professional duty and obligation to offer proper and adequate counselling about the various options open to the couple. But the choice to be taken must be left to the couple though family members may have to be involved especially when the couple is minor or dependant or incapable to taking decision. Special counselling would be called for when prenatal testing reveals an unexpected abnormality other than the one being looked for. In general, a counselling should be nondirective, although opinions are divided about the extent to which our views, opinions, tenets and beliefs should be allowed, if at all, to influence the couple's decision. Some of the couples opting for terminating pregnancy may need counselling after pregnancy termination to help them get over depression and guilt feeling. Maintaining total confidentiality about all information concerning our patients is a long recognised basis of our professional conduct. Prenatal diagnosis sometimes leads to difficult ethical situations regarding such confidentiality. If prenatal testing reveals that the husband is not the biological father of the fetus, should he be told the truth or be left with a false belief that he is a carrier? Secondly, should the biological father be informed that he is a carrier? Theoretically, the woman should be encouraged and helped to reveal the truth to the persons involved but her wishes and decisions must be honoured and confidentiality strictly maintained. On occasions, it would be advisable for the patient to inform her siblings about her genetic make up and the desirability of their undergoing genetic evaluation in their own interest. Sometimes, the family members may want to know the results of the patient's genetic testing as these would affect them indirectly or directly. Patient's employers and her insurance company would be interested in knowing the results of her genetic and other testing for obvious reasons. Under all such circumstances it would be unethical and illegal to divulge the patient's confidential information to any third party without her written consent. She can refuse the permission. Should a couple adopting a child be given genetic information of the biological parents in the interest of the child being adopted? Incidently, patient's DNA material stored in the laboratory can have tremendous unforeseen potential to reveal in the future information about them which they may not want to be revealed. Hence they have the right to order destruction of their DNA material at any time.

Advising and conducting prenatal diagnosis when indicated is our duty. Not carrying it out would be negligence and potential invitation for medicolegal action under CPA. But undertaking invasive prenatal diagnosis without proper indication can also land us in medicolegal problems if complications result from such testing. It must be added that all our actions are judged by what our colleagues of similar qualifications and standing practice in our circumstances with same facilities are doing.

Preimplantation diagnosis by employing polymer chain reaction technology and studying single cell biopsies of 8 cell embryos or better still by studying polar bodies can replace prenatal diagnosis eliminating all its problems. But this involves IVFET a very expensive proposition having its own complications and a poor success rate. Lastly, the impact of gene therapy on prenatal diagnosis cannot be predicted in its entirety. Gene therapy is on the horizon - the controversies about germline gene therapy notwithstanding. Hopefully, it would eliminate most of the ethical and medicolegal problems involving pregnancy termination and current intrauterine therapy following prenatal diagnosis. It would no doubt create it's own problems. But then that what progress is - replacing old problems with new ones.

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