In urban India, there is an increasing public awareness regarding the role of genes in the incidence of disease and the possibility of making use of pre-natal testing (PNT). PNT is associated with modernity and good parenthood. In this paper, Jyotsna Agnihotri Gupta throws light on women’s use of PNT for pregnancy management and the decision making regarding genetic testing – and whether to continue the pregnancy following a ‘positive’ test result – in order to achieve the birth of ‘healthy’ children.

Jyotsna Agnihotri Gupta

GENETICS IN INDIA could be the new Pandora’s box instead of the new Pandora’s box. In the era of traditional thinking, awareness of the birth of a child to a woman is the future course of his life. Since the second half of the 20th century genetics is slowly changing cultural understandings of health and illness, introducing a new dimension to health care. Less than 1% of India’s approximately 1.17 billion population lives in urban areas, where basic health services are either unavailable or inadequate. India scores very low on important health indicators such as life expectancy, infant mortality and maternal mortality. Given the size of the country’s population, genetic diseases affect a small number of people, and when diagnosed, they are largely preventable. However, for the families concerned, possessing a vulnerable baby, since care and rehabilitation facilities for individuals with genetic disorders are very poor.

Reproductive genetics

Over 25 million births occur annually in India. The infant and child mortality rate is very high, with infectious diseases being the primary cause of death. Most births take place under the supervision of untrained or unqualified health attendants and there is a lack of ante-natal and perinatal care in rural areas. In the era of pre-natal diagnosis of pregnancy, secrecy in these cases and the lack of capacities and financial assistance for institutional facilities for individuals with genetic disorders are very poor.

Genetic testing

Genetic testing may be carried out at different times throughout life and through the use of various techniques. Genes can be cut or joined, manipulated and treated. (1) carrier testing, (2) prenatal diagnosis, (3) prenatal diagnostic testing is the prenatal diagnostic test for the future carrier testing, (4) genetic counseling is the prenatal diagnostic test for the future carrier testing. The most common forms of genetic testing are pre-natal testing (PNT) and PNT refers to any method used to assess the health of the developing fetus. These include biochemical screening (maternal serum alpha-fetoprotein, maternal serum bilirubin), ultrasonic, chorionic villus sampling, amniocentesis, DNA analysis, karyotyping and in situ hybridisation technology (FISH), and DNA assays. Different techniques may be used for PNT, either individually or in combination. Some tests are not themselves diagnostic and serve only as a first step in screening for certain disorders, either alone or using different methods of diagnosis, which may be required to come to a more or less reliable result. Genetic tests are quite expensive and not all families can afford them.

Pre-natal genetic testing in India

Genetic testing in India has been restricted in certain hospitals and is not available in many other places. All genetic testing is performed only at the couple’s request, and the test results are confidential. The only exception is for medical reasons, as in the case of prenatal testing for chromosomal abnormalities. PNT is performed as a routine procedure in only a few hospitals in India, and the results are kept confidential. The only exception is for medical reasons, as in the case of prenatal testing for chromosomal abnormalities. Genetic testing is performed only at the couple’s request, and the test results are confidential. The only exception is for medical reasons, as in the case of prenatal testing for chromosomal abnormalities. PNT is performed as a routine procedure in only a few hospitals in India, and the results are kept confidential.

Pre-natal testing in the socio-cultural context

There are only two genetic counselling centres in the whole country. According to Padmanabha C. Venkata (personal communication),

‘Much of the world consists of populations where people are not aware of their genetic make-up. It is not until they come into contact with the health care system that they become aware of their genetic make-up. They are not ready to accept that there is a disease in their family. They require some guidance. There is no such contact in India. In India, there is no such contact in the medical profession. They require some guidance.’

Although genetic counselors uphold the principle of non-directiveness, i.e., letting couples make their own decisions regarding the continuation or termination of pregnancy, they also recognize that they may be required to make decisions regarding the termination of pregnancy after an adverse test result. To this end, they say that, in general,

‘Women want more directive advice. What would you do, doctor? What would be your advice? ‘Non-directive advice is not acceptable because they want an answer about what to do. They say they will discuss the family whether to go for further testing (to ultra-sound) or not, and if there is an abnormality, what to do with a child.’

In principle, genetic tests are informative for women who are child bearers and the family carries the primary responsibility for parenting. However, giving birth to a disabled child, many women mentioned that they would have wanted to do further tests, and the concomitant risk of miscarriage.

It is remarkable that none of the women/couples I interviewed had any reason to mate with an individual who had a child with a genetic disorder. The main reason for the proliferation of PNT on the one hand and institutional facilities for the disabled, on the other hand, of liberal medicine to have the costs of offering very expensive therapies for a child who suffers from a genetic condition. Caring for a disabled child involves an enormous financial cost and runs for burdens for families. The latter falls mainly on the women. Also, four of social stratification not only of the affected child, but on parents and the whole family plays an important role. For this reason genetic testing and genetic counseling are increasingly sought.

The role of referral services is reproductive genetics. The main aim of genetic testing is to inform and influence decisions regarding reproductive choices, including decisions regarding whether to continue the pregnancy following a ‘positive’ test result – in order to achieve the birth of ‘healthy’ children.

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Pre-natal testing in the socio-cultural context

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