The Psychological Aspects Of Prenatal Diagnosis

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Dorota Kornas-Biela, Ph.D, is a psychology professor at the Catholic University in Lublin, Poland. As will be noted from her article, Dr. Kornas-Biela does not subscribe to the modernist concept that “technological science cannot be thought together with what is given us concerning justice and truth” (George Grant, English Speaking Justice, 77). Nor does she subscribe to the view that ‘right’ precedes good regardless of the consequences. Rather, she raises critical questions about the nature of human life, and reasons why the good of individual family members and the well-being of the family itself must be included in recommendations for technological solutions.

Every family, when they are expecting a child, wonders about the sex, health and future of their offspring. The pregnancy period, called the blessed one in the Bible, is not always a blissful time for the parents. When there is a possibility that the child might have abnormalities families can experience intensive stress.

Modern medicine offers help for such families through prenatal diagnosis which evaluates the child’s development. In most cases this diagnosis decreases the parents’ anxiety, reduces the intensity of stress and provides psychological comfort.

However, such diagnostic techniques can arouse uncertainties and issues which should be considered by both the medical staff and the parents. This article will discuss some of the controversial moral and psychological issues related to prenatal diagnosis as well as the positive values of these procedures.

Prenatal Diagnosis in a Genetic Counseling Process

Deep psychological concerns arise for parents when prenatal diagnosis results in recommendations for counseling due to the possibility of genetic risk. The family’s
difficulties can be aggravated by procreative misfortunes such as the death of a child, stillbirth, spontaneous abortion, or infertility. If the family already has a handicapped child they may have also encountered discriminatory or [other] negative attitudes directed toward the ‘imperfect’ people in society. Such social rejection can result in depression, hopelessness, helplessness, guilt, anxiety, low self-esteem, and a sense of being wronged. The awareness of risks and concerns relating to the future create a strong need for information concerning the child’s health. While genetic counseling can provide a main source of information for parents, discrepancies can arise between the aims stated by a counselor and the parents’ expectations.

Psychologically, denial reactions can occur in which people misinterpret their risk level or simply appear unable to remember it. These phenomena develop as a result of the stress which accompanies the transmission of information concerning genetic risk to the child, even if the risk level is low. Both intellectual factors, such as individual risk perception style or intellectual capacity, enter into the situation. Non-intellectual factors, such as the personality traits of the counselor, the duration of counseling, emotional reaction under stress conditions, reproductive plans, number of children in a family, age of the mother, type of education, professional activity, social background, values hierarchy, level of anxiety, and religious attitudes are involved in genetic information processing and memorizing.

Other risk assessment effects can result: risk ignorance; overestimation of a risk level as prospective parents try to justify and rationalize their lack of willingness to sacrifice and rear an affected child; and underestimation in cases where the patient has a strong sense of guilt, a lack of a sense of control over events or a perception that procreation may be dangerous.

Another factor which can determine inadequate risk level perception is caused by the manner in which a counselor presents the parents with the probability of birth of an affected child. The counselor’s message may be based on scientifically derived risk factors while the parents’ assessments of genetic risk are not linked to statistics or inductive logic but are related to analogical personal inferences relating to their lives and the life of their child. In this situation, genetic information transmission could fail to either correspond to a natural pattern of human thinking under stress conditions or to cognitive perceptions. In addition, pregnancy risks can activate fears in the woman which may make her particularly susceptible to suggestions, nonverbal components of communication from the physician, or irrational decision-making.
Assumptions are made in the counseling process that the counselor will maintain an attitude of neutrality while providing information relating to decisions such as prenatal tests and abortion. Neutrality requirements are difficult to fulfill, in some respects presenting a psychological paradox, since the provision of information is specifically aimed at forming the attitude of the client towards procreation and prenatal diagnosis. Moreover, efficient counseling for parents is interpreted in terms of changing their decision for procreation through the use of prenatal diagnosis.

If the aim of counseling and the criterion of its effectiveness is defined in the above way, it is impossible for counseling to be nondirective. Conscientious counselors work effectively by controlling the counseling process in order to achieve their purpose. Although they may not direct the parents or give them ready patterns of problem solving this does not guarantee nondirective contact during counseling. It is quite possible for parents to perceive the counselor’s attitudes towards prenatal diagnosis, abortion in general and the abortion of a child with genetic problems.

Clues which can assist the parents in working with genetic counselors include the identification of the medical institution where the counseling occurs and the role of the physician within that institution; the terminology used by the physician; the manner in which the message is transmitted; the length of time taken for the definition of the problem; the emotional involvement revealed in gestures and voice timbre; the sequence of messages (for example, a description of a level of risk followed by a message about the possibility of prenatal tests and abortion in the case of an affected fetus); and concealment of source statements concerning the moral aspect of abortion. The physician is in a position to exert his/her own influence on the parental decision in a nonverbal way since the parents have become dependent upon the physician in his/her role of a professional authority. Moreover, they are eager to follow the physician’s suggestions, selectively listening for information that confirms their own desires or justifies a moral decision which has already been made.

Directiveness can be detected in the terminology used in counseling. A definition of risk level as low, medium, and high is made arbitrarily. The frequency rates are easily manipulated when accentuating either risk of birth of an affected child (5/100) or the chance of birth of a normal child (95/100).

It should be noted that the use of the term “risk” itself is a form of interpretation, since a decision concerning a given level of probability that a child will be affected is a risk for the parents themselves. Psychologically, parents may or may not interpret some events as risk.
When parents are told that the possibility of their having an affected child is higher than in the general population, it means simply that an interpretation of a neutral statistical fact has been given to them.

Using “risk” terminology infers that if it is something risky it should be avoided because it is dangerous or undesired. In this case when a child does not fulfill specific criterion of health and physical or mental standards, it is interpreted as a “risk” for the family. The interpretation of “risk” or danger for the family would be the reason for a selective abortion. Thus, when terminology of a pejorative character is used it forms social bias against disabled people generally.

There are also other terms used in counseling which manipulate the parents’ awareness. In some cases they are told that they are free to decide about continuing or terminating the gestation, but the affected child is treated as a disorder in the woman’s organism rather than described in terms of another human being. Physicians also use the term “therapeutic abortion,” when eliminating both the disease and the sick person. This is not a therapy at all. Physicians also interpret parents’ procreation plans through the aid of prenatal diagnosis as rational decision making. In fact, this interpretation is presumptive since the assessment of a given alternative as rational should be made by the couple themselves.

Counselors describe prenatal diagnosis as a method of testing a fetus in order to give the parents sufficient information to make a decision about abortion. In these cases it is common to use the word “fetus” rather than “child.” Unfortunately, advisors are sometimes negative rather than positive when relating information which might help the parents prepare for the birth of an affected child.

The optimal time for amniocentesis is between 16 to 18 weeks of gestation. Test results can be obtained between 20 and 22 weeks. This period is interpreted as “early gestation” but nobody tells the parents what level of development a child reaches at that time in order that they may assume their parental role and form emotional bonds to the child. The woman does not often receive consideration concerning her emotional experiences when feeling the fetus’ movement, listening to the heartbeats of her child, or watching its image on the ultrasound monitor screen. The fracture of the mother/child bonding as a result of abortion results in feelings of sorrow because of the loss of a child, and a long term feeling of guilt.

A physician is obliged to inform each family about the level of genetic risk if the family asks for it. At the same time the counselor frequently does not take into account whether a risk level for a given family is large enough to be compared with a population risk, that is,
whether it is worth putting this family through the long term stress involved in a counseling diagnostic cycle. Advisors should be sensitive to whether it is an appropriate time for the family to be given risk level information or whether this information might increase tension in a family, resulting in divorce or other serious problems. Parents should not be left alone with this knowledge.

Important psychosocial consequences can occur for parents who are labeled “high risk.” They can either be viewed or view themselves as “abnormal.” These parents need to be assisted in accepting their situation while efforts are made to restructure their self-esteem or the image of the marriage partner. Their plans may also have to be changed when both the risk factor and the prenatal diagnosis are taken into account. Under such conditions immature defense mechanisms or neurotic reactions might be aroused. Counselors should be trained to understand their personal responsibility in non-directive and non-coercive counseling in order to assist parents with difficult moral dilemmas.

Prenatal Diagnosis as Prevention of Abnormalities

Prenatal diagnosis is usually treated as the prevention of innate disabilities in a population. Serious questions arise relating to the preventative aim of this diagnosis.

Why must parents consider an epidemiological aspect of their procreative decision when families themselves have personal goals to be fulfilled which may not be limited to a guarantee of completely healthy children? Family’s goals should not be identified with the goals of the society which definitively decides that it is better “not to have handicapped children.” Who will decide under what conditions particular defects and diseases should be “prevented?” This becomes a fundamental question as medical technology develops new techniques of prenatal identification. What will be the criterion for selective abortion as a prevention of abnormalities in future populations?

The number and kinds of defects and diseases to be prevented depends on concepts of health, sickness, and disability within a given society. The meaning of these concepts is determined by several factors related to the level of medicine and technique development, system of education and social security, social services, and cultural level standards. The level of social tolerance for differences, such as using toes instead of fingers for eating when one does not have hands, as well as respecting a person’s right to be sick or exceptional, determines the distinction between the so-called normal and abnormal human life.
The categorization of defects or “catastrophic genes” which “must be prevented” is based upon arbitrary decision-making since the development of new therapeutic methods may decrease the effects of a disability. There are various criteria to assess the seriousness of disabilities. According to subjective evaluations even so-called “small defects” may be qualified as serious if families expect negative social attitudes towards their child.

The concept of “genetic health” is unclear since everyone carries deleterious genes. Dangers of racial extermination can exist in situations of ethnical disease conditioning through the removal of both the affected individual and the carriers of the catastrophic genes in forthcoming generations. Other dangers include the removal of children with abnormal karyotypes (e.g. XYY) for whom prognosis is ambiguous or the risk of abortion of an unaffected child because of the possibility of sex-linked disease (e.g. hemophilia).

Prenatal diagnosis does not necessarily prevent defects in individual families. After genetic counseling a woman may make a decision to become pregnant “experimentally.” When she is unsuccessful she faces an abortion which arouses a new moral and psychological problem. Then the woman must be offered intensive psychological help to break her behavioral cycle. The cycle is renewed with her next unfulfilled hope to have a healthy child, followed by her conviction of self-deficiency and helplessness which, in turn, results in a stronger desire for self-esteem and her husband’s acceptance. A prospective child can be used in this situation as a means of satisfying the parents’ personal goals. If the unborn child does not fulfill these conditions, it may become an object of the woman’s aggressions. Psychotherapy should help these parents to find out new values and to restructure their life goals in order to make them more realistic.

Accentuation of an affected child’s suffering, may be a projection of the parents’ own fear. Predictions of a child’s future suffering are unreliable. Even seriously sick, retarded or crippled children can be treated medically in order to eliminate or reduce their physical pain. Many have a chance for a good life if they are treated with love. Whatever the choices, no moral rights exist which justify killing to prevent human suffering. Prenatal diagnosis cannot be justified as eugenic activity based on compassion. It is simply the termination of human life on the basis of a constructed rationale.

Psychosocial Dimensions of Prenatal Diagnosis

The right to abort affected preborn children raises serious questions concerning the right to live for incurable, disabled and retarded adults. Medical treatment can decrease the
consequences of disabilities. At the same time, the mitigating effect of medical treatment may increase the number of disabled people in the population at large. This would also increase the number of disabled people engaged in reproductive activity during the course of their lives spreading the disability in the population.

Prenatal diagnosis could also have a strong impact on the attachment of the sick and disabled child to their parents. They may realize that they have survived “by accident” or through “incorrect testing.” Healthy children are also influenced when they discover that they were born after negative results in prenatal testing. On the other hand, the parents’ knowledge that their child is a carrier of an undesired trait could cause emotional rejection or overprotection.

If the goal of prenatal diagnosis is to check the progress of the pregnancy in order to decrease the risk of complication and secure its correct course, to provide medical treatment for mother and fetus, to prepare parents for the birth of an affected child and to secure the newborn an early intervention just after birth, then this diagnosis has a therapeutic purpose and meets requirements for standard medical examination. Medical diagnosis has to serve the patient, to attend and save life, to decrease pain, and restore health. When a diagnosis lacks a therapeutic perspective, it undermines the physicians’ authority. The prenatal child is also a patient who should not be the object of medical examination which might impair his/her life. In this case the patient can neither reject nor accept the role assigned by either the parents or the physician.

Conclusion

Some cost-benefit analysis shows that it is much less expensive to provide prenatal diagnosis and selective abortion of affected unborn children than it is to provide treatment. Such argumentation can become a form of “black-mail” or even a pressure imposed on citizens. Financial interpretations ignore the humanity of the subjects both before and after birth. The moral context of selective abortion is neither considered nor discussed in this construct. Human life in this context is treated as a product with its value dependent on a criterion of perfection.

The fundamental problem in evaluating prenatal diagnosis used for selective abortion turns on the anthropological question of when human life begins. Contemporary genetic investigations say explicitly that this moment strictly comes with conception. If such understanding of the beginning of human life is accepted there is no possibility for moral
justification of any kind of abortion. Thus, the human fetus must be treated as an unborn child; that is, as a human being who has an unconditioned right to live.

Psychological analysis allows us to indicate some controversial issues concerned with prenatal diagnosis. Instead of drawing conclusions we must seriously consider the following general questions which resulted during this study:

Why is the elimination of affected unborn children viewed as a more appropriate method of problem solving than rehabilitation? Why must the value of a human being’s life be determined by health, productivity, abilities or appearance? Who will decide, and under what conditions, which defects or diseases must be prevented? Is any social control possible to prevent misuses of prenatal diagnosis? Why is the preborn defective child not treated as a patient who possesses, just as living individuals, an unconditional right to life? Why is that child treated in a manner which might impair his life? Should the social and political interests of abortion prevail over the moral and private attitudes of individuals? Is abortion justifiable at all in light of the biological and genetic principle that human life comes into existence at conception?

New Maternal Blood Test Gauges Downs Syndrome Risk

A new maternal blood test is reported as “dramatically improving” doctors’ ability to determine which pregnant women under the age of 35 “are likely to benefit” from amniocentesis testing to detect the disorder.

About “1 in 650 babies born are affected with Downs Syndrome.” Downs Syndrome can cause “mild to moderate retardation,” identifiable physical characteristics, a shortened life span and congenital defects. The syndrome can be detected through analysis of fetal cells obtained, either by amniocentesis, a method in which amniotic fluid is extracted from the womb, or through chorionic villus sampling (CVS). With CVS, placental cells are removed through a catheter inserted into the womb. CVS can be done during the first three months of pregnancy, but amniocentesis can only be performed in the second three months. Both CVS and amniocentesis involve a risk of miscarriage. CVS has a miscarriage rate of 1 in 200 (also see “CVS and Risks of Limb Anomalies,” PRI Review, Sept./Oct., 7).

Amniocentesis has been recommended for women with abnormal blood levels of alpha-fetoprotein. However, this method led to the identification of only about 20 percent of
Downs Syndrome cases. The new test is expected to lead to the identification of up to 60 percent of Downs Syndrome cases and “can be incorporated” in routine prenatal screening (Boston, UPI. 26 August 1992).