The dilemma of prenatal screening

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Abstract

Prenatal screening of pregnancy for fetal abnormality is increasingly routine in western countries. It was introduced to improve outcomes and increase choice for women. While women who value human life from the time of fertilization have opposed the practice of prenatal screening if abortion is an intended outcome, problems with informed consent, scope of testing, impact of termination for fetal anomaly, and discrimination against those who refuse termination make the procedure ethically problematic for all participants. In view of these issues, this paper questions the place of routine prenatal screening as an ethical way of increasing consumer choice.

Introduction

When a woman is presented to her family physician for antenatal care, she is not surprised when she is referred for blood tests and scans. This is the expected rite of passage for pregnant women in the western world and generally not resented as modern reproductive medicine has come a long way in improving both fetal and maternal outcome.[1] However, in the tests aiming to check the health of the mother and fetus, increasingly there are also tests to check whether the fetus is normal. The routine manner in which such tests are viewed by both women and healthcare professionals, as well as their inclusion through 'piggy-backing' with tests that promote health, diminishes the opportunity for women to make an informed choice regarding what is, in fact, an optional procedure: prenatal screening for fetal abnormality.[2]

Prenatal screening is a non-diagnostic, non-invasive procedure comprising ultrasound screening and a series of maternal blood tests. It is non-diagnostic in that it determines the *risk* of the fetus having a chromosomal or structural abnormality, rather than a definite *diagnosis.* The level of risk is assessed by reviewing the results of these tests with consideration of the mother's age, weight, and pregnancy gestation. If there is an increased risk of abnormality, the woman can choose to undergo further invasive testing, such as amniocentesis or chorionic villus sampling (CVS), to accurately identify whether an abnormality exists. These tests carry a small risk of miscarriage, as well as risks to both the normal development of the fetus and the healthy progression of the pregnancy.[3] Amniocentesis and CVS will be offered to women who are found to have a high risk or fetal abnormality and performed only when the woman consents. Prenatal genetic testing is therefore performed in the context of a wanted pregnancy, which is expected to progress to term—all being well.

The process of deciding which tests, if any, are best for mother and fetus is a complex one, potentially involving a series of difficult decisions to be made in a short period of time. Using the traditional tests, one in 20-25 women will be told that her fetus is at increased risk of a problem but most of the fetuses assessed will subsequently be found to be normal and healthy.[4] This cannot be confirmed until after the invasive diagnostic test results are available. The reason for this high rate of possible risk is because the net aiming to catch the 'at risk' pregnancies is cast wide at

the outset. The danger of invasive testing is not to be discounted. Due to the chance of miscarriage with these tests, it has been estimated that for every 660 Down syndrome (Trisomy 21) fetuses that are detected and terminated in England and Wales each year, 400 normal fetuses die as well.[5]

In deciding whether they want to have prenatal screening tests, women may not be concerned only about the risk of miscarriage. Research shows that women undergoing tests like amniocentesis often feel ambivalent. Sapp and colleagues found tensions among the intellectual, moral, and spiritual values of all women undergoing amniocentesis in their study of women with positive attitudes to screening. Competing desires, such as seeing amniocentesis as a powerful tool for choice while wanting to protect the pregnancy from harm, created conflict.[6] Women may also be influenced by concerns about caring for a child with a disability, whether they want to know prior to the birth if there is a problem and whether termination of the pregnancy is acceptable to them.[6] The reasons women give for refusing screening are not necessarily straightforward opposition to abortion. They often employ similar arguments to those who accept screening, such as framing their decision in terms of risk.[6]

Currently underway is the introduction of non-invasive prenatal testing (NIPT), analyzing cell-free fetal DNA from maternal blood that can give a *diagnosis* of genetic abnormality without the subsequent invasive tests.[7] The number of diseases that can be screened for and diagnosed using these tests is constantly rising with genome-wide screening likely to be increasingly available as the cost of testing is reduced. Genome-wide testing will introduce new levels of uncertainty into the process of prenatal screening as—apart from the large amount of information to be processed both before and after testing—the potential for incidental findings means that families may be faced with problems they had not been seeking nor were prepared to face and that the high incidence of findings of unknown significance can be confusing and worrying.[6]

While procedures are available to address some fetal problems during or after the pregnancy, many conditions have no treatment available and can involve significant risks even when accessible.[8] This does not mean the screening tests have no utility. Test results may be used to plan the management of the pregnancy, prepare for a difficult delivery, arrange care of a child with special needs, arrange for the adoption of the baby, as well as inform the woman's decision regarding continuation or termination of the pregnancy.[9] Moral opposition to termination of pregnancy, therefore, is not necessarily a reason to avoid screening. However, many women diagnosed with a fetal anomaly do choose to terminate the pregnancy, proportions ranging from 47% to 90%.[10]

Prenatal screening for fetal anomaly was introduced to improve outcomes of pregnancy and give women a greater choice in determining the outcome of their pregnancy,[11] but the nature of the screening process seems to be shaping and constraining the choices available to women. The realization of freedom for women has often failed, as they may approach testing without adequate information of what is involved. Furthermore, the continuing increase in scope of testing, the psychological impact of termination for fetal anomaly on the women who choose this path, and discrimination against those who refuse termination when an anomaly is diagnosed,

make the procedure ethically problematic. As well as interfering with autonomy, this can result in harm to the women involved as they try to negotiate the road to parenthood. In this essay I will explore the ethical problems involved in prenatal testing for fetal anomaly and question its ability, independent of questions about the inherent moral significance of the human fetus, to ethically facilitate maternal choice.

Informed Consent

Prenatal screening for fetal anomaly is a complex procedure with potentially serious implications. Patient autonomy requires that the mentally-competent adult individual should fully understand proposed medical procedures before they can ethically be performed. This autonomy is realized by obtaining informed consent from the patient. Informed consent requires that the patient have knowledge and understanding of the benefits and risks involved in medical care to make a voluntary decision.[12] While counselling can help to resolve the ambivalence experienced by pregnant women offered screening,[13-15] the complexity of decision-making involved in prenatal screening means that counselling needs to be accurate and individualized. This is not currently happening. Harris and colleagues found that risks of genetic testing could only be justified when testing was limited to women holding a true individual preference for fetal chromosomal information.[16] This is not reflected in routinization of screening where consent is assumed. International research has shown that pregnant women in industrialized countries often expect to routinely have one of the screening tests for Down syndrome—the Nuchal Translucency (NT) ultrasound scan—with little understanding of what the test means.[17] An Australian study found that one-third of women undergoing prenatal genetic screening for Down syndrome did not realize that if they were found to have an increased risk from the screening test, confirming a diagnosis would require a test which carried a risk of miscarriage. Only two- thirds realized that if Down syndrome were diagnosed, they would be offered an abortion.[18] It is not implied that all women walk ignorantly into prenatal screening without any idea of what they are doing. For some it is an active decision, such as those with a family history of disease. But problems with informed consent cannot be ignored.

In order to reduce the risk of women agreeing to prenatal screening without fully understanding the process, professional organizations such as the Royal Australian and New Zealand College of Obstetricians and Gynecologists recommend that all genetic testing should be preceded by counselling.[19] But even when it occurs, the adequacy of counselling remains a significant problem. There are several reasons for this.

Many screening tests need to be done early in a normal pregnancy, so general practitioners may order them before a woman sees an obstetrician. Generalists may not have full knowledge of the conditions being tested or be able to explain exactly what is involved in the testing process.[20] Health professionals need to clearly understand the complexities of probabilistic reasoning in order to communicate risk information effectively, and this is a difficult concept for anyone to understand.[21] Often there will be time constraints in the consultation, and it may be difficult to provide comprehensive genetic counselling in a busy medical practice.[22] General practitioners in Britain reported that it was difficult to raise possible adverse outcomes

of screening, such as the diagnosis of disability and the termination with someone who is excited at finding out she is pregnant.[23] Some authors suggest it is not feasible to give so much information in a way that is meaningful to the mother. Confusingly, other authors have complained that women are already given too much information regarding prenatal genetic screening, which gives them too many choices and impairs their decision-making ability.[6] This problem will only become more complex as the testing becomes more comprehensive through NIPT, especially with the proposed introduction of genome-wide screening and the range of possible results that can be received.[24]

Furthermore, medical counselling is often construed as a medical directive by the women seeking antenatal care.[25] Moral imperatives imbedded in the information offered may be difficult to counter if the woman is unfamiliar with the screening process. There is an innate power imbalance in the doctor-patient relationship which puts the woman in a position where the autonomous choice to screen is in fact experienced as an inability to justify not doing so. Press and Browner found that the attitude of the health practitioner had a significant impact on whether Californian women would undergo prenatal screening, with clinics that pressured women regarding testing having twice the national average acceptance rate.[26] Clinicians regard testing as a way to identify problems while women connect it with protecting and nurturing their pregnancy.[27] Although doctors in a British study offered a choice, they knew they consciously offered genetic screening tests as routine and put the process in a positive light, due to lack of time while being aware that a key motivation for women's positive perceptions of screening was their sense of obligation to undertake any test that would benefit their unborn baby, thereby exploiting the maternal instincts of the women involved.[28]

Fully informed consent requires a comprehensive explanation of the results at each stage of the screening and diagnosis process. This includes the meaning of genetic risk, the nature of the genetic abnormality diagnosed, the concepts of variation in genotype and phenotype (your genetic makeup versus how those genes are expressed physically), practical information about the impact of chromosomal abnormalities on the life of an affected person, and the opportunity to speak to someone who cares for them. Such information is known to increase the number of parents who are prepared to care for a disabled child. Currently, such information is not routinely given, despite some women voicing an interest in this information.[29] While many of these problems in counselling pregnant women are understandable, they still represent a violation of the informed consent process.[25,30]

While the newer genetic tests (NIPT) are easy and safe and avoid the risks of invasive procedures, some authors have suggested that informed consent may become even more difficult with their introduction.[31] The possibility is raised that, because non-invasive testing is easy and safe and can be performed early in pregnancy, both testing and selective abortion may become 'normalized.' The possibility of earlier detection of affected fetuses may also increase the uptake of abortion, as many people consider that the moral significance of the human embryo increases over time.[32] It is also possible that the reduced risks involved may mean that less care will be taken with informed consent.[33]

Apart from the ethical problems involved with inadequate disclosure of all the facts when women are not fully informed, it means that women may not think through the implications of a positive diagnosis before undergoing the testing. This is particularly important as, with widening of scope of testing and increased sensitivity of ultrasound scans, women may get unexpected results for conditions for which they did not know the fetus would be tested. Thus, they may not be prepared to handle the situation. This problem is only going to get worse. De Jong and colleagues suggest that easy, safe, and early techniques such as NIPT will challenge the notion of prenatal screening serving reproductive autonomy.[34] The limited ability of the patient to meaningfully engage with even more diverse and complex measures of risk will further stress the doctor–patient relationship, especially as distress associated with being high-risk in prenatal screening can persist, despite a negative diagnostic finding.[18] In the future, the support of all involved by experts in genetic interpretation is likely to be necessary.

Scope of Testing

Prenatal genetic screening and diagnosis were initially aimed at identifying serious, life-threatening conditions present at birth. With the rapid broadening of the scope of genetic testing conditions which are treatable, adult-onsets or only partially penetrable illnesses (such as hereditary cancers) are now also the focus of investigations. While recommendations have been made that prenatal diagnosis not be used for minor conditions or characteristics, the question of who decides what a minor condition is and how that decision is made, is not clear.[6]

In their 2005 review, the Human Fertilisation and Embryology Authority in the United Kingdom reviewed which conditions could be screened in preimplantation genetic diagnosis (PGD), a process whereby embryos created by in vitro fertilization are genetically examined prior to implantation in the womb. They considered penetrance (the likelihood that the genetic abnormality will lead to disease), treatability, and age of onset in their investigation. They decided that a 30-80% risk of developing a condition is significant enough to test (and possibly discard) an embryo. They suggested that any disease requiring 'regular invasive treatment' (such as regular blood transfusions) would be enough to warrant testing (and possible discarding) of an embryo. Lastly, they put no limit on the age of onset before PGD was permissible. This raises the possibility of a pregnancy being terminated for conditions which may never develop, are treatable, or, if they do not develop until adulthood (at least 20 and up to approximately 80 years later), may be treatable by the time they occur. This technology is now available for use in prenatal screening. While many commentators suggest termination is done in the interests of the child (to avoid suffering), as the interval of anticipated disease-free life increases, this is more difficult to justify.

Impact of Termination of Pregnancy

Women whose infants are diagnosed with a congenital anomaly can experience an emotional crisis.[18] Whether the diagnosis is made pre or post-natally, both parents exhibit higher levels of psychological distress than parents of healthy infants with mothers impacted more than fathers.[18] Consideration of termination decisions are difficult and can entail ambivalence between commitment to the pregnancy and

the desire to protect the child, themselves, and their families from the burden of disability.[35]

Elective abortion for fetal abnormality in a wanted pregnancy is quite different from termination of an unwanted pregnancy. It represents the loss of future hopes and entails the risk of severe and complicated grieving.[36] A significant proportion of women undergoing termination for fetal abnormality can experience pathological levels of distress.[37] Korenromp and colleagues found that four months after termination, 46% of their sample of Dutch women showed pathological levels of posttraumatic stress symptoms, decreasing to 20.5% after 16 months. 28% of women were depressed, falling to 13% after 16 months. Strong feelings of regret for the decision were mentioned by only 2.7% of women, yet over one in five women had significant psychological distress that persisted for over a year.[38]

These reactions were more complicated when they were not anticipated. Research indicates that women are often ill-prepared for bad news about the health of their unborn child if pathology is found on prenatal screening, as they had not been given adequate information about the purpose of the test and the choices with which they may be faced.[39] The long-term posttraumatic stress response and grief can continue long-term[40] and causes psychological distress comparable to the experience of having a stillborn child.[41]

France and colleagues found that it was common for couples to conceal the nature of their pregnancy loss from many people in their social network, noting that they were not given information on how to go about disclosing their decision.[38,42] Reasons for limited disclosure included guilt over the decision and the desire to avoid being judged. Some reasons for disclosure were practical, such as needing time off work or physical help and/or emotional support during diagnosis and termination. While disclosure could lead to getting more support and less criticism than expected, it could also provoke disapproval. This could lead to less support overall. Some men said they found it hard to access emotional support from their social networks because of expectations about how men "should" deal with emotions.[43]

Furthermore, there is concern that even when prenatal screening is not undertaken with a view to possible termination of imperfect children, parents may wait for the birth with increasing anxiety and distress, wondering how their child measures up, instead of learning to love their baby unconditionally.[44] More research is needed to understand the long-term implications of this experience, but the assumption that early detection and termination for fetal anomaly is beneficial for women has been questioned, calling for greater attention to be paid to the psychological sequelae.[30,45,46]

Discrimination

Opting against termination of pregnancy after the diagnosis of fetal anomaly—while against the trend—is not an irrational decision. Emotional and psychological trauma aside, some women do not consider a congenital anomaly to be grounds for abortion and think that a society without persons with a disability would be a poorer place.[47-49] The introduction of routine prenatal diagnosis has resulted in a significant fall in the birth prevalence of children with congenital anomalies, due to the high rate of pregnancy terminations.[50] Disability groups fear that when physicians encourage the abortion of fetuses with diseases or disabilities, they are fostering intolerance

of disabled people who have already been born.[43] In one study of seventy-three parents-to-be undergoing prenatal screening, 30% said they thought screening might encourage negative attitudes toward the disabled, and 50% thought that mothers of children with a disability would be blamed for their failure to undergo screening or have abortions.[51,52] And they were right.

Women who chose not to have prenatal testing or who chose to continue a pregnancy after a prenatal diagnosis have experienced discrimination. Some have felt pressured to have diagnostic tests after screening positive[53] or felt that their obstetrician was pressuring them to terminate a pregnancy by providing aggressively directive, erroneous, and highly negative information.[54] The California Prenatal Screening Program described pregnancies that are continued as "missed opportunities,"[30] indicating the political interest in reducing the number of individuals with disabilities born into the community. Health insurance companies have been known to refuse to cover newborns unless the mother underwent prenatal testing and agreed to terminate the pregnancy if the fetus was affected.[55] These developments represent social and economic coercion to limit reproductive choice.[56]

Much has been written on the ways disability has been socially constructed. Writers such as Wendell have pointed out that it is not the impairment itself which causes disability so much as society's reluctance to accommodate it.[57] Furthermore, lack of assistance needed by people with disabilities to function effectively contributes to their "handicap" status. It appears that the discourse surrounding prenatal screening has adopted the social construction of disability, rather than allowing each woman to think through the implications of personally having a child with disability in her own family.

True Freedom of Choice

One can construe the directive that all pregnant women need to be informed of the availability of antenatal screening as a positive educative step, but it will not help women if their information needs are disregarded. It will not empower women if there are unwritten rules to the game that they cannot ignore. True freedom of choice would have counselling that is accurate and non-coercive with adequate government support for those caring for children with a disability, making the option of continuing a high-risk pregnancy a real one for all women. Women need to be free to make their own decisions in line with their own values with no pressure from the medical system or society regarding which is the "correct" decision.

But it is difficult to see how this will happen. Lippman comments on the cultural climate whereby all pregnancies are designated some level of "risk,"[58] thereby allowing medicine to reconstruct the experience of pregnancy, one that involves medical supervision to manage this "risk." She further notes that if the purpose of quantifying risk is meant to reassure the pregnant woman, why is it in the area of congenital abnormality that this reassurance is given? More babies are born underweight and premature than with genetic anomalies. Why not ensure appropriate nutrition for pregnant women? Why not ensure adequate and accessible prenatal care for all pregnancies? Why is genetic testing more reassuring than provision of resources needed to cope with a disabled child once it is born? Why has so much fear been generated in the community regarding the possible birth of a child with Down

syndrome, which is responsible for only a minority of cases of mild to moderate intellectual disability, except that we have a test to detect—and therefore eliminate—it?

Rothman correctly predicted that with genetic abortion reducing the incidence of genetic disease, the impetus to find cures for these conditions would be reduced.[56] Consider the amount of time and money now spent in identifying and terminating fetuses with disabilities. Neuroscientist Dr. Alberto Costa, who conducts trials involving ways to improve memory in Down syndrome, has noticed a reduction in available research funding since NIPT has been in development. "The geneticists expect Down syndrome to disappear," he says, "so why fund treatments?"[59]

It could also be hypothesized that with a reduced number of disabled children being born, the pressure on women to screen and abort will increase as the familiarity and tolerance of disability in our society have been reduced. Inherent in all these arguments for prenatal screening is the idea that some lives are not worth living. You could say that simply existing is in the created child's best interests, as life is a basic good. But the argument we are hearing now is that it is only good if you are normal, healthy, and wanted by your parents.

Conclusion

The introduction of antenatal screening was done in the name of choice and the name of freedom. However, in reality, this has not necessarily been the case, as the "choices" have been constrained in real terms. As time goes on, the pressure to screen pregnancies and avoid burdening society with our disabled offspring is building. Healthy women are being subjected to tests, some of which post distinct risks to themselves and their children. This highly medicalized version of reproduction is seeing informed consent eroded to the point where there is actual coercion regarding these tests and procedures. If this is reproductive freedom, the victory was a hollow one, as the obligation to serve society's "best interests" grows greater and the liberty to opt out steadily decreases. Urgent community discussion of this process is therefore recommended to increase transparency of antenatal screening programs and reduce further harm to the women and offspring involved.

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