
Moral Issues In Technology: Ethical Issues Raised By Prenatal DNA Sequencing

Introduction

Modern technology enables us to prenatally diagnose birth defects of genetic disorders inherited from the family. Examples of these disorders are the abnormal growth of the body, mental retardation and other conditions which might affect the child and the parents in the future. A new technology called prenatal screening is used to detect such irregularities before delivery. Prenatal screening for the diagnosis of specific fetal conditions has turned into an essential prenatal care for some women. Testing techniques range from non-invasive advancements to invasive but this paper focuses on the invasive techniques used during this procedure. Two well-known invasive tests are chorionic villus sampling (CVS) and amniocentesis where cells are extracted from the fetus and analyzed under a microscope. Geneticists can then determine whether the fetus has too few or too many chromosomes, or if the chromosomes are damaged and could result in a genetic problem. This rapidly emerging technology raises the following question: "Is it morally permissible to use prenatal screening in order to interrupt a pregnancy based on found genetic disorders?"

In order to answer this research question these ethical concerns are going to be evaluated: accuracy of the tests, importance of medical information about the consequences of a particular genetic disorder, risk associated and societal pressure on an individual's decision. Contrary to this, arguments are made that this technology could improve the well-being of both the parents and the child. The moral actors considered are the parents as well as the fetus as both can have their lives go better or worse due to the technology. In this analysis, they are considered equally important.

Moral analysis

This chapter consists of arguments that defend the moral permissibility of the use of prenatal screening. These arguments are the accuracy of the process, medical provided information, the including risks and the society pressure.

Accuracy

In most cases, genetic screening (non-invasive) is offered to pregnant women during the first

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meeting between the doctor and the pregnant woman. The parents are free to decide whether they want the procedure to be done or not. Screening tests can assess the possibilities that the embryo may have a certain common birth defects. However, they cannot indicate for sure if the child has a genetic disorder as the accuracy is around 10% lower than the invasive tests. A prenatal genetic screening has an accuracy around 90-95% also there is a 2,5% where the results can be false positive. It is inaccurate, conflicting and also an inadequate test does not give judgments of disabilities, but rather the likelihood that a possible child may have a disorder, which may or may not be true. However, these disorders may affect different people in different way. While some of them need more medical attention, others can lead a healthy life. If parents make a decision based on inaccurate results, they might accidentally take a decision that would terminate the birth of a healthy child. Therefore the technology would not be morally permissible.

Medical information

Before and after having the information provided by the prenatal genetic screening, all parents have to be informed about their situation. Information beforehand is required, as it may be a risk for the mother or the child. Additional information is required after the screening in order to know what to expect of a child with Down syndrome. To promote the freedom of choice of individuals comprehensive and neutral information must be provided to parents on screening processes and the consequences. Information about the consequences of having a child with Down syndrome is important, as different genetic conditions lead to highly variable consequences in terms of the quality of life of the child. Depending on the condition's severity, a person with Down syndrome can either have a relatively autonomous existence with a little help for everyday life or be forced to live in an environment for non-autonomous persons. Some studies show that in some prenatal screening programs the explanations given by health professionals were considered inadequate, unclear or insufficient by the mothers, as well as, that the understanding of the professionals regarding some aspects of the process of the technology was deficient. The perception of the parents is also influenced by the views of the health care personnel who provide the information. It seems that the professionals' specialization, religion, sex, number of children that they have and ethnic origin could influence the information they impart and, consequently, on the choices offered to the parents. The complexity of genetics coupled, and the notion of risk makes the information provided even more difficult to understand for the parents, especially when they are vulnerable and anxious in the face of an important decision about their child. The waiting period before obtaining the results and the uncertainty regarding the results are a source of stress and anxiety for the future parents.

Risks

Non-invasive screening tests are safe for the mother and fetus. However this is not the case for

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the invasive diagnostic. The invasive diagnostic tests can detect numerous genetic conditions caused by imperfections in a gene or chromosome. They can indicate the existence of a genetic problem with high accuracy but some of the diagnostic tests are risky and can lead to a miscarriage. The pregnant woman is at risk, both physically and psychologically, during the process of testing. While the likelihood of a miscarriage is low, it still is present. This chance of fetal loss also includes healthy fetuses that could have been born alive and in good health, if the diagnostic test had not been performed (Health and commissioner, 2008, 20). In conclusion, implementing the test can give an outcome in end that people from the medical world; the parents; the family members and society people actually want to prevent from happening. Consequentialism indicates that an act is morally permissible if and only if (and because) it promotes as much good, impartially considered, as any other available action act. This technology that makes it possible accidentally terminate a pregnancy is not acceptable because it does not promote good, instead it includes a risk of the death of a child. The death of a perfectly fine fetus is a huge risk which can have different negative side effects on the parents (emotionally and even health-wise for the mother). From this we can say that this technology is morally not permissible.

Pressure from society

Every individual should have the chance to make their own decision whether they want children or not. Despite the contrary, the perceptions of future parents are influenced by the perceptions of society. The choices of the parents, whether to do the diagnostic test that might result in the decision for them to keep the child or not, is a reflection of the social currents, for instance the society's frame of mind towards handicapped people and its thought of 'normalcy'. In general prenatal diagnostic testing occurs within a context of social pressure that can restrict parental freedom of choice to a significant degree. To undergo a prenatal genetic screening test entails the preliminary belief that terminating a pregnancy or agreeing to give birth to a genetically disabled fetus both depict reasonable choices in our society. That is the reason why using this prenatal diagnostic technology is not an option for some people. Individuals have an obligation to evaluate the moral norms of their society, to reject them if they're mistaken, and to do the right thing. But like mentioned before, parents understandings can be influenced by a number of different factors that extend from culture to religion, sexual orientation, past experience and of course pressure from the society. How society deals with the prenatal diagnosis will impact upon social values: moral, legal, and ethical perspectives. The pressure from the society can have a negative mental and physical influence on the future parents. If the well-being of the parents is negatively impacted, then it is not morally permissible to use this technology.

Arguing for the moral permissibility

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The strongest claims against the permissibility of prenatal screening are outlined in this section. Additionally, counter arguments to these arguments are provided after each argument. The first claim argues that the parents should have the right to not have a child if its genetic condition would make it such that they are unable to provide sufficient care. The second claim views the moral issue via a welfare hedonism point of view and argues that an optimal overall well-being is achieved whenever the child is not born.

Providing adequate care

When deciding whether prenatal screening is morally permissible, a closer look is taken at the goodness of the outcome of using it. While several factors are important when determining this, the well-being of the parents (and consequentially the well-being of the child) are examined. A big part of promoting the well-being of a child is taking care of it and spending time with it. When a couple is expecting a child, they often consider how the child is going to affect their lives. Depending on their findings, they might make changes to their lifestyle such that they can take care of the child adequately. However, if after birth of the child it turns out that it has a genetic disorder, for example the syndrome of Down, then the lives of the parents are affected in a different way than they expected. While financial support as well as support from family caregivers is available, the life of the parents will still be influenced heavily. Not only the intensity of the care that these children need increases, also the length with which they need it does. While most children become independent once they become older, several genetic disorders severely limit or even prevent the affected people from becoming independent of their parents.

Using prenatal DNA sequencing, genetic disorders of the child can be identified in an early stage of pregnancy. Having this information would allow parents to make a more informed decision on whether they have the ability to take care of child. Allowing parents to have this information will ensure that sufficient care is given to the child, which will make its life go better than it would have without this care. Apart from the life of the child, the life of the parents is affected too. The parents will have fewer (unexpected) compromises they need to make to their life. While most parents will gladly do this, the parents can find themselves in a situation where they are forced to change their life in an unexpected manner in order to provide adequate care for the child. Additionally, having a child with a genetic disorder causes a lot of stress for the parents. If the parents would have known about the genetic disorder in an early stage of the pregnancy, they could have made an educated decision on whether to continue with the pregnancy. Having the knowledge of the genetic condition of the unborn child lowers will allow parents that deem themselves unable to provide sufficient care to terminate the pregnancy. Parents have the right to make this informed decision and technology that allows them to do this is therefore morally permissible.

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Equal Opportunities

The first argument above states that the information obtained by using this technology can be used by the parents to make an informed decision on whether they will have the capacity to take care of the child. Since this is based on an assumption on the amount of care the child would need it is not morally permissible as not all child with Down syndrome need the same cares. People have the tendency to take worst-case scenarios to base their decisions on when deciding on matters like the one described in this argument. Another objection with this argument is that every child should have equal opportunities and a decision on whether a child fits with the lifestyle of the parents should not be based on genetic discrepancies since it gives the opportunity for parents to discriminate and use other genetic information to choose a child that suits their ideas of the perfect child. This idea was also posted by all participants of the survey held in the following paper. They agreed that unconditional acceptance of children is the most praiseworthy approach.

Another objection raised in this paper is the obsession with a physical perfection in society. This approach in the future could put even more social pressure on disabled people since it is not one hundred percent accurate and it will not mean that no disabled children will be born in the future. This type of decision making based on possibly incorrect information and assumptions about the live of a child should therefore not be allowed.

Child's well-being

An argument in favour of this technology based on the well-being of the child and parents will be considered. Suppose a woman is pregnant and the test results show that the child has a genetic disorder. Being born might be less favorable due to the fact that the child might suffer and have low quality of life due to the disabilities. Looking at this situation from a welfare hedonism point of view, which states that well-being is solely dependent on the presence of happiness/enjoyment and the absence of pain/suffering, might lead to the conclusion that in this situation it would be more favorable if the child was not born therefore it would promote the most amount of total well-being for this situation.

Under these conditions the information given by the prenatal testing can be important for the outcome of this scenario and an argument can be made that the information given by this technology has the potential to make well informed decisions leading to a situation with an overall increase of well-being. This situation therefore, shows that it should be allowed to use the technology of prenatal diagnosing to gather information that has the potential to lead to a situation where there is more well-being.

Mental state theories

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The argument is made that a genetically disabled baby not being born can lead to a situation that has the highest overall well-being, as the life of the baby consists of little happiness while pain and suffering are present. However, when looking at the self-reported happiness of people with a severe disability, it turns out that the majority report their life quality as good to excellent. This is likely because the quality of life is not judged only based on health, as it is often seen as a balance between body, mind and spirit. The people suffering from a disability can adapt to their situation and find other goals or means to increase the quality of their life. This can be made clearer when looking at the well-being of the disabled from different theoretical points of view.

Mental state theorists will say that the mental state of the people is all that determines their well-being and therefore, their well-being is indeed just as high as that of non-disabled people. However, a desire satisfaction theorist might not agree with this. Consider a person who is physically disabled in such a way that running a relay race is impossible. If this person manages to take part in this relay race in a wheelchair, then the well-being of this person is increased, as he or she will be in a positive frame of mind (according to a mental state theorist). According to the desire satisfaction theorist, the real desire, to run a relay race, is not desired and the well-being is therefore not increased. However, if the person adapts to the disability and accordingly changes their desires, then the desire satisfaction theorists would agree that the well-being of this person is indeed as high as they claim it to be. Therefore the notion that according to welfarism it is better for a child not to be born is invalid.

Conclusion

All in all, there are various moral and social issues related to prenatal screening. Paradoxically, screening tests invade what were the most private areas of life. These concerns vary in nature: the requirement of free and informed consent and the support given to future parents struggling with difficult decisions; the risk and the accuracy of the technology. Contrary to this, arguments are made to defend the technology: parents should have the right to know whether they can provide adequate care for the child. Additionally, an argument is made that the overall well-being might be highest if a disabled child is not born. Counter to these arguments are then provided. Based on this we can conclude that it is not morally permissible to use prenatal screening in order to interrupt the pregnancy based on found genetic disorders.

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