

## **The Bioethics of Prenatal Screening: Reproductive Autonomy & Informed Choice or the New Eugenics?**

Prenatal genetic screening is a form of testing that provides parents with information regarding the health of their fetus and the likelihood of the fetus having certain types of genetic disorders. Genetic disorders result from changes in the fetus's genes; these changes include missing, extra or mutated genes and may result in health conditions and disabilities that can affect the child's life. One type of disability often screened using these tests is Down Syndrome. Screening tests, unlike diagnostic tests, do not provide the parents with a definitive diagnosis rather, they simply indicate an increased risk for the development of a genetic disorder. The tests are offered during the first and second trimesters and include ultrasounds and blood tests testing both the mother's blood and fetal DNA found in the mother's blood. A mother who receives a high-risk diagnosis is left with decisions to make regarding further diagnostic testing and decisions on moving forward with the pregnancy, which in some cases includes the option of terminating the pregnancy(American College of Obstetricians and Gynaecologists, 2020). Screening tests have resulted in bioethical issues where some individuals believe the tests support the parent's right to reproductive autonomy and making informed choices regarding their pregnancies. In contrast, others believe it is a form of "new eugenics" and aims to erase disabilities. This paper seeks to examine both points of view.

### **Reproductive Autonomy & Informed Choice**

Reproductive autonomy refers to the rights a woman has regarding her own body and the right to decide to terminate a pregnancy. The focus is on providing mothers with enough information to make informed choices when exercising their reproductive rights; the quality and

quantity of the information on the fetus's health provided to the mothers empower women to make decisions that are best for them and their families and aids them in having less stressful pregnancies (Begović, 2019). While such screening procedures that show a high-risk pregnancy may result in the choice to terminate the pregnancy, it is not the only choice facing parents. The improvements in genetic screening technologies now allow parents to make autonomous reproductive decisions that were previously left to nature, leaving parents with no control over the outcomes (Garcia et al., 2011). A study on the attitudes of parents and medical professions towards prenatal testing found that women considered that increased knowledge about the fetus's health was beneficial to them. The same study found that both the mothers and professionals viewed testing as a way to increase reproductive autonomy rather than a way to promote abortion and the termination of fetuses with disabilities (Ngan et al., 2020).

Several factors play a role in the choices parents make regarding their pregnancies. One study found that the perceived severity of the disability, the difficulties parents suspected they would have in raising the child as a result of their knowledge and abilities to provide care for a disabled child, and the financial and social implications on the family unit were factors that impacted parent's decisions to terminate the pregnancy (Ngan et al., 2020). The quality of life the parents imagined for their child also played a large part in the parents' decision to terminate the pregnancy. Parents who expected their child would suffer found it morally acceptable to terminate a pregnancy. Mothers felt responsible for providing their children with a good quality of life and the ability to care for their children; if doing so was not seen as a possibility, terminating the pregnancy seemed like a viable choice (Garcia et al., 2011). Given that caring for a child with a disability would directly affect the quality of life of the parents, choosing to

terminate the pregnancy would be in line with the reproductive autonomy stance; this is evident in that mothers who presumed that raising a child with a disability would be a rewarding life experience were less likely to consider terminating the pregnancy (Ngan et al., 2020). In some societies where disability is highly stigmatized and having a child with a disability was perceived as punishment for a parent's bad deeds, women considered terminating pregnancies to save themselves from feelings of guilt and shame (Ngan et al., 2020). A woman's reproductive autonomy extends to autonomy over her life; choosing to terminate a pregnancy to provide herself with a life free of guilt and shame can be seen as her right under reproductive autonomy.

Not all parents who receive a high-risk result from screening choose to terminate the pregnancy. One of the most significant advantages that prenatal screening provides parents is time to prepare for raising a child with a disability. In a study on fathers' perceptions of prenatal screening, fathers stated that the value of the test was the time it provided them; three areas regarding the importance of time were highlighted, first the time to research and learn about their child's disability and thus time to prepare themselves. Second, the time to accept the diagnosis, parents who can come to terms with the diagnosis may be able to get over the initial shock and potential grief before the child is born. Finally, it provided them with time to prepare friends and family by informing them of the diagnosis (How et al., 2018). In a study on the perception of mothers and service providers, the value of time to prepare was also evident in their responses (Ngan et al., 2020). Interestingly, in a study on the perception of individuals with Down Syndrome on prenatal screening, they too found that time to prepare was a valuable outcome and believed that knowing about their disability would have helped their parents understand them.

Furthermore, one respondent stated that if she got pregnant, she would want to know if her child would have a disability to "prevent shock." (Barter et al., 2016)

### **The New Eugenics**

Eugenics refers to practices and policies which aim to improve the population by promoting the reproduction of desirable attributes and limit the reproduction of those with undesirable attributes with the belief that the world would be better if everyone is born "healthy." (Thomas & Rothman, 2016) Eugenics also has its place in politics and history, such as the "Nazi eugenics" during the holocaust. The practices of eugenics seem to be justified because those who are victims of it are considered defective; this places the lives of individuals with disabilities at risk (Reinders et al., 2019). Prenatal screening, which can identify the risk of having a child with a disability, puts the fetus at risk of being aborted and thus undergoing a form of eugenics where their genes are considered undesirable and unworthy of life. Statistics on the termination of fetuses with Down Syndrome support this view with 90-92% termination in the UK, 90% in the USA, 88% in European countries (Barter et al., 2016), 95% in certain parts of Australia (Thomas & Rothman, 2016), and Iceland reporting that it is on its way to becoming the first country to be free of Down Syndrome (Reinders et al., 2019). Those who do not support prenatal screening believe that providing women with reproductive autonomy and choice when it is known that the choice they are likely to make, as supported by the statistics, is to terminate the pregnancy is aiding eugenic practices (Wilkinson, 2014). Parents have indicated that after receiving results, they often felt pressure to terminate the pregnancy from health professionals, family and friends, as well as their own internalized beliefs resulting from the information provided to them by health care professionals and found on the internet (How et al.,

2018). Furthermore, in one study, some professionals admitted to highlighting only the negative aspects of Down Syndrome and encouraging pregnant women to terminate (Wilkinson, 2014).

Presumed poor quality of life was a significant factor in the choice to terminate a pregnancy under the reproductive autonomy stance; those who believe that screening leads to a "new eugenics" argue that the actual quality of life of a child with a disability is likely not the same as what parents and medical practitioners presume. Although parents acknowledged the many difficulties associated with raising and caring for a child with a disability, including medical, educational and social challenges, they recognized that raising their children did not only bring challenges but brought joy as well and noted that people should not view their situation as disastrous as many believe (Thomas & Rothman, 2016). More importantly, a study that looked at the lives of 294 individuals with Down Syndrome found that 99% were happy and 97% liked who they are (Reinders et al., 2019), although Down Syndrome is not the only condition screened for, considering the statistics on the number of terminated births of fetuses with Down Syndrome, it is important to consider whether inconsistencies between actual and perceived quality of life are the reality in many different conditions. A second argument regarding the presumed quality of life and its defence of prenatal screening is the fact that prenatal screening cannot provide information about the quality of life of the fetus as it provides minimal phenotypic information (Johnston et al., 2017). There is the potential for significant variance in the phenotypic outcomes of genotypic information; therefore, the prognosis of 2 fetuses with the same screening results might vary tremendously in the child's quality of life. With the improvement of services and the focus on early intervention, the quality of life of individuals with disabilities is improving; however, this seems to coincide with an increase in

pregnancy termination of fetuses with disabilities. The mismatch between actual quality of life and perceived quality of life leaves one questioning whether people are not given the right idea about life with disabilities which can be harmful in its effects to present termination as a moral and viable option.

Negative perceptions and attitudes of individuals with disabilities and the termination of fetuses with disabilities (only made possible by prenatal screening) are both the cause and effect of one another. The negative perceptions lead to increased terminations, and the terminations reinforce and worsen the perceptions and attitudes; they both speak volumes to how society values the lives of individuals with disabilities. Those who believe that prenatal screening leads to eugenics argue that in a society that perceives a disabled life as devastating and tragic, society can justify the choice to terminate a pregnancy (Reinders et al., 2019), the "burden assumption" refers to the belief that a disabled life is one not worth living, and those who are disabled become burdens to those who care for them (Rubeis & Steger, 2018) is one way in which society's perceptions aid eugenics.

### **How "informed" is the Informed Choice?**

There is sufficient research supporting both positions; the major stakeholders (parents, individuals with disabilities and medical professionals) have provided their opinions supporting both positions. When it comes to the position that screening leads to eugenics, the statistics show evidence for a decreasing number of individuals with disabilities, and qualitative data shows the negative attitudes towards individuals with disabilities and how those attitudes are both a cause of and reinforced by the eugenic effect of prenatal screening such as the proof that professionals were likely to suggest termination to parents. The research supporting the reproductive autonomy

and informed choice position is also strong, where the major stakeholders have all indicated that the screening is to a certain degree helpful. Qualitative research showed that parents who found that it gave them time to prepare for their child with a disability and allowed mothers to make choices about terminating a pregnancy that would have significant effects on their family's quality of life.

A significant factor supporting reproductive autonomy is that it provided parents with the opportunity to make informed choices. The quality of the informed choice was a common theme in both the research on reproductive autonomy and screening as a form of eugenics. Those who believed that it was a form of eugenics showed concern regarding the quality of information given to parents about the different disabilities and worried that the information presented only highlights the challenges and medical complications associated with disabilities, thus portraying a picture of a "tragic" life and a reason to terminate the pregnancy. Fathers who found value in the time given to prepare to care for their child also indicated that the quality of information is an important factor and should be balanced information that portrays the reality and not just the medical predictions (How et al., 2018). In the study on individuals with Down Syndrome's perceptions, they too indicated that they felt that prospective parents are not well informed and do not understand what living with Down Syndrome is like and suggested that these mothers be provided with information from people living with Down Syndrome to create a more balanced view (Barter et al., 2016). The use of prenatal screening may not result in discriminatory attitudes and eugenic effects if screening is combined with parent counselling that is unbiased and provides a clear picture, including the perspective of those with disabilities (Rubeis & Steger, 2018).

**Reproductive Autonomy & Informed Choice or the New Eugenics? Where I Stand.**

There is no doubt that although society's attitudes towards individuals with disabilities have improved over the past decade, there is more work to be done in terms of social reform to improve the quality of life and perceptions of those with disabilities. It is clear from the research that as long as individuals with disabilities are perceived negatively and have few services and support to improve the quality of their lives, the choice to terminate pregnancies of fetuses with disabilities will present itself as a moral and viable option that could result in eugenic outcomes. With that being said, I stand with the position that prenatal genetic screening is a tool to practice reproductive autonomy and making informed choices regarding pregnancies, if, as mentioned above, the information provided to these parents is balanced and provides them with the perspective of individuals with disabilities, showing the strengths and joys rather than simply highlighting the challenges and complications. An informed choice is not fully informed if the information is lacking. Prenatal screening does not always result in the termination of pregnancies, and the benefits it provides to families who choose not to terminate can significantly improve the quality of life of the child and family unit. Knowing that a child might be born with a disability can help parents go through the initial shock and grief period before the child is born (How et al., 2018), allowing the parent to be more present and engaged when the child is born. Knowing about the disability can also help parents plan for early intervention before the child's birth, thus maximizing the potential benefits and quality of life outcomes.

My position is grounded in ensuring the best outcome for the child with the disability; while some may argue that no life is worse than a life with bad outcomes, I believe that in cases where termination is chosen, the mother may be an unfit mother to the child had she not

terminated the pregnancy. According to the biopsychosocial model of disability, individuals with disabilities' outcomes are a result of an interaction between the individual's biology (genotype/medical disability), emotional experiences and environmental factors (Smeltzer, 2007), according to this model, a child's environment and relationship with family can have devastating effects on the outcomes of his/her quality of life; therefore, a mother who does not have the option to terminate a pregnancy may be negatively impacted by having a child with a disability which would result in stress or psychopathology that can harm both her and the child's life. Ultimately, taking a stand with reproductive autonomy and the right to make informed choices can positively affect the child and the family unit at large.

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