

Should we limit the conditions for which genetic tests are permitted?

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Series Editor

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There is much concern about the increasing number of genetic tests becoming available, both to detect specific conditions and to determine the carrier status of fetuses. Should the use of genetic testing in these ways be restricted, and if so, how?



An Australian High Court judge, Justice Michael Kirby, recently expressed concern at an ethics meeting in Brisbane about the increasing number of genetic tests becoming available and the possibility that parents will use them to choose the type of children they have.¹ He reportedly referred to fetuses being aborted after a prenatal genetic test because they have genes for conditions such as schizophrenia, early baldness or homosexuality and said that we should consider whether new laws are needed to limit the conditions for which genetic tests are permitted.

Dr Robert Boyle, a Melbourne geneticist, raised similar issues at an ethics seminar at the Murdoch Institute in Melbourne a month later (16 July 2001). In particular, he asked whether genetic testing should be permitted to determine carrier status of a fetus *in utero*. In some cases, a carrier will be detected when testing for an affected fetus – this is the case with fragile X syndrome, for example.

However, if parents request a genetic test for haemophilia on a fetus known to be female, they want to know whether the fetus is a carrier because only male children actually suffer from the disease. Carriers generally have no illness, but they do, of course, have the same risk of passing on the disorder as their carrier parent. The parents may want the test to eradicate the genetic disorder from the family, or to save the child from having to make a similar decision about prenatal genetic testing and possible termination of a pregnancy. Should this type of genetic testing be prohibited – and, if so, how should the prohibition be achieved?

Limitations of genetic testing

Genetic testing is limited in what it can achieve. At present, the number of genetic tests that can be performed is low, but the number is likely to increase as technology improves. Also, it will be possible to detect more genetic abnormalities

when we find out about their association with physical conditions.

This does not mean that parents will then be able to choose the type of child they want. As more tests become available, the odds of having a fetus with desired traits will go down as an exponential function of the number of traits tested for, especially as many complex characteristics are influenced by many different genes. (This argument was put to me by Professor John Mattick, Director of the Australian Genome Research Facility and the ARC Special Research Centre for Functional and Applied Genomics, and Co-Director of the Institute for Molecular Bioscience at the University of Queensland. I also acknowledge Professor Mattick's contribution to other arguments in this article.) A long list of desired characteristics is simply impractical. At most, it will be possible to test for only a few of them and parents will naturally choose the ones that seem to them most significant, particularly characteristics causing early death or serious injury or suffering.

Termination of pregnancy

Parents do not make the decision to terminate pregnancies lightly. This is always a

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very difficult decision. Experience indicates that many parents will choose to continue a pregnancy despite significant disorders, such as cleft lip and palate. Also, many genetic abnormalities are not detectable until the pregnancy is well advanced, perhaps at 15 or 16 weeks' gestation. This, in itself, is a real disincentive to termination – the fetus is a baby and others will be aware of the pregnancy.

Community support of parents

The community generally supports parents making decisions for their children. Parents have to make many decisions about the future of their children, often at great personal cost or sacrifice. They do everything possible to maximise their child's happiness and to give the child a good start in life. The community usually trusts parents to act in their children's best interests and is reluctant to interfere. Is a parent's beneficent decision to save a future child the agonising experience of prenatal testing, and possible termination of pregnancy, so different from a decision to circumcise a male infant or to undertake cosmetic surgery to remove a birthmark?

Legality of abortion

Australians are relatively free to terminate pregnancies for reasons far short of fetal carrier status. Abortion is still unlawful in most Australian jurisdictions unless there is a serious risk to the mother's life or physical or mental health. However, this has been liberally interpreted and there are now between 80,000 and 100,000 terminations in Australia every year. Only about 1% of these are carried out because of genetic disorders. Many people strongly disapprove of abortion, but many more condone it. If we countenance laws that, in practical terms, allow people to terminate pregnancies for less cogent reasons, surely we should not prevent them from terminating for genetic reasons even if they fall short of a serious disorder.

Which genetic tests should be allowed?

It will be very difficult to distinguish which genetic tests should be permitted and which barred and how this should be implemented. Most people in the community probably support prenatal genetic testing to detect serious genetic abnormalities that cause early death or severe pain and suffering. This support may increase if a test is possible before implantation, so it is not necessary to terminate a pregnancy.

However, as the disorder becomes less serious, community support for the testing and possible termination is reduced. Tests for Down syndrome or cystic fibrosis may be readily acceptable; tests for cleft lip and palate may possibly be supported although these conditions can be alleviated by surgery; and tests for carrier status may be refused. But how will we determine where on this spectrum to place the tests for many other factors that will become available in the future? Who is to decide?

Concluding remarks

Making and enforcing laws concerning genetic testing and the terminating of pregnancies for genetic reasons will be problematic. What if doctors and parents seek tests abroad and then obtain terminations for traditional reasons? Surely it is better at the moment to leave the decisions to individual doctors and parents, especially given the small number of genetic tests and subsequent terminations that presently occur in practice.

Series Editor's comment

The principle of aborting a fetus with characteristics assessed as incompatible with 'normal' life has already been established – what is now being debated is the extent of application of that principle. For example, screening of the 'elderly' gravid patient to see if the fetus has Down syndrome is now routine. Why screen if not to give the mother the

option of terminating the pregnancy? But there are some in the community who would argue for the right of Down syndrome children to live. Further, in some countries, infanticide of children with 'undesirable' characteristics is reportedly common – even when the characteristic is simply the child's sex.

We live in a society polarised between two extremes – on the one hand there are those who hold that all life is sacred and is to be protected at all costs, and on the other there are those who see life as discretionary. As citizens, we are entitled to have a personal view. As doctors, we have to be very careful that we do not allow our new techniques and technologies to run ahead of the community's ability to understand the implications, and to form a view on them. The process of development of public policy may seem frustratingly slow, inefficient and overly influenced by squeaky hinges, but if we run ahead of it, we do so at our own risk.

There is a tendency to think that once a genie is out of the bottle it is impossible to control it. Many still fear that because mass annihilation by a nuclear holocaust is now possible, it will inevitably happen. But 50 years after the first atomic explosion we are still here. Perhaps the same fears were expressed when the bow and arrow were first introduced into warfare.

As ever, the balance is between private autonomy and public policy – between private and public morality. Individual doctors deal with patients one by one, and hence may become so focused on the individual that they lose sight of the bigger picture. Yes, it is our role to be medical advocates for our patients, but we also have a broader duty to society. This encompasses both advising society on new techniques and technologies and waiting for society to tell us how and if they want them applied. MT

Reference

1. Paul Osborne, Brisbane, AAP 25 June 2001.