

Bioethics and prenatal diagnosis of foetal diseases

The development of prenatal tests to detect structural and chromosomal abnormalities in single and multiple fetuses started some 30 years ago. The use of amniocentesis and analysis of amniotic fluid allowed obstetricians to detect and assess the severity of rhesus disease in the unborn child and decide on the need for early delivery. Today, numerous prenatal testing techniques, including maternal blood sampling, ultrasound, chorionic villi biopsy, and amniocentesis are used to detect a variety of medical conditions in the foetus. The use of molecular diagnosis and other sophisticated techniques allows obstetricians to diagnose many genetic conditions accurately before the baby is born.

Indeed, pregnancy has come under increasing medical control, with good and bad aspects. On the positive side, pregnancy and childbirth have become safer for the mother. Likewise, maternal and infant mortality rates have gradually declined in Hong Kong and other developed countries. Compared with the past, there is also a greater awareness of the nature of the unborn child, not only on the part of doctors and midwives but also on the part of parents. The ultrasound scan, which allows the mother to see her foetus clearly, has been especially influential; the unborn child seems somehow more real when it can be seen. On the negative side, pregnancy can be treated like a disease. The availability of tests to detect foetal abnormality has led to subtle social pressure on both mothers and clinicians to use abortion to prevent the birth of disabled and handicapped children. The whole issue is compounded by our community's obsession with excellence. Many parents now expect their child to be a 'perfect' baby and cannot contemplate having a foetus with major or minor congenital abnormalities. This attitude has been wryly coined the 'Perfect Baby Syndrome'

Both the medical profession and pregnant women now see prenatal diagnosis as a necessary part of prenatal care. Yet the choice the mother will face if a foetal abnormality is found, irrespective of whether it is a major abnormality such as severe congenital heart disease or a minor abnormality such as isolated polydactyly, is a cause of much distress and a matter of moral concern. While some prenatal diagnostic tests are undertaken to promote a safe pregnancy and birth, there are a number whose primary aim is to detect foetal abnormalities. Thus, the ethical issues relating to prenatal diagnosis have become a major area of medical academic discussion in recent years.

In early 2005, a Working Group on Ethical Issues of Prenatal Diagnosis comprising representatives from the Hong Kong Bioethics Association, the Hong Kong Society of Medical Genetics, the Hong Kong Medical Association, the Medical Ethics Unit of the Faculty of Medicine of the University of Hong Kong, the Social Work Department of the Hong Kong Baptist University, and the Hong Kong Down's Syndrome Association was set up to explore and discuss the related ethical issues in Hong Kong. Several

clinical ethical issues relating to prenatal diagnosis were identified. Firstly, the ethical principles governing the allocation of public health resources to screening for genetic disease in all babies born in Hong Kong have to be defined. Secondly, the problems concerning the confidentiality of prenatal screening results need to be considered. This is particularly important nowadays as many genetic diseases can be diagnosed accurately via molecular diagnostic techniques in newborn babies and the carrier state for several inheritable diseases, eg Huntington's disease can be detected in utero. Both the right to know and the right not to know an individual's genetic traits have to be addressed. Thirdly, clinicians may have difficulty with antenatal management when a foetus is found to have structural abnormalities such as a cleft palate, hydronephrosis, and spina bifida. Fourthly, the rights of individual fetuses in multiple pregnancies also constitute an area of clinical concern.

In the past 12 months, the Working Group has conducted two focus group meetings for professionals from a wide range of disciplines, including medical ethicists, obstetricians, paediatricians, family physicians, sociologists, and parents of children with congenital malformations such as cleft palate. A survey on the understanding of prenatal screening services in Hong Kong and the rehabilitation of disabled children was conducted by the Social Work Department of the Hong Kong Baptist University. In January this year, an Open Forum on Prenatal Diagnosis and Medical Ethics was held at the Hong Kong Baptist University. Several speakers including obstetricians, geneticists, medical ethicists and representatives from the Medical Ethics Committee of the Hong Kong Medical Association spoke before the forum was opened for discussion. The well-attended meeting aroused much interest in both medical and academic sectors.

Medical ethics is now an important part of undergraduate medical education in other developed countries. With the advent of sophisticated medical technology and the diversity of cultures and beliefs in our pluralistic society, there is a need for the medical profession to promote public awareness of the ethical issues related to prenatal diagnosis. All health care professionals may have to update themselves on the controversial aspects of prenatal diagnosis. More local academic research on areas of conflict needs to be done soon.

RKN Yuen, FHKAM (Paediatrics), FHKCPaed
(e-mail: dr_rknyuen@yahoo.com.hk)

Hong Kong Bioethics Association

STS Lam, FHKAM (Paediatrics), FHKCPaed

Hong Kong Society of Medical Genetics

D Allison, MA (Cantab)

Chairman, Strategic and Management Committee,
Hong Kong Early Childhood Development Research
Foundation