Selective abortion on the basis of prenatal genetic diagnosis: ethical problems faced by the doctor

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“Every night and every Morn
Some to Misery are Born.

Every Morn and every Night
Some are Born to sweet Delight”.

William Blake¹

¹ Lane, 1996
Table of contents

Introduction
Why does Prenatal Diagnosis deserve our Attention?................................................4

Chapter I
Prenatal Diagnosis.......................................................................................................6
1. Short description of Prenatal Diagnosis.................................................................6
2. Defining the patient in Prenatal Diagnosis............................................................7
3. How can prenatal diagnosis benefit the fetus and the mother..............................8
4. Prenatal Diagnostic procedures............................................................................11

Chapter II
Ethical problems of Selective Abortion on the Basis of Prenatal Diagnosis..............16
1. Moral status of the fetus.........................................................................................17
2. Justification of selective abortion on the basis of prenatal diagnosis.....................19
3. Prenatal diagnosis – an instrument to mother’s autonomy and a right to healthy children........................................................................................................23

Chapter III
Ethical Problems Facing the Doctor in Prenatal Diagnosis......................................25
1. Types of medical counselling..................................................................................26
2. Decision-making process.......................................................................................30
3. Six steps to make an autonomous decision wisely.................................................32
4. Some ethical principles that every doctor, who is engaged in prenatal diagnosis and care should be aware of.................................................................34

Conclusions..............................................................................................................38

Works Cited and Consulted.....................................................................................42
Introduction

Why does Prenatal Diagnosis deserve our attention?

The modern world is facing a revolutionary development in the clinical medicine and biomedical sciences. Due to the different life supporting systems, it is easily possible to keep patients with severe diseases alive. With organ transplantation a lot of people, who would otherwise die can live long and happy lives. In vitro fertilization allows a woman to bear the child that is not genetically related to her. Due to the possibility of contraception, safe abortions and prenatal diagnosis, women and couples can make preferable choices concerning their future child. Such medical developments and improvements have a great impact on our life, and provoke a lot of ethical questions and moral dilemmas.

The aim of this thesis is to answer the question whether prenatal diagnosis can be justified as it mainly leads to the selective abortion, whether and when the fetus counts as a person and whether the prospective parents can perform selective abortion on the basis of fetal disability; and to discuss ethical problems that are experienced by the doctor, who brings the news into the family and what is his/her role in the decision-making process.

For those who are “pro-life” the strongest argument against prenatal diagnosis is that it gives the prospective parents the choice of aborting abnormal fetus. What options are laid on the scales after performing prenatal diagnostic procedures? Can disability justify selective abortion? What about the autonomy of the prospective parents and their right to have healthy children? What are the ethical hardships that doctor has to face in delivering the news to the prospective parents? What is his role in the decision-making process? Answers to these questions are very controversial, therefore deserve our attention.

Nowadays a pregnant woman may undergo different kinds of prenatal diagnostic procedures, starting with an ultrasound and continuing with amniocentesis. One of the major goals of such procedures is to prevent the birth of disabled children, which makes
the abortion an integral part of the whole diagnostic procedure\textsuperscript{2}. Abortions are strongly encouraged today: all women that are in the age of 35-40 are offered tests to detect chromosomal abnormalities in the fetus. There are even suggestions in some hospitals to offer those tests to all pregnant women. Some physicians believe that a woman would prefer to perform an abortion if the fetus has a chromosomal abnormalities, or congenital defects, but is this indeed so? Abortion is not a simple decision. Performing it can not be compared, for example, to the nail cutting or the tooth extraction. Even if the fetus is severely disabled and its life would bring only suffering, some assume that it is still a human being that deserves our protection.

Prenatal diagnosis is considered to be the most important part of prenatal care and regardless of knowing that the test may reveal unpleasant results, the news that a fetus carries an abnormality will always be a tremendous shock to the prospective parents that will force them to make extremely difficult decisions.

\textsuperscript{2} Sutton, 1990 p.1
Chapter I
Prenatal Diagnosis

1. Short introduction of Prenatal Genetic Diagnosis

First of all it would be important to answer the question of what is prenatal genetic diagnosis and why it is performed. Prenatal diagnosis employs a variety of techniques to determine the health and condition of an unborn fetus. Specifically, prenatal diagnosis is helpful for:

- Determining the outcome of the pregnancy
- Planning for possible complications with the birth process
- Planning for problems that may occur in the newborn infant
- Deciding whether to continue the pregnancy
- Finding conditions that may affect future pregnancies
- Prenatal treatment if possible

There is a variety of non-invasive and invasive techniques available for prenatal diagnosis. Each of them can be applied only in specific time periods during the pregnancy for the greatest utility. The techniques employed for prenatal diagnosis include:

- Ultrasonography
- Amniocentesis
- Chorionic villus sampling
- Fetal blood cells in maternal blood
- Maternal serum alpha-fetoprotein
- Maternal serum beta-HCG
- Maternal serum estriol
Let us begin with the explanation of under what circumstances those techniques may be performed and for what purposes. Prenatal genetic diagnosis, which is performed in early stages of the pregnancy aims to find the defects of the fetus and to terminate the pregnancy, late diagnosis of fetal illness is usually undertaken to promote the fetal well-being and to determinate the optimal time of delivery\(^3\). Prenatal diagnosis is recommended for women who are older than 35, as they are under greater risk of delivering a baby with Down syndrome; mothers with family histories involving abnormalities, for example, if the mother has already had a child with any genetic disorder, or there are known incidents in the family history. Mothers with chromosomal abnormalities, or whose husbands are affected with such abnormalities, women who are rhesus-negative are in the high risk of developing antibodies directed at rhesus-positive fetuses are also offered the procedure. Women with transmissible diseases should undergo prenatal tests, as for example, in the case of syphilis, it is possible to prevent the child from developing the disease\(^4\).

**2. Defining the patient in prenatal diagnosis**

It is important to define who the patient is in prenatal diagnosis. There are different opinions concerning this issue. Some hold the idea that the patient is the pregnant woman, hence her interests have to be the priority, and others claim that prenatal diagnosis has to serve the interests of the fetus solely. I agree with Sutton, who argues that prenatal diagnosis is the procedure that has two patients to consider: the mother and the fetus. “Two lives are at stake in prenatal diagnosis, so it is of vital importance, that the interests of two patients are taken into account, and risks and burdens of tests against the potential benefits are thoroughly outweighed\(^5\)”. According to Sutton, prenatal diagnosis can never be justified by the reference to the mother’s interests alone. The justifiability of prenatal diagnostic procedures depends primarily on the balance of the potential benefits to the child. Sutton suggests that there are two conditions that have to

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\(^3\) Sutton, 1990 p.10

\(^4\) Ibid. p.12

\(^5\) Ibid, p. 133
be fulfilled in order to justify prenatal diagnosis. “First is that the procedure has to be therapeutic and aimed at promoting the health of the unborn child, and second, in order to promote the unborn child’s health and welfare, one should ensure that the risks to which it is exposed are outweighed by the potential benefits to the child itself of having its condition diagnosed”.

3. How can prenatal diagnosis benefit the fetus and the mother

Indeed, prenatal diagnosis may be of a great value to the fetus, as there are a certain number of diseases that can be treated in the mother’s womb. For example, a Vitamin B12-responsive methylmalonic acidemia. This is a metabolic disorder that can be diagnosed by chorion biopsy, amniocentesis or fetal blood sampling. The treatment lies in giving the large doses of vitamin B-12 to the mother. Biotin-dependant multiple carboxylase deficiency may be improved by giving the mother biotin supplements during the second half of the pregnancy. It is also a hereditary disease that can be diagnosed by amniocentesis or fetal blood sampling, and certain enzyme tests. If the fetus has galactosemia, mother is recommended a low galactose diet.

A respiratory distress syndrome, that is the condition characterised as the difficulties of breathing caused by the deficiency in the surfactant system in the immature newborn lung, may also be diagnosed due to the amniocentesis and can be treated during the pregnancy.

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6 Sutton, 1990 p.134
7 Methylmalonic acidemia is a genetically heterogeneous disorder of methylmalonate and cobalamin (vitamin B12) metabolism. It clinically manifests with profound metabolic acidosis, developmental retardation, and an unusual biochemical triad: methylmalonic aciduria, long chain ketonuria, and intermittent hyperglycinemia.
8 Galactosemia is a rare genetic metabolic disorder. The child with classic galactosemia inherits a gene for galactosemia from both parents, who are carriers. Galactosemia means too much galactose in the blood caused by the individual "missing" the enzyme (known as GALT) to convert galactose into glucose. This accumulation of galactose is a poison to the body and can cause serious complications such as the following and if untreated, as high as 75% of infants will die: an enlarged liver, kidney failure, cataract and brain damage.
9 Sutton, 1990 p.41
10 Ibid. p.41
Rhesus haemophilic disease can be treated by the means of invasive surgical procedures and has been proved to be very successful. “There is a number of other conditions which might benefit from the minor intra-uterine surgery such as needle aspiration or the introduction of a shunt for drainage of excess fluid\textsuperscript{11}”. A hereditary abnormality of the thyroid gland – congenital hypothyroidism, can be diagnosed with the help of amniocentesis or fetal blood sampling and the fetus can also benefit from intra-amniotic medication. The intra-amniotic injection of thyreoid hormone could be of a great benefit to the affected child\textsuperscript{12}.

Furthermore, fetus is not the only one who can benefit from prenatal genetic diagnosis. It plays a very important role for the mother as well. For example “fetal hydrocephalus\textsuperscript{13}” may require the caesarean section or preterm delivery in order to avoid a long and difficult labour. Urinary tract obstruction may necessitate early delivery with a view to neonatal surgery\textsuperscript{14}. According to Sutton “ruptured omphalocele and gastroschisis\textsuperscript{15}” call for early labour in order to remove the exposed intestines from the harmful contact with the amniotic fluid\textsuperscript{16}.

These examples show that prenatal diagnosis has the therapeutic effect and can be of a great benefit to both mother and a child. As Philip Kitcher writes in his book \textit{The Lives to Come}, prenatal diagnosis gives us a chance to “envisage a world in which fewer parents observe, with unending anguish the half-lives their children lead\textsuperscript{17}”. Indeed, prenatal diagnosis gives prospective parents an opportunity to be aware of the health

\textsuperscript{11} Sutton, 1990 p.41
\textsuperscript{12} Ibid.p.42
\textsuperscript{13} Hydrocephalus is an abnormal accumulation of cerebrospinal fluid within cavities called ventricles inside the brain. The most obvious indication of hydrocephalus is often the rapid increase in head circumstance or an unusually large head size. In older children and adults, symptoms may include headache followed by vomiting, nausea, papilledema (swelling of the optic disk, which is part of the optic nerve), downward deviation of the eyes (called "sunsetting"), problems with balance, poor coordination, gait disturbance, urinary incontinence, slowing or loss of development (in children), lethargy, drowsiness, irritability, or other changes in personality or cognition, including memory loss. There is no known way to prevent or cure hydrocephalus.
\textsuperscript{14} Sutton, 1990 pp.42-43
\textsuperscript{15} Omphalocele results from the incomplete closure of the umbilicus. The birth defect involves the protrusion of abdominal organs such as the intestine and liver into the umbilical cord. Infants with omphalocele may have other birth defects, including chromosomal abnormalities. Gastroschisis does not involve the umbilicus. The birth defect results from the protrusion of intestine and sometimes liver outside of the abdomen. Infants with gastroschisis tend not to have other birth defects. Gastroschisis is not associated with chromosomal abnormalities.
\textsuperscript{16} Sutton, 1990 p.43
\textsuperscript{17} Kitcher, 1996 p.15
condition of their future child and whether it is possible to start treatment as soon as possible. Nevertheless, there is also a negative side of the coin: invasive procedures of prenatal diagnosis may cause severe harm to the fetus or may even lead to involuntary miscarriages\textsuperscript{18}. Hence the use of invasive techniques of prenatal diagnosis can be justified only when the potential benefits and dangers are given thorough consideration. According to Sutton, “the two patients affected by prenatal diagnosis, mother and the child, are of equal value both as patients and human individuals and are endowed with the same right to life\textsuperscript{19}”. “Intentionally and directly to harm one patient in order to promote the interests of the other is therefore unjust\textsuperscript{20}”. As a child is the one being diagnosed and is put under the risk, its benefits must be outweighed against the potential risks, therefore any other comparison of the risks and benefits would be unfair.

Sutton suggests eight principles which prenatal diagnostic procedures have to satisfy in order to be justified\textsuperscript{21}.

First of all the test must be reasonably reliable, the risk of revealing false results must be as minimal as possible. It is hard to disagree with this requirement, as otherwise this may create a lot of inconveniences: falsely positive results may place the parents into condition of unnecessary anxiety and give the possibility of abortion of completely normal embryo and vice-versa - falsely negative results will have surprisingly unhappy consequences in future. Second principle states that “in order to promote the health of the child, the information concerning its state of health needs to be obtained before birth\textsuperscript{22}”, and the third as follows, the medical condition to be investigated must be such that the child could benefit either from treatment in uteri, early delivery or from special preparations to ensure that it is delivered under the optimal conditions\textsuperscript{23}. In case, when the mentioned above reasons are not the main purpose of performing the test, the positive result of the test leads only to the selective abortion, plus poses the fetus into the risk of the procedure, which according to Sutton is unacceptable.

\textsuperscript{18} According to pregnancy information on-line, about 1 in 200 women (0.5%) will miscarry after amniocentesis
\textsuperscript{19} Sutton, 1990 p.139
\textsuperscript{20} Ibid. p.139
\textsuperscript{21} Ibid. p.140
\textsuperscript{22} Ibid. p.140
\textsuperscript{23} Ibid. p.140
Who would argue with the fourth principle which states that non-invasive procedures must be preferred to invasive ones, when possible? Certainly, it is better to perform an ultrasound, which is safe and painless, when possible, than invasive procedure like amniocentesis, which causes pain, is stressful and has a risk of causing a miscarriage.

The essence of the fifth requirement is that “the probability of a particular degree of fetal injury or harm resulting from the suspected condition must be significantly greater that the probability that the child will suffer injury to the same degree by the diagnostic procedure itself\textsuperscript{24}”. That means that prenatal diagnostic procedure should be performed only if for example both parents are carriers of the mutated gene that causes certain disease, so there is a great possibility that the fetus is affected as well, consequently prenatal diagnosis cannot be performed as a form of reassurance for the parents, it should be based on certain grounds and the end result should justify the procedure.

The sixth principle is similar to the fifth, it holds that in order to perform the procedure, the probability that the fetus is affected has to be significantly greater then the possibility that the fetus is not affected. The seventh principle states the obvious, as it requires that the medical practitioners performing the procedure have to be very well-skilled and educated. And the last one requirement demands that the procedure must be as less burdensome as possible to the mother of the child.

On the ground of these requirements, Sutton suggests the analysis of the justifiability of the prenatal diagnostic procedures. In order to view the procedure on the much deeper level it would be important to discuss each procedure separately.

4. Prenatal diagnostic procedures

It is very difficult to disagree, that the development of ultrasonography was the great step forward in the whole history of medicine. It is the procedure that every mother undergoes at least two times during the whole period of pregnancy. It is a non-invasive procedure that is completely harmless to both: the fetus and the mother. The developing

\textsuperscript{24} Sutton, 1990 p.140
embryo can first be visualized at about 6 weeks of gestation, and between 16-th and 20-th week it is already possible to recognise the major internal organs, extremities and possible abnormalities of the future baby. Subtle abnormalities may not be detected until later in pregnancy, or may not be detected at all. A good example of this is the Down syndrome, where the morphologic abnormalities are often not marked. That is why, if an abnormality is suspected, invasive methods of prenatal diagnosis are recommended.

**Amniocentesis** is an invasive procedure in which a needle is passed through the mother’s lower abdomen into the amniotic cavity inside the uterus. It can be performed, since the 14-th week of gestation. In the amniotic fluid there are cells of the fetus, which give the information about the lung maturity, which is very important for prevention of the respiratory distress syndrome\(^{25}\) after birth. The risks of such procedure are highly uncommon, but in 0.5% cases it may lead to a fetus loss and maternal rhesus sensitization. In the light of these facts, amniocentesis may have a therapeutic aim, when identifying the respiratory distress syndrome, although the risks of the procedure do not outweigh the possible benefits, especially if the antenatal treatment of the respiratory disease is very simple - an oxygen hood for a short time to assist with breathing. According to Sutton, the main purpose of amniocentesis is more abortion-oriented than therapeutic. “Furthermore, early amniocentesis with a view to detecting neural tube defects fails to satisfy the first of the conditions stipulated above because it is inadmissibly inaccurate, especially in the low-risk pregnancies\(^{26}\).”

**Chorionic Villus Sampling (CVS).** In this procedure, a catheter is passed via the vagina through the cervix and into the uterus to the developing placenta under ultrasound guidance. It can be also done transvaginally and transabdominally. The obtained cells can be used to determine the karyotype of the fetus. CVS is performed between 9.5 and 12.5 weeks of gestation. CVS has the disadvantage of being an invasive procedure, and it has a small but significant rate of morbidity for the fetus; this loss rate is about 0.5 to 1% higher than for women undergoing amniocentesis. Rarely, CVS can be associated with the limb defects in the fetus. The possibility of maternal rhesus sensitization is present. According to Sutton, this procedure was “exclusively designed for detecting defective

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\(^{25}\) Respiratory distress syndrome is one of the most common lung disorders in premature infants and causes increasing difficulty in breathing.

\(^{26}\) Sutton, 1990 p.145
fetuses with the view to aborting them\textsuperscript{27}. CVS can be used instead of amniocentesis and can be performed much earlier (in the first trimester of the pregnancy) in order to identify certain number of diseases that can be treated intra-uterine, but the possible risks to the fetus are much higher then the benefits. Therefore, the aim of this procedure is the elimination of the pregnancy, and it does not satisfy the fourth condition set by Sutton, (CVS is much risky than amniocentesis), hence is preferable not to use it. Nevertheless, chorion biopsy may be used very exceptionally, when it is essential to obtain information about the fetus in the first trimester of the pregnancy\textsuperscript{28}.

\textbf{Maternal blood sampling for fetal blood cells.} This is a new technique that makes use of the phenomenon of fetal blood cells gaining access to maternal circulation through the placental villi. This method can give us the information about particular DNA sequences, but fortunately without any risk. It is possible to identify particular chromosomes of the fetal cells recovered from maternal blood and diagnose such conditions as the trisomies\textsuperscript{29} and monosomy X\textsuperscript{30}. The problem with this technique is that it is difficult to get many fetal blood cells. There may not be enough to reliably determine anomalies of the fetal karyotype or assay for other abnormalities. The advantage of such technique is that it does not pose any risks to the fetus, but it places the abortion as the main option in the further decision-making.

\textbf{Maternal serum alpha-fetoprotein test (MSAF)} can be used to determine the levels of the alpha-fetoprotein (AFP) of the fetus. The persistence of AFP in amniotic liquid testifies about the neural tube defect of the baby. The incidence of such defects is about 1 to 2 births per 1000. With the help of this method the defects in the abdominal wall of the child can be also found. The MSAFP has the greatest sensitivity between 16

\begin{footnotesize}
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\item \textsuperscript{27} Sutton, 1990 p.145
\item \textsuperscript{28} Ibid. p.146
\item \textsuperscript{29} The term “trisomy” is used to describe the presence of three chromosomes, rather than the usual pair of chromosomes. For example, if a baby is born with three #21 chromosomes, rather than the usual pair, the baby would be said to have “trisomy 21”. Trisomy 21 is also known as Down syndrome. Other examples of trisomy include trisomy 18 and trisomy 13. Again, trisomy 18 or trisomy 13 simply means there are three copies of the #18 chromosome (or of the #13 chromosome) present in each cell of the body, rather than the usual pair.
\item \textsuperscript{30} Monosomy X or Turner syndrome is a genetic condition that occurs only in females. Female cells normally have two X chromosomes. In Turner syndrome, the girl's cells are missing an X chromosome, or part of an X chromosome. There are a variety of signs and symptoms that can result, but the most common are short height, lack of developing ovaries, and infertility.
\end{itemize}
\end{footnotesize}
and 18 weeks of gestation, but can still be useful between 15 and 22 week. Prevention of many neural tube defects can be accomplished by supplementation of the maternal diet with only 4 mg of folic acid per day. The MSAFP can also be useful in the screening for Down syndrome and other diseases of such a kind. This test is most commonly used as a test for pregnancy and can be also useful in early periods of the pregnancy when the abortion or ectopic pregnancy (explanation) is suspected. Later in pregnancy, the beta-HCG can be used in conjunction with the MSAFP to screen for chromosomal abnormalities, and Down syndrome in particular. This technique has both the therapeutic effect, as it can identify the neural tube defect, which can be treated in uteri, and it also makes abortion an option for prospective parents.

Maternal serum estriol. The measurement of serial estriol levels in the third trimester will give an indication of the general well-being of the fetus. If the estriol level drops, then the fetus is threatened and delivery may emerge. Estriol tends to be lower in the case of Down syndrome and is present in the case of adrenal hypoplasia with anencephaly.

This description of the main prenatal diagnostic procedures shows that their main purpose is the elimination of the defective fetuses. Nevertheless it is obvious that most of them may also have the therapeutic purposes as well and may be used in order to promote the health and the well-being of an unborn child and its mother. I agree with Sutton, that prenatal diagnosis should be used wisely: only when the risk of carrying the abnormal fetus is extremely high (that is when both of the parents are carriers of the defective gene, or there is a history of abnormality in the family) and when the benefits outweigh the risks of the procedure itself (when the suspected disease or abnormality may be treated prenatally). In my opinion prenatal diagnosis should never be performed on the basis of solely the parental anxiety.

According to Sutton, justifiability of prenatal diagnosis is based solely on its therapeutic purposes; hence the procedures that deliberately lead to selective abortion

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31 Anencephaly is a defect in the brain development resulting in small or missing brain hemispheres. A congenital absence of the brain and cranial vault, with the cerebral hemispheres is completely missing or greatly reduced in size.
32 One or both parents have a family history of genetic diseases
33 Prenatal diagnostic procedure may enclose the disease that can be treated prenatally. Or there is a risk of fetus carrying a lethal disease, and elimination of the fetus may be an option.
should not be performed. The question is whether it is indeed so? I would argue that it
depends on the attitude to the selective abortion itself. On the one hand it is a murder, but
on the other it is a way to prevent the prospective parents from future troubles and
problems concerning the birth of a disabled child and it may prevent that a child suffered
severely. The eight requirements, suggested by Sutton surely manage to protect the fetus
and the mother, as they both are the patients in prenatal diagnosis. However, Sutton’s
main justification of prenatal diagnosis is based on its denial of selective abortion. The
author fails to take the mother’s/parent’s opinion and autonomy into account. I consider
that it is wrong, as the prospective parents have a right to make their own autonomous
well-considered decisions. However, I will discuss this issue later in the next chapter.

Since prenatal diagnosis may reveal results that confirm the abnormality,
prospective parents have an option of aborting the fetus. Consequently, the logical
question is whether selective abortion is a murder of already existing person, or it is a
mercy - killing and expression of autonomy of the parents?
Chapter II

Ethical problems of selective abortion on the basis of prenatal diagnosis

In this chapter I will argue that severe disability of the fetus can justify selective abortion, and it can be counted as a mercy killing as it will relieve both: the fetus and the parents from inescapable future sufferings. However, together with moderate gradualists I support selective abortion only before the 18-th week of the pregnancy, when the fetus is believed not to have any pain reactions, and only in case of an extremely severe disability of the fetus with no prospect of cure and pain relief.

The performance of prenatal diagnostic procedures is justified only if one accepts the selective abortion as a moral alternative. Nevertheless there are different attitudes towards selective abortion based on the different arguments.

Due to prenatal diagnosis it is possible to view the fetus, its parts of the body, and its chromosomes inside genes. When something appears to be anatomically or “chromosomically” not normal, a decision about abortion is taken into consideration. Revealing a negative result, prenatal diagnosis forces prospective parents to making the choice either to continue the pregnancy or to perform the abortion. On the one hand it is so hard to let go all the dreams of happiness and hopes of the future maternity and on the other the vision of hospitals filled with sorrow and pain reveals the thoughts about eliminating the pregnancy.

Abortion of the fetus results in the ending of life. If that fetus has carried alleles that would have caused the severe suffering to the future child and would anyway lead to death, many people would regard such end as merciful. Is it indeed an act of mercy to deny the life of a disabled fetus? Some people discern no mercy in the deliberate destruction of a human life, in the murder of a person. They believe that the use of abortion as a tool to make life more convenient degrades the value of human life, even when it is employed solely by the best intentions.

On the other hand selective abortion is seen as a way to promote valuable human lives. How can abortion of a fetus with congenital abnormalities or defective genes be
justified as an act of mercy? Some qualify abortion as a murder because it is a future child that is destroyed, a very young person. Nevertheless, the appealing question is whether and when the fetus begins to count as a person?

1. Moral status of the fetus

There are different philosophical and medical theories concerning the exact time when the fetus may be considered as a person, but generally there are three opinions regarding this issue.

Radical gradualists and pro-abortion (pro-choice) rights advocates claim that the fetus is not fully a human or a person with moral rights.

Looking back to the Western history “fetal development has been described in terms of an evolutionary recapitulation in which the fetus goes through vegetative and animal phases before reaching the human phase at some time late in pregnancy or at birth34”. This emphasizes that fetus is not a person; it is rather some kind of an animal until the late months in pregnancy or even after the birth. There has been made assumptions that fetuses’ behaviour is purely reflexive and their brain has been compared to that of a lower animal. Some philosophers use to refer to fetuses as “human animals35”, claiming that the five to six month fetus has the less capacity for sensation and pain than “a fish or an insect”36. Handicapped fetuses were especially depersonalised in the history; some physicians used to refer to them as to “vegetables”.

Immanuel Kant, who probably has the greatest influence on the modern thinking about personhood as a moral category, defined “persons” as the rational autonomous human beings capable of imposing moral laws upon themselves37. Therefore they are ends in themselves and this is the fact of an intrinsic worth. “That is, they are valuable in and of themselves regardless of their usefulness to or desirability in the eyes of the others38”. The value of the intrinsic worth gives the obligation to respect persons and

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34 Boss, 1993, p.104
35 Ibid p.104
36 Ibid p.104
37 Ibid p.102
38 Ibid p.103
forbids using them merely as means. Accordingly, fetuses lack intrinsic worth and therefore cannot be treated as persons. Michael Tooley has suggested that:

A person has to possess consciousness, have preferences, conscious desires, feelings, can experience pleasure and pain, have thoughts, be self-conscious, capable of rational thought, have a sense of time, can remember its own past actions and mental states, can envisage a future for itself, have no-momentary interests, involving a unification of desires over time, be capable of rational deliberation, can take moral considerations into account in choosing between possible actions, have traits of character that undergo change in a reasonably non-chaotic fashion, can interact socially with others and can communicate with others.\(^{39}\)

Given this requirements, it is very difficult to disagree with radical gradualists that the fetus does not have a special moral status. Furthermore some philosophers argue that fetuses cannot think or feel or experience anything, hence they can not want anything and consequently they do not have any interests. “Therefore abortion, throughout most of gestation, does not pit the interests of the pregnant woman against the interests of the fetus.\(^{40}\)” Consequently, if the fetus is not a person and does not have any interests, selective abortion can be morally justified.

However there are also other thoughts concerning this issue. For example, absolutists\(^{41}\) state that the fetus becomes a person from the very moment of conception. They consider a pregnant woman to have the same moral obligations to the fetus as to the born child. Abortion of the fetus, even abnormal one would be as wrong as a killing of a born child. Absolutists condemn prenatal diagnosis that would lead to selective abortion.

Consequently both radical gradualists and absolutists defend their stand points, which in my opinion appear to be too radical. Radical gradualists neglect the rights of the fetus completely and absolutists, vice-versa show absolute disrespect to the woman’s right to free choice.

Moderate gradualists are not that radical. They even seem to be the “golden middle” as they consider the fetus to “moderately” become a person during 18 - 24 weeks of

\(^{39}\) Tooley, 2001 p.120

\(^{40}\) Steinbock, 2001p.136

\(^{41}\) Absolutists claim that there are absolute standards against which moral questions can be judged, and that certain actions are good or evil, regardless of the context of the act

\(^{42}\) Kuhse, Singer, 2001 p.137
gestation, when it is believed to start having some painful reactions as they already have peripheral nerve endings that are connected to the spinal cord, allowing them to react to touch and other stimuli. Despite that fact that pro-choicers argue that this is just a simple reflex response that has no conscious awareness associated with and that there is no experience of pain because the nerve circuit is not interacting with the brain, accordingly there is no necessary connection between fetal movement and mental awareness. Some scientists believe and I myself support this view that the fetus can indeed experience pain. In 1987, an influential paper by a leading British expert on pain, Dr. K.J.S. Anand, helped to persuade the medical community that fetus can feel pain\(^{43}\). He showed it by performing surgeries on premature babies. Anand has demonstrated that painful stimuli to premature babies resulted in hormonal and other physiological stress responses, including increased blood pressure, heart rate, and respiratory rate. He also showed that premature babies given pain medication for surgery had lower complication and death rates than babies that went without\(^{44}\). Relying on these facts it is reasonable to think that fetuses can feel pain starting from the period of 18 – 24 week of the pregnancy; hence they are considered to be persons after this period of time.

2. Justification of selective abortion on the basis of prenatal diagnosis

When prenatal diagnosis reveals positive results that a fetus has chromosomal or physical abnormalities, a woman has to make a choice whether to keep it or not. Those who are against abortion and consider life to be a sacred gift from God view prenatal diagnosis as a pure evil, as they see it as a straight track to selective abortion only, and do not count the possible therapeutic benefits to the fetus. Those who are pro-choice and support the women’s autonomy claim that prenatal diagnosis is of a great value as it gives the prospective parents the right for healthy children. Can woman’s autonomy justify

\(^{43}\) Anand, 1987 pp-1321-1329

selective abortion on the basis of fetal abnormality and can this elimination of the fetus count as a mercy killing?

As a start, it would be important to mention that a pregnant woman would not perform amniocentesis, just to be sure that the fetus does not have any abnormalities, without even considering performing the abortion in the event of abnormality. Amniocentesis is offered only to the women that are in the risk group, it will be not performed unless the abortion is at least an option\textsuperscript{45}. Some practitioners say that the woman must be at least committed to abortion, before the diagnosis will be performed\textsuperscript{46}. “For the first time selective abortion is not an occasional and regrettable act, but the planned outcome of deliberate programs of the medical practice\textsuperscript{47}”.

Prenatal diagnosis produces certain benefits to the individual families. Actually it even “protects families from emotional and economical strains of bearing and rearing a child with the genetic or physical disorder\textsuperscript{48}”. For instance if amniocentesis reveals that the fetus will develop hydrocephalus that can not be treated and is incompatible with life, prospective parents will be offered to perform an abortion as a future baby will be disabled and the prognosis for life is not more than a year.

The main clinical symptom of hydrocephalus – “water in the brain”, is a rapid increase of the size of the head, because of an excessive accumulation of the fluid in the brain\textsuperscript{49}. Unfortunately this child’s condition will not be limited by the physical and mental abnormality only; it will also have to go through a lot of inhumane sufferings and afterwards death is inescapable. The baby would suffer from permanent exhausting headaches because of the high pressure in the brain. Such children are not able to live like the others: they will never be able to sit, because of the heaviness of the head, and their brains will never be able to develop. Permanent headaches will be followed by vomiting and nausea. It will be impossible for the child to hold the feeding bottle in its hands, it will not be able see the surrounding world because of the destruction of the optic nerve. It is hardly possible to call such existence a life, as such babies tend to cry all the time and demand a very thorough care, which not all the parents are able to provide. As a result the

\textsuperscript{45} Lebacqz, 1995 p.129
\textsuperscript{46} Ibid, p.129
\textsuperscript{47} Ibid. p.131
\textsuperscript{48} Ibid. p.131
\textsuperscript{49} Available at: \url{http://www.nlm.nih.gov/medlineplus/hydrocephalus.html}, (Accessed 17 may 2006)
child is often placed to an orphanage, where completely alien people will be taking care
of it. The other horrifying example is the Tay-Sachs disease – a fatal genetic lipid storage
disorder in which harmful quantities of a fatty substance build up in tissues and nerve
cells in the brain. Infants with Tay-Sachs disease appear to develop normally for the first
few months of life. Then, as nerve cells become distended with fatty material, a relentless
deterioration of mental and physical abilities occurs. The child becomes blind, deaf, and
unable to swallow. Muscles begin to atrophy and paralysis sets in. Other neurological
symptoms include dementia, seizures, and an increased startle reflex to noise. Both
parents must carry the mutated gene in order to give birth to an affected child. In these
instances, there is a 25 percent chance with each pregnancy that the child will be affected
with Tay-Sachs disease. There is no treatment of this disease, besides such children may
eventually need a feeding tube. Even with the best care children with Tay-Sachs disease
usually die by the age of four from recurring infection50.

In the light of these facts, is this the exact kind of a future the loving parents would
wish their children to have? Moreover the child will not suffer alone; it will also burden
the parents by killing their dreams of happy parenthood in future. Isn’t it disappointing to
carry a child, knowing that there is no chance for it to survive, isn’t awfully painful to see
your own child suffering? Who can disagree that in such circumstances parents will be
filled with a deep feeling of guilt and regret for deliberately not aborting a fetus and
preventing it from sufferings? These two examples show that selective abortion can be
justified as an act of mercy-killing, but of course, depending on the severity of the
disease.

Furthermore, many couples that had previously had a child, born with a disorder
are afraid to make any attempts of conceiving another baby unless they can have prenatal
diagnosis. Those who are already familiar with the exact feelings of having a disabled
child are afraid of giving birth to another one with the same disease. The reasons for this
are completely understandable. It is not just an emotional burden to the family, but also a
financial one. Normally children with congenital defects or chromosomal abnormalities
demand a full-time attention. That would require from one of the parents to quit the job

50 NINDS Tay-Sachs Disease Information Page
or to hire a specialized care-taker, who could always be with the child, in order to provide all the needs during the day. For example, children with Down’s syndrome are physically active; they just have certain difficulties understanding and realising things. In order to develop and become more socialized they demand permanent care and supervision. Such individuals can live up to fifty years, and although they tend to socialize and lead comparatively normal lives, “family members and caretakers of an adult with Down syndrome must be prepared to intervene when the individual begins to lose the skills required for independent living, as premature aging is a characteristic of adults with the Down syndrome⁵¹”. Adults with the Down syndrome may develop dementia, or memory loss and impaired judgment similar to that occurring in Alzheimer disease patients, usually when the person is younger than forty years old.

Of course it does not apply to all the children with Down syndrome, as there are different forms of the disease: some children lead almost normal socialized lives, while others are very severely demented and need fulltime care and assistance. Nevertheless the need for full-time attention and economical issues by no means justify selective abortion. Some people with Down’s syndrome lead completely normal lives; I do not think it would be wise to abort the fetus on these grounds only. It is impossible to predict the severity, but there is always a great chance that the fetus will be almost normal. Perhaps some would argue that this statement is a rejection of parental autonomy, but my response would be that there is always a way to compromise. For instance, in that case when a child turns out to be severely demented prospective parents will always be able to place it to the special care clinics or orphanages, where such children are taken good care of and are prepared for adult life. The fact whether the child will benefit from this is questionable, but at least parents will give it a chance.

Consequently, selective abortion can be justified and clarified as an act of mercy-killing, but only when the abnormality or the disease is extremely severe, with no prospect of cure or pain relief. I think that such diseases as Down syndrome can not justify the selective abortion of a fetus.

3. Prenatal diagnosis – an instrument of mother’s autonomy and a right to healthy children

Prenatal testing can serve as a tool to promote mother’s/parents autonomy as well. When parents know in advance that their future child carries a defective gene, they can prevent themselves from future hardships connected with birth of such a child and abort the fetus. Why not? It seems like a perfect solution to all the problems. Nevertheless, the question is whether the autonomy of the prospective parents or the mother solely overrides the autonomy of the fetus and whether it can justify the selective abortion.

In the past few decades, there has emerged a persuasive attitude regarding the right to privacy and autonomy as an absolute right, especially concerning a woman’s right to perform an abortion. Consequently the acceptance of selective abortion as a matter of personal choice has increased enormously.

Firstly it is necessary to define autonomy itself. Autonomy is the word derived from the Greek *autos* (“self”) and *nomos* (“rule”). It implies self-governance, liberty rights, privacy, individual choice, freedom of the will, causing ones own behaviour and being one’s own person. According to Tom L. Beauchamp and James F. Childress, personal autonomy is, at a minimum, a self-rule that is free from controlling interference by the others and from limitations, such as inadequate understanding, that prevent meaningful choice. The autonomous individual acts freely in accordance with a self-chosen plan. Consequently, one of the parts of autonomy is a right to independent choosing. Individual autonomy calls for respect, and it involves not just respectful attitude, but an action as well. It requires more than just non-interference in other’s personal affairs. “It includes, at least at some contexts, obligation to build up or maintain others conditions that destroy or disrupt their autonomous actions. Respect on this account, involves acknowledging decision-making rights and enabling persons to act autonomously, whereas disrespect for autonomy involves attitudes and actions that ignore, insult, or demean other’s rights of autonomy.”

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52 Beauchamp, Childress, 2001 pp. 57-58
53 Ibid, p.58
54 Ibid, p.63
made by the parents, depending on their wishes and attitude and has to be respected and encouraged by the others. From this perspective, the rights of the fetus can be neglected completely.

If one does not view the fetus as a person, the previous statement can be completely justified. I have discussed the theories concerning the personhood of the fetus above, and as I have already mentioned that I support the idea that the fetus can be counted as a person starting from the 18 week of the pregnancy, when it is believed that a fetus can feel pain. Accordingly I believe that till that moment parents have a right to decide the destiny of their disabled fetus. Consequently, autonomy of the pregnant woman/parents can override the autonomy of the fetus until it reaches 20 week of gestation and is considered to be a person. The decision of the prospective parents should be thoroughly considered and has to be made wisely. In my opinion parents without medical and ethical education are not completely capable of making well-considered decisions themselves. They need an objective assistance of a competent physician. Exactly the role of the physician in this complicated decision making process and possible ethical problems that he will have to face will be discussed in the next chapter.
Chapter III
Ethical problems facing the doctor

Every woman in the high risk\textsuperscript{55} group of giving birth to the defective child is recommended to perform a prenatal diagnostic procedure, in order to confirm or decline the suspicions of the doctor about the possible abnormality of the fetus. In the case of disappointing results the physician is obliged to inform the parents about the possibility of aborting the fetus. However, taking into consideration the severity of the disease and the possibility that prenatal diagnosis is mistaken\textsuperscript{56}, the decision is not always that easy. Prospective parents are in the position of making the decision, but what is the role of the physician in this decision-making process? Should he/she stay aside, should he/she be directive and influence their decision, or should he/she just provide the prospective parents with all the needed information concerning the future of the child.

Since long time ago physicians are believed to have special obligations and responsibilities towards those who are in need for medical care. It was stated in the Hippocratic Oath that the doctor has a primary responsibility to promote the patient’s welfare, to do no harm and keep confidentiality. Recently another requirement has been added stating that the patients can decide for themselves what is exactly in their best interests.

The first requirement that states that the physician has to promote patient’s welfare creates some problems in prenatal diagnosis, as it was defined before, there are two patients in prenatal diagnosis, and the interests of both mother and fetus should be respected. Hence the doctor has to do his/her best in order to promote interests of both his patients.

\textsuperscript{55} Women in high risk groups are those, who are older than 35 years old, mothers with family histories involving abnormalities, or there are known incidents in the family history. Mothers with chromosomal abnormalities, or whose husbands are affected with such abnormalities, women who are rhesus-negative are in the high risk of developing antibodies directed at rhesus-positive fetuses and women with transmissible diseases are also offered the procedure.

\textsuperscript{56} Unfortunately, I cannot present the statistics, but in the literature, I have read, some authors mention that there is a small chance when prenatal diagnosis is mistaken. One of the reasons is incompetence of the doctor.
The second one states *primum non nocere* - do no harm. Consequently, prenatal diagnosis is justified only if its main goal is the promotion of the welfare of the both, mother and the fetus. Prenatal diagnostic procedures that cause more harm than benefits should not be performed.

Principle of confidentiality is not less important in prenatal diagnosis, as very often prospective parents prefer to remain discreet about their personal reproductive problems.

The last requirement concerning the autonomy of the patient has already been discussed as well, and as I have concluded, despite the each individual’s right to autonomy, it still can not override the right of the fetus for life. Hence, the doctor’s obligation to respect the autonomy of the pregnant woman should be integrated with his/her obligation to respect maternal autonomy towards the unborn child. Nevertheless the main goal of this chapter is to discuss the role and obligations of any medical doctor, who participates in prenatal care of every pregnant woman and her future child and different ethical problems he/she may have to face in his/her medical practice.

### 1. Types of medical counselling

“There cannot be a universal model for medical counselling because counselling is an understanding of a set of facts according to the counsellors’ frame of reference, background in the science of genetics, and previous training and experience in effectively communicating with the consultee⁵⁷. It is essential for every doctor, no matter whether obstetrician, geneticist or paediatrician to take into consideration the educational background of the consultee, in order to disclose or limit the information properly.

As a rule, prenatal counselling usually begins from genetic counselling. Nowadays a lot of couples, and not only those who are definite that they are in the risk group of conceiving the fetus with abnormality, prefer to be sure that they will give birth to healthy generations. Generally speaking, genetic counselling is the process of revealing the risk information about genes. It is the integration of information about diagnosed genetic conditions, in a way that allows the persons to make their own autonomous

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decisions while safeguarding the emotional and ethical character of the person who asks for conclusion. Chadwick defines genetic counselling as (1) advising adults before conception, of the possibility of their conceiving a child who will be a carrier of the genetic disorder and (2) advising adults, after the conception, the use of some method for fetal diagnosis, as to whether or not a fetus is suffering from a genetic disorder and (3) advising adults the possible options of actions\textsuperscript{58}. Angus Clarke emphasizes genetic counselling as following: (1) an early, precise diagnosis of the condition causing concern; (2) the screening for complications of genetic disease, thereby assisting in the management of affected individuals; (3) the provision of social and practical support for those individuals and families; (4) the development and application of specific therapies for genetic disorders\textsuperscript{59}.

In general, medical counselling can be distinguished into two types: directive and non-directive. Nondirectiveness means refraining from making recommendations regarding the content of the decision, and on the contrary directiveness indicates giving advice about which decision is the best\textsuperscript{60}. “In the major international survey of genetic counselling it was found that non-directive approaches are preferred by more than 90 percent of the counsellors”\textsuperscript{61}. Non-directive counselling can be emphasized as “decision-facilitation” accordingly its aim is to provide information, leaving decisions up to the patient's autonomy.

Directive approach was more commonly seen in Germany, Hungary, or India, where they considered it to be important to give more advice and guidance\textsuperscript{62}. However, a lot of countries are against directiveness in counselling, as it neglects the prospective parent’s right to autonomy – their legal right to decide on their own what is the best for them. I, myself, clearly support nondirective decision-making. It is the parent’s right to decide about their future. However, I believe that the physician has to play a significantly important role in this decision making process as well.

According to Anders Nordgren directiveness/nondirectiveness regarding the particular decision needs to be clarified in relation to the following three possible aspects of

\textsuperscript{58} Chadwick, 1994, 19:43-46.
\textsuperscript{59} Clarke, 1993, 19:47-49.
\textsuperscript{60} Nordgren, 2002, p.282
\textsuperscript{61} Macer, 1998, pp. 999-1024
\textsuperscript{62} Ibid, pp. 999-1024
reproductive counselling: ‘giving neutral information’, ‘giving psychological support’
and ‘giving assistance in decision-making’. Non-directiveness emphasizes providing
the needed information to the patient, without interfering in the patient’s decisions.
However, according to Nordgren, non-directiveness is compatible with giving
psychological support, as well as assistance in decision-making. “As long as the
counsellor is refraining from making recommendations regarding the content of the
decision, he or she may very well provide psychological support or assistance.”
Consequently, it is very well possible to combine nondirectiveness regarding the content
of the decision with psychological support and even assistance in decision-making. The
counsellor should remain neutral in decision-making process, however he/she should be
supportive and do whatever is possible in order to help the parents to make their own
decision. It is in his/her responsibility to disclose all the needed information during the
whole period of the pregnancy.

During the first months of the pregnancy, the woman has a possibility to perform
prenatal diagnostic procedures. There is no way that a doctor can push her into the
procedure. Firstly she has to be informed by the doctor whether she is in the risk-group
and consequently whether there are convincing reasons to perform the procedure. That
fact that the woman is older than 35 is not a reason enough to perform a procedure, as
there are a lot of examples of women beyond 35 years old, who gave birth to developed
and healthy children. As it was mentioned, prenatal diagnosis can not be simply used as a
means of reassurance, as it has some chance of harming the fetus and may cause
miscarriages. Therefore the risks and the benefits of the procedure should be thoroughly
outweighed. Physician’s role here is clearly understandable; he has to provide all the
needed information about the reasons to perform the procedure and about its possible
risks. World Health Organisation gives an account of the major counselling points that
physician has to provide to his patients. The doctor should mention names and general
characteristics of the major disorders that may be identified by the test and their effects

63 Nordgren, 2002 p.282
64 Ibid, p.282
65 World Health Organization. Proposed International Guidelines on Ethical Issues in Medical Genetics
and Genetic Services. Available at: http://www1.umn.edu/humanrts/instree/guidelineproposal.html
(Accessed 18 February 2006)
on the future child. The medical professional should also mention all the possibilities of the treatment of the disorder after birth and the availability of supportive care. Patients should be also informed of the description of the likelihood (risk) that the fetus may have the disorder. Risks should be expressed in several ways: the percentage, as a proportion and verbally. The couple or the woman should be aware of the possibility of unfavourable test results or of unexpected findings. Mother should be informed that some of the procedures may cause harm either to her or the baby and that non-invasive screens used early in pregnancy, such as maternal serum alpha fetoprotein screening, may be the first step on the road to prenatal diagnosis and possible decision about abortion.

The second step of prenatal counselling is after the procedure has been performed, when the presence of abnormality is confirmed. Here the question about the abortion may arise. Doctor is obliged to give all the needed information about the alternatives available for those with an affected fetus, for example, carrying the fetus to term and caring for the child at home; placing the child in an institutional setting, if available; placing the child for adoption; termination of pregnancy; prenatal treatment of the fetus or early treatment after birth. It is also important to remember that ambiguous laboratory or ultrasonography results are possible.

In an extremely supportive way, medical workers have to explain that most of the conditions diagnosed in the fetus cannot be treated before birth and that knowing about the existence of the condition, may not help the fetus. The doctor is obliged to disclose the information concerning the disease of the fetus. He has in simple understandable words to explain the severity of the disease, the condition in which the child will be able to live. The doctor has to describe the changes to the lives of the parents the birth of such a child will bring. The information about the possible treatment of the disease should be disclosed. Keeping the principle of autonomy in mind, physicians should disclose all clinically relevant findings to the woman or couple, including the full range of variability in the manifestations of the condition under discussion. Therefore the woman's and/or the couple's choices in a pregnancy with an affected fetus should be respected and protected,

66 Within this context autonomy refers to the capacity of a rational individual to make an informed, uncoerced decision.
within the framework of the family and of the laws, culture and social structure of the country. The couple, not the health professional, should make the choice.

Doctors should also provide the couple, with the names and addresses of genetic support groups or organizations for persons with genetic disorders that people can contact if they wish.\textsuperscript{67} According to WHO, pre-test counselling makes post-test counselling (for those with an affected fetus) much less difficult because prospective parents are much better prepared.

To conclude, the non-directive way of counselling seems to be the most appropriate as it respects the autonomy and the prospective parents are in the position to make their own decisions. However I think that the judgement should be made on case-to-case principle, as sometimes due to certain circumstances the prospective parents are not able to make reasonable choices. Such circumstance may be: incompetence, which implies that the patient is legally speaking a minor, or is mentally retarded or ill, or temporarily diminished responsibility, the patient is temporarily incapacitated due to physical illness, fatigue or emotional strain.\textsuperscript{68} In case for clients with mental disorders, who can not make decisions themselves, if their partner or family is unable to help or considered not to be acting in the patient's best interests, the counsellor can seek advice of both colleagues and third parties who may be able to confirm, refine or reject the counsellor's decision. In cases, when incapable of making reasonable decisions parents wish to perform selective abortion, when there is a great chance for the child to be normal, in the patient’s own sake I consider that it would be acceptable for the doctor to act in a more paternalistic way. The physician by no means should force the prospective parents, even incompetent ones to perform selective abortion.

\textbf{2. Decision-making process}

It is obvious that prenatal counselling is of the great importance, to both the prospective parents and the fetus, despite that fact that it may bring a lot of unpleasant


\textsuperscript{68} Sutton, 1990 p.151
surprises. In my opinion the doctor plays a very important role here. He is an integral part in this decision-making process.

As it was already previously stated there are two types of counselling: directive and non-directive. Despite the doctor’s professional opinion, he has to be as neutral as possible and refrain from recommending a specific decision\(^69\). Although it does not mean that the physician can not be supportive. Moreover I agree that he has to help the couple to reach their own decision wisely\(^70\). Nordgren for instance disagrees with the statement that the doctor who has adopted a non-directive way of counselling has to refrain from giving emotional and social support as well as assistance in decision-making. He states that as long as the counsellor does not give any recommendations regarding the content of the decision, he/she may still very well provide psychological support and assistance\(^71\). This assistance implies ethical aspects or merely personal preferences. Accordingly, the main goal of genetic counselling should be helping the parents to reach their own autonomous decision wisely. This view combines respect for autonomy with recognition of the need for assistance in decision-making. He states that the counsellor should be non-directive with regard to the content of decision, but directive in decision-making process. However in practice it is very difficult for the counsellors to remain completely neutral in decision-making process. Even involuntary, the doctor may influence the decision of the prospective patients. It happens in the way he/she chooses to present and select information. For instance, when interpreting the probability even for a single gene disease, the counsellor, depending on his level of personal emotional involvement in the particular case, may bias or slant the data. “The counsellor may not change the truth but his tone, manner of speech and other facial and body gestures can influence the information transfer\(^72\)”. It is likely that the decision that parents make almost always depends on which counsellor they get advice from. Anyway, the procreation issues are extremely valuable to the individuals, so that it should be them to decide about their own future. The counsellor’s goal is to assist the parents in decision-making, as they require it.

\(^69\) Nordgren, 2002 p.282
\(^70\) Shiloh, 1996, p.87
\(^71\) Nordgren, 2002 p.282
Accessed (09 May 2006)
It is often that parents want to make a well-considered decision, but often are much confused. “The counsellor should try to help them with this without putting pressure on them with regard to the content of decision”.

3. Six steps to make an autonomous decision wisely

The prospective parents want to make a decision that is reasonably satisfying in their own particular situation. The goal of the physician should be to assist them in this, and still remain non-directive concerning the content of the decision. At this matter, Nordgren suggests six steps which the parents have to take in order to reach their own autonomous decision wisely. These six steps combine nondirectiveness regarding the content of the decision with directiveness concerning the decision making process.

The essence of the first step is the clarification of the concrete problem. Such questions should be answered: whether it is the problem of having a healthy child or for example, one with Down’s syndrome? In the case of testing is there a treatment available or not? What information do they need? Accordingly, it is very important for the parents to find out whether they want to know if their fetus carries an abnormality or not.

The second step is context-sensitive. It is important to identify the regulations and governmental recommendations regarding reproduction in their particular country. Is reproductive autonomy restricted in some way? What alternatives of actions are socially accepted? What is the religious standpoint of the religion to which the prospective parents belong? Consequently it is important to determine whether the selective abortion on the basis of the fetal abnormality is allowed and accepted by the parents and a community they belong to.

The third step aims to identify the prospective parents as the decision-makers. Who are they? Are they young or old, hetero- or homosexual, male or female? Are they already parents? To which community they belong and how does it influence their view of themselves? This step is essential for identifying their own preferences.

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73 Nordgren, 2002, p.284
74 Ibid, pp.284-285
The next fourth step is to clarify the prospective parent’s view of what values are at stake. The counsellor should help the prospective parents in identifying their true values, as they may not always know that. It is important to find out how strong their desire is to have healthy children. What is important for them in life? What are their reproductive plans? Would they be prepared to terminate pregnancy if prenatal testing indicates that the fetus has a defect? How do they perceive the benefit of the test in reducing uncertainty?

The task of the fifth step is the consideration of alternative views on what values and principles are at stake. Helping prospective parents in reaching their own decision wisely implies that the counsellor challenges their standpoints without pressuring them. They should be encouraged to use their moral imagination and take into consideration many different perspectives, alternatives of action, and arguments.

The final step is the decision making. This step should be made solely by the parents. The counsellor can not help them with respect to their autonomy.

According to Nordgren by encouraging prospective parents to proceed in this decision-making process, parents can reach their own decision wisely. At the same time their autonomy is respected, since they make their own particular interpretation and ranking of ethical principles and values. And the role of the physician is also very significant as he/she helps the prospective parents to realise their own values and preferences, by giving all the needed information. I agree and support this decision-making method. The counsellor refrains from recommending to the prospective parents a particular decision and instead recommends using this decision making method, which enables them to investigate their own values and have them challenged by the variety of ethical problems. Consequently, the parent’s autonomy is respected and the optimal decision is being made.
4. **Some ethical principles that every doctor, who is engaged in prenatal diagnosis and care, has to be aware of**

Every doctor, who is engaged in prenatal diagnosis, whether geneticist, obstetrician or paediatrician in his/her everyday practice will definitely have to face some ethical problems and the right way of behaving in such situations is not always that obvious, that is the reason why I have decided to include the following ethical principles which every medical professional should be aware of.

1.) A lot of authors point out the great importance of truth – telling in prenatal counselling. In the case when the couple demands disclosing all the information concerning their chances of conceiving an disabled child, the medical counsellor is obliged to tell them the truth, regardless of whether that is a good news or bad. The prospective parents can make autonomous and informed decisions only when they are properly informed.\(^{75}\)

2.) Parents who already have had miscarriages or children born with certain abnormalities come to genetic counsellor to find out the possibility of the recurrence. There are numerous occasions where the geneticist is unable to provide the couple with an accurate recurrence risk.\(^{76}\) The counsellor has to do his/her best in order to escape giving the wrong recurrence risk as in the case when it is very high it may lead to deterioration from future pregnancies, and vice-versa, when it is very low it will result in future having of the defected child. I think that is essential for the geneticist to be as accurate as possible, as any mistake would have negative impact on the prospective parents.

3.) It is extremely important for the counsellor (geneticist, obstetrician or paediatrician) to rely on adequate understanding of the risk and information about the disease and to adequately present it to the clients. Due to emotional barriers it is often possible to underestimate the given information. Some may interpret 0.1 percent risk as a high one,

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\(^{75}\) Clarke, 1994, p.31  
\(^{76}\) Ibid, p.131
while others interpret 10 percent risk as low. Different surveys in various countries have shown wide variations in the concept of risk. Studies suggest that unrealistic optimism of genetic risk is not related with personal experience of the risk\textsuperscript{77}. An American study of the proportion of women who would use selective abortion when the chances of the diagnosis being correct increased, has shown that there was a 50 percent increase in the number who would perform abortion of the fetus if the possibility that the fetus would have a serious neural tube defect increased from 95 to 100 percent\textsuperscript{78}. This view of certainty versus high chance, a 19 in 20 chance, is interesting. The definition of what constitutes a serious risk varies between patient and the counsellor. Consequently, even the slightest percent can change somebody’s fate; hence the information presented by the counsellor has to be as accurate and adequate as possible.

4.) It often happens that the fetal abnormality is unexpectedly found during the pregnancy by an ultrasound. This puts the obstetrician into a very delicate situation. It is important to explain the parents the likely implications of such a finding. “Truthfulness is of paramount importance, but inevitably the counsellor’s personal views may have some influence on how information comes across\textsuperscript{79}”. It is the most problematic when there is a wide variation known to occur with the sex chromosome aneuploidies, so that the prognosis for any individual fetus can not be accurate. It may be very difficult to characterize ‘marker’ chromosomes, which diminishes the accuracy of the prognosis extremely. According to Caroline Berry in this situation it is important to explore the couple’s view on termination of the pregnancy. As those prospective parents who would eliminate the fetus in the case of mental handicap would continue the pregnancy in this case, while the couple, who did not plan the pregnancy, would be more likely to opt the termination. In cases when the fetus is diagnosed, for example, to have anencephaly, some parents may decide to continue the pregnancy, knowing that the child will die right after its birth. Supposedly, they would feel less guilty, than after the termination of the pregnancy. “In this delicate area it is important to give the individual couple as accurate

\textsuperscript{77} Macer, 1998, pp.999-1024
\textsuperscript{78} Faden, Chwalow, Quaid, 1987, pp.288-90
\textsuperscript{79} Clarke, 1991, p.37
picture as possible of the likely prognosis and to work out with them whether the termination or continuation of the pregnancy is the right way forward them\textsuperscript{80}.”

5.) According to Berry, the geneticist has to be careful to see the information from the client’s point of view and has to make sure that the information that is disclosed is not only true, but also useful and necessary\textsuperscript{81}. As for example it is essential for the geneticist to inform the parents that their child with Von Hippel Lindau disease\textsuperscript{82} will be in the high risk of developing renal carcinomas and retinal lesions which, if not treated can lead to visual impairment\textsuperscript{83}. Thus the parents would be aware that their child would require frequent medical care.

6.) In some cases, due to religious beliefs and cultural customs the family may wish to suppress the truth that a genetic test may reveal. Parents may claim to be unaware of the need to inform their children of genetic risks or may deliberately suppress the facts. This is especially popular in the countries where the culture and tradition give the women a low status. For a woman to find out that she is a “gene carrier” of any kind may result in the loss of the husband, security and the status. Consequently, though truth telling is fundamental to communication in clinical counselling, the physician needs to be careful and respect his/her patient’s right to confidentiality, as sometimes the truth may cause more harm than a genetic disorder\textsuperscript{84}.

7.) Berry mentions another ethical problem that a doctor may meet. It often happens that in the case of autosomal dominant disorders prenatal diagnosis is available, but the doctor is

\textsuperscript{80} Clarke, 1994 p.37
\textsuperscript{81} Ibid, p.32
\textsuperscript{82} Von Hippel-Lindau disease (VHL) is a rare, genetic multi-system disorder characterized by the abnormal growth of tumours in certain parts of the body. The tumours of the central nervous system (CNS) are benign and are comprised of a nest of blood vessels and are called hemangioblastomas (or angiomas in the eye). Hemangioblastomas may develop in the brain, the retina of the eyes, and other areas of the nervous system. Other types of tumours develop in the adrenal glands, the kidneys, or the pancreas. Symptoms of VHL vary among patients and depend on the size and location of the tumours. Symptoms may include headaches, problems with balance and walking, dizziness, weakness of the limbs, vision problems, and high blood pressure. Cysts (fluid-filled sacs) and/or tumours (benign or cancerous) may develop around the hemangioblastomas and cause the symptoms listed above. Individuals with VHL are also at a higher risk than normal for certain types of cancer, especially kidney cancer
\textsuperscript{83} Clarke, 1994, p.33
\textsuperscript{84} Ibid, p.34
hesitant about raising the matter, as he is afraid of offending the client. “The fact that the
test is possible does not mean that is either necessary or appropriate and it is entirely
possible for this to be made clear as the topic is introduced\(^\text{85}\). The appropriate solution
for the doctor is simply to give the opportunity for the prospective parents to let him/her
know their views themselves.

In the light of these facts, it is obvious that ethical problems and moral dilemmas
are inescapable in the clinical practice. In order to be a good doctor perfect medical
knowledge solely is not enough. As ancient Greeks used to say \textit{medicus philosophus est}
therefore the knowledge of ethics is definitely of vital importance to every self-respecting
doctor. As his/her main professional task is not just to heal wounds and diseases, but to
be a good listener, be responsive to his/her patient’s concerns, respect patient’s
autonomy and to be as supportive as possible as well.

\footnotesize{\cite{Clarke, 1994, p.37}}
Conclusions

In conclusion, it would be important to mention once again that prenatal diagnosis deserves our undivided attention, as it opens the door to many ethical problems and moral dilemmas that both the prospective parents and medical practitioners would have to face.

Prenatal diagnosis employs a variety of techniques to determine the health and the condition of an unborn fetus. It is helpful for identifying the outcome of the pregnancy, prenatal treatment if available and deciding whether to continue the pregnancy and finding conditions that may affect future pregnancies. Prenatal diagnosis has two patients to consider: the mother and the fetus. “Two lives are at stake in prenatal diagnosis, so it is of vital importance, that the interests of two patients are taken into account, and risks and burdens of the tests against the potential benefits are thoroughly outweighed” 86.

Prenatal diagnosis is justified when the potential benefits to the child and the mother are balanced. As a matter of fact there are a lot of advantages of prenatal diagnosis. A lot of disorders, which if diagnosed prenatally can be treated in the mother’s womb. The procedures may identify some conditions in the fetus, which may call for the caesarean section or preterm delivery in order to avoid a long and difficult labour in future. Undoubtedly prenatal diagnosis is of a great importance, however the invasive diagnostic procedures have a 0,5 % chance of causing miscarriages or harming the fetus. Hence the use of invasive techniques of prenatal diagnosis can be justified only when the potential benefits and dangers are given thorough consideration.

Sutton suggests eight requirements, which if fulfilled justify prenatal diagnosis. Accordingly, the test has to be reasonably reliable and the medical condition of the fetus must be such that the child could benefit either from treatment in uteri, early delivery or from special preparations to ensure that it is delivered under the optimal conditions 87. Non-invasive procedures have to be preferred to invasive ones. The probability that the child would suffer from the disease has to be significantly greater than that the child would suffer from the procedure. The possibility that the fetus is affected has to be much greater than the probability that it is not affected. Medical practitioners who perform the procedure have to be very well-skilled and educated. These requirements protect the

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86 Sutton, 1990 p.133
87 Ibid, p.140
mother and the fetus; however the author fails to take the autonomy and the right to self
determination of the prospective parents into account. Since prenatal diagnosis may
reveal the results that confirm the abnormality, prospective parents have an option of
aborting the fetus. Therefore, the question is whether selective abortion is a murder of
already existing person, or it is a mercy-killing and expression of autonomy of the
parents.

Firstly it is important to answer the question of whether the fetus counts as a person.
There are different views concerning this issue. Radical gradualists claim that the fetus is
not a person and does not have any moral rights. Absolutists state that the fetus becomes
fully a person from the very moment of conception. As it was stated above I support
moderate gradualists, who state that as fetuses can begin feeling pain in the period of 18-
24 weeks of the pregnancy as its nervous system is developing and since then they can be
counted as persons.

Prenatal diagnosis produces certain benefits to the individual families. Actually it
“protects families from emotional and economical strains of bearing and rearing a child
with genetic or physical disorder”88. As certain diseases like Tay-Sachs syndrome or
untreatable forms of hydrocephalus predict only sufferings to the both: the future child
and the parents. Therefore I think that the parents have a right to undergo selective
abortion on the basis of serious reasons, and by that I mean presence of the severe
disorder in the fetus without prospect of cure and pain relief, that will anyway result in
the early death of the child.

Prenatal diagnosis can serve as a tool to promote the parent’s/mother’s autonomy.
Prospective parents are definitely in the position to decide whether they wish to continue
the pregnancy, or not. However their decision should be very well-considered and
thoroughly outweighed. Moreover they need an objective assistance of a competent
physician, who since long time ago is believed to have special responsibilities and
obligations towards his/her patients.

Nowadays, there two types of medical counselling: directive and non-directive.
Nondirectiveness means refraining from making any recommendations regarding the
content of the decision, and on the contrary directiveness indicates giving advice about

88 Kitcher, 1996, p.15
which decision is the best. Together with Nordgren I believe that non-directiveness can be very well combined with psychological support and even assistance in decision-making. The medical counsellor should remain neutral in decision-making process, however he/she should be supportive and do whatever is possible in order to help the couple to make their own decision wisely.

The physician plays an integral part in decision making-process. It is in his responsibility to disclose all the needed information during the whole period of the pregnancy. Despite his/her own personal opinion the physician has to remain as neutral as possible and has to refrain from recommending a specific decision. Nevertheless he/she can provide his/her patients with psychological support and assistance. The main goal of the counselling is helping the parents to reach their own autonomous decision wisely. This view combines the respect for autonomy with the recognition of the need in decision-making.

Nordgren states that the counsellor should be non-directive with regard to the content of decision, but directive in decision-making process. He suggests six steps for the parents in order to make their own decision wisely. The essence of the first step is the clarification of the problem itself. The second one is context-sensitive, as it is important to clarify the regulations and governmental recommendations regarding reproduction in particular country. In the third one, it is needed to identify the prospective parents as decision-makers. In the next-fourth step the physician has to help the prospective parent’s to clarify their own true values. The essence of the fifth step is the consideration of alternative views on what values and alternatives are at stake. The final sixth step is actually decision-making and has to be done solely by the prospective parents. According to Nordgren by encouraging the prospective parents to proceed in this decision-making process, the parents can reach their own decision wisely and at the same time their autonomy remains respected.

I think that every doctor has to be very-well educated either medically and ethically. As he/she, will definitely have to face various ethical and moral problems in his/her medical practice. And it is his/her obligation to find a decent way of dealing with them.

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89 Nordgren, 2002, p.282
90 Ibid, pp.284-285
As the physician’s main professional task is not just healing of the wounds and diseases, but being a good listener, being responsive to his/her patient’s concerns, respective towards the patient’s autonomy and being as supportive as possible as well.
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