ORIGINAL ARTICLE

Is there an ethical difference between preimplantation genetic diagnosis and abortion?

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J Med Ethics 2003;**29**:90–92

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Revised version received 4 June 2002
Accepted for publication 2 July 2002

When a person at risk of having a child with a genetic illness or disease wishes to have an unaffected child, this can involve difficult choices. If the pregnancy is established by sexual intercourse, the fetus can be tested early in pregnancy, and if affected a decision can be made to abort in the hope that a future pregnancy with an unaffected fetus ensures. Alternatively, preimplantation genetic diagnosis (PGD) can be used after in vitro fertilisation (IVF) to select and implant an unaffected embryo that hopefully will proceed to term and produce a healthy baby. We are aware that many individuals at risk regard the latter as ethically more acceptable than the former, and examine whether there is an ethical difference between these options. We conclude that PGD and implantation of an unaffected embryo is a more acceptable choice ethically than prenatal diagnosis (PND) followed by abortion for the following reasons:
(1) Choice after PGD is seen as ethically neutral because a positive result ("a healthy pregnancy") balances a negative result ("the destruction of the affected embryo") simultaneously (assuming the pregnancy proceeds to full term and a healthy baby is born). While there is usually the intention to establish a healthy pregnancy after an abortion, this is not simultaneous;
(2) A woman sees abortion as a personal physical violation of her integrity, and as the pregnancy proceeds she increasingly identifies with and gives ethical status to the embryo/fetus as it develops in utero and not in the laboratory;
(3) Many people see aborting a fetus as "killing", whereas in the case of PGD the spare embryos are "allowed to die". We argue that this difference of opinion gives further weight to our conclusion, but note that this has been addressed and debated at length by others.

Most countries accept termination of pregnancy as one acceptable choice when a conceptus (embryo or fetus) is shown to be affected by a serious medical condition, whether inherited or acquired. This practice is explicitly legal in some states in Australia and in most European countries, and is separate in law from any general right of a woman to determine whether a pregnancy can be terminated (as in the United States). There is growing concern, both on the part of "disability activists" and the community, as to whether this practice is unethical because it implies discrimination against those with disability, especially those with the disability that is being tested for.

During a recent meeting on ethics and genetics in Melbourne, a discussion of prenatal diagnosis (PND) for achondroplasia (a dwarfing condition where there is no intellectual disability, moderate to severe skeletal problems, and mild to moderate social stigma) led to a discussion of alternative technologies. Prenatal diagnosis for achondroplasia, as for most single gene disorders, can be offered to families known to be at risk either by DNA analysis of chorionic villi sampled early in an established pregnancy, or by DNA analysis of one cell from an eight cell embryo (preimplantation genetic diagnosis, or PGD). If the latter method is used, only unaffected embryos are implanted in the womb, and any resulting pregnancy will be unaffected by achondroplasia.

POSSIBLE TIMING OF PRENATAL DIAGNOSIS

Tests on an embryo or fetus can be carried out at different times, depending on technical resources and the nature of the disorder, including prefertilisation, preimplantation, at 10 to 14 weeks by chorionic villus sampling (CVS), between 10 and 20 weeks by ultrasound and/or maternal serum screening, by amniocentesis at more than 15 weeks, or by *x* ray. We will consider two of the options available in Melbourne for single gene disorders, DNA testing of an embryo after IVF (following which an embryo that is genetically shown to be unaffected is implanted) or DNA testing by chorionic villus sampling at 10 to 12 weeks (following which an affected fetus can be aborted). These are, in our experience, the major options offered to and considered by couples wishing to avoid the birth of a child with a genetic handicap.

THE NATURE OF THE DILEMMA

At the Melbourne meeting, the point was made by Dr Tom Shakespeare, an academic sociologist who has achondroplasia, that he has fewer problems with choice of an embryo unaffected by achondroplasia for implantation after IVF than he does with diagnosis and termination early in pregnancy. This is also the position taken by women who had experienced IVF for infertility reasons or who are at high risk of having an affected embryo due to a single gene disorder.[1] In the recent experience of Genetic Health Services Victoria, couples at one in four risk of having a child with a serious inherited disease will often choose IVF followed by PGD, rather than abortion following CVS.

Both IVF and termination during first trimester are invasive procedures. If "life begins at fertilisation", then IVF and abortion equally involve the "killing" of a fetus (or "allowing embryos to die" which may be viewed as "killing").[2] Both involve selection against handicap. Why is there an ethical difference in how individuals view PGD as compared to abortion following CVS?

THE ETHICS OF TERMINATION OF PREGNANCY BECAUSE A FETUS IS AFFECTED BY A GENETIC DISABILITY

The avoidance of the birth of a child who would be affected by a serious disability was one of the justifications for the

introduction of access to abortion during the 1970s, when PND first became available. Some disability activists now argue, however, that the use of PND in this way discriminates against people with disabilities for various reasons, including their lives not being valued as equal to those people who do not have a disability. The International Sub-Committee of the British Council of Disabled People, in a statement on "the new genetics", points out that there are far more persons with disability due to environmental causes such as traffic accidents and accidents at work than due to genetic disorders.[3] They argue that free choice can only exist in the context of a society that does not discriminate against individuals with a disability, and that supporting the right of choice for termination requires an equal commitment to supporting the rights of the disabled.[3]

It should be noted, however, that society does not condone or encourage disability in environmental contexts; indeed, society spends significant resources (financial, educational, and otherwise) trying to prevent such accidents from happening. As an example, resources aimed at reducing road accidents, including media campaigns and police resources, are significant. This allocation of resources would not be regarded as discriminatory. It has been equally strongly argued that the decision to terminate an "affected pregnancy" does not make a discriminatory statement against the disabled. Women who request an abortion on such grounds do so because "they cannot, for whatever reason, take on the care of that particular kind of child at that time".[4] As Furedi points out, the harm of the notion of forcing a woman to have and raise a child against her will far outweighs the harm of abortion.[4] A distinction needs to be made between disability and people with disabilities. In making the decision to abort, parents are not "saying that life with a genetic disorder is not worth living . . ." and they "do not see themselves as making a moral judgment about the worth or rights of people living with that genetic condition".[5]

THE ETHICS OF SELECTION OF IVF EMBRYOS

As with abortion, some disability activists believe it is discriminatory to select an embryo that does not have an "affected gene". Other ethicists argue that if an informed choice can be made, the mother (or the parents) has a moral obligation to select an embryo without a disabling gene. It can be argued that given a choice between several possible children, the child to be born should be the one with the chance for the best possible life. Savulescu states that: "selection for non-disease genes which significantly impact on well-being is morally required." He believes that mothers/parents should be given all available test results followed by non-coercive advice as to which child will have the opportunity of having the best possible life, and argues that it is the parents' decision which embryo to select.[6]

In relation to discrimination, the same arguments apply as for abortion. As Savulescu points out, a distinction needs to be made between disability and people living with a disability. "Selection reduces the former but is silent on the latter."[6] He suggests that savings from selection against affected embryos could be used to improve the well being of people with disabilities.[6]

THE MORAL STATUS OF THE EMBRYO

All human life deserves respect, although in law this respect is reserved for a child after birth; the embryo and fetus have no legal status, at least before viability, in most jurisdictions. This respect is not normally accorded in the same way to human skin or blood cells in culture, or human sperm or eggs prior to fertilisation. While there is no agreement on "when human life begins", key events occur at fertilisation of the egg by the sperm, at implantation of the embryo in the uterus (about eight days), and at the point when a developing nervous system can be detected (about fourteen days). More than half of the total number of embryos (eggs fertilised by sperm) spontaneously abort, however, and pregnancies are not regarded as established clinically until the end of the first trimester (thirteen weeks). Traditionally, most women increase their identification with an embryo as pregnancy progresses, giving full respect to its individuality after quickening (about 15–18 weeks of pregnancy) when they begin to feel fetal movements.

THE IMPACT OF SCANNING

Until recently the pregnant woman had no way to confirm her pregnancy until quickening. With modern ultrasound equipment the fetus can now be monitored almost from conception, and many illnesses and abnormalities can be detected early. The fetus is visualised and is seen as an active individual to be, "a complex responsive organism interacting actively with its intrauterine environment".[7] This is one reason why both pregnant women and health care professionals are more reluctant than previously to offer the option of abortion at later stages of pregnancy. The availability of scanning early in pregnancy results in pregnant women identifying with the embryo and giving it individual moral status earlier. It also puts pressure on women to make an earlier choice on whether to end a pregnancy that will result in disability. This may, in part, explain why women who are at risk of having a child with an inherited genetic disability prefer PGD to CVS.[1]

THE SIGNIFICANCE OF TIMING

Once having made a decision to have a child, the woman (or the parents) becomes conscious of time in a number of ways. Initially she is anxious to establish a healthy pregnancy, as soon as possible. This is not always possible, particularly in the context of genetic risk.

When a woman (or couple) is at risk of having a child with a genetic illness, choosing PGD ensures the woman has an embryo unaffected by the genetic illness implanted in her womb from the beginning of the pregnancy. Prenatal genetic diagnosis therefore eliminates the anxiety experienced during the first weeks of a pregnancy established by sexual intercourse, before CVS could be performed, even if the pregnancy is unaffected and proceeds to term.

THE DISTINCTION BETWEEN PGD AND CVS/ABORTION

(a)In each case, the intention is to allow the birth of a healthy child. In the case of a dominant disorder such as achondroplasia, one of the parents is affected by the disorder (unless penetrance is highly variable, which is not the case for achondroplasia). Making a choice to terminate an affected pregnancy may be seen as a very personal issue for the affected parent and his/her partner. Termination of pregnancy in the first trimester is usually perceived as a procedure involving the killing of a living fetus in utero.

(b) In most cases where a pregnancy is terminated during the first trimester because the fetus is affected by a serious inherited disease, the couple conceive again within a year. They continue to conceive (using PND for each pregnancy) until they achieve the number of healthy children desired.

(c) If diagnosis is by CVS at approximately ten weeks, however, followed by termination of an affected pregnancy, there is a temporal difference between the termination and the establishment of a successful unaffected pregnancy. Even if a successful unaffected pregnancy results, as it often does, this occurs later than and independent of the terminated pregnancy. We believe that for many people this would be thought of as "killing".

(d) If diagnosis takes place by embryo biopsy after IVF, several equivalent embryos are tested simultaneously. Some will be affected, some will not. A choice is made to implant some that will give children who are not affected. The others are discarded. The decision to choose an unaffected embryo is made simultaneously with the decision not to choose an affected embryo. There is both a decision to "let live" and a decision to "let die".

(e) When the eight cell embryo is in culture, it has not acquired the additional respect and emotional attachment associated with implantation, growth or ultrasound visualisation. The embryo is still in the charge of a laboratory, and decisions that are taken do not involve the mother in a physical process where she participates in termination of pregnancy. An eight cell embryo can be regarded as a "possible life", similar to an egg and sperm or a human skin cell, while a ten week embryo in utero has more status, perhaps equivalent to a "developing life" with greater realised potential.

We suggest that the major ethical distinction between these two cases is the fact that creating an unaffected and presumably more healthy fetus (and ultimately child) is made simultaneously with the decision to allow the affected embryo to die. In this decision positives balance negatives. This compares with a decision to terminate a ten week embryo following CVS, which can be regarded as "killing" rather than "letting die" and which has no intrinsic balance at the time (although this balance may be restored if there is a later successful unaffected pregnancy).

A second difference relates to the increasing status and attachment that a woman gives to an embryo in utero as it develops, as against an embryo in a laboratory. Although the couple participate in the decision as to how the laboratory staff will treat an unused IVF embryo, the laboratory staff carry out these decisions without direct participation by the woman or her partner. When invasive procedures are performed at 10 to 12 weeks, the woman is intimately involved.

What we find most interesting in this scenario is that the ethical decisions taken are far closer to an ad hoc, relativist, and utilitarian model than one based on any of religious codes, scientific knowledge, consistency in the view of the status of the embryo, or a rigid view of the value of someone with a disability. The ethics of prenatal testing change with the technology available, at least from the point of view of the couple at risk of having a child who will be severely affected.

ACKNOWLEDGEMENTS

The authors thank Agnes Bankier, Caroline Bowditch, David McCarthy, and Julian Savulescu for helpful criticisms.

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