

Record

308

File Number

10275

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Title: Ethics: Genetic counselling

Original source: Interaction Volume 6 Number 2 1992/1993

Resource type: Written

Publication Date: 1/1/1993

Publisher Info: NCID

Abstract

This brief paper discusses the ethics of selective abortion and raises some of the issues which should be thought about, such as doctors, the media and society promoting the view that "imperfect products should be discarded". Prospective mothers are often presented with no other option but termination. In addition, the support required so that parents can cope and adjust to the knowledge that their child has a disability, is lacking.

Keywords: Ethics, Women

ETHICS

Genetic Counselling

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*Paper presented at the IASSMD
Conference, Gold Coast, August 1992*

Defective foetus are aborted every year in Australia. No one knows exactly how many, and only South Australia requires the figures to be declared. Estimates put the figures in the hundreds.

Abortion is one of the most controversial issues in the Western world. It can provoke bitter debate, providing grist for political campaigns and an anguished dispute with families. In particular, devout people of all Christian denominations, for whom religion is important, tend to oppose abortion.

In Western countries (Britain, the United States and Australia), most people would allow abortion when the child would have a serious birth defect. In a study into Australian attitudes published in 1984, Kelley and Evans found that 70% of Australians answered "definitely yes"; 4% said "probably no" and the rest, 10%, said "definitely no".

It should be mentioned here that public opinion has swung strongly in favour of such abortions since the late 1960s when a bare majority would allow them. Now only 8% of Australians are definitely against

abortion in any circumstance, with 22% mostly against it.

In answer to the question, "Do you think it should be possible for a pregnant woman to obtain a legal abortion if she is not married and does not want to marry the man?", 40% of Australians answered "definitely yes"; when asked whether a legal abortion should be allowed if the baby might be defective; a further 20% said, "probably yes"; 10% said "probably no"; and the rest, 30% said "definitely no".

When comparing these figures, the 30% difference indicates that, regardless of attitudes to abortion in general, broad agreement exists that where "in such devastating circumstances as a serious defect, the decision about abortion should be up to the individual". This, of course, raises the question of "What is a serious defect?" and whether this is being left up to the individual.

The question, "Is the decision being left up to the individual?", is easier to answer. From my experience, parents frequently feel that they are strongly directed in their decision, even to the extent that the choice is not theirs.

Some doctors believe that, if women are prepared to undergo an amniocentesis test, they must also be prepared to have an abortion, otherwise there would have been no point in taking the additional risk to the pregnancy which accompanies the test. Several women who have

spoken about this feel that the risk is not great and, for their peace of mind, they would rather know than not know.

The point has also been made that, although you can discuss the possible options at an hypothetical level, when you are faced with such a decision in real life, it can affect you differently. We therefore need to respect an individual's right to reconsider her options.

Last year, in one major teaching hospital, 40 babies with a disability were aborted. Few of the parents of these babies knew any more than a medical diagnosis and so made their decision to abort on the doctor's advice. Too many doctors are keeping patients in ignorance and effectively making judgments for them.

Some doctors have become locked into the ethic of a disposable society, where by child-bearing is a production line from which the imperfect products are discarded. Society and the media often reinforce this view.

These attitudes reflect the fact that having a child with a disability has far more to do with in society than with the disability itself. People with disabilities still face a hostile cultural environment shaped by discriminatory practices and attitudes.

To quote from the National Health & Medical Research Council's "The Ethics of Limiting Life-Sustaining Treatment": The arrival of a child with severe birth defects is always a tragedy for the parents and often for other family members. This quotation, taken from Bailey's recent book, *Human Rights: Australia in an International*

Context, is "indicative of dominant social attitudes which see disability as involving an inherent tragedy, rather than seeing the tragedy lying in the handicapped situations which people with disabilities face in society".

Child-bearing is a production line from which the imperfect products are discarded

To quote from Christopher Newell's critical Evaluation of the NH & MRC's "The Ethics of Limiting Life-Sustaining Treatment and Related Perspectives on the Bioethics of Disability": the NH & MRC's paper takes as a major premise a common view in society, which is perpetuated by the media, that having a disability inherently predisposes one to a life of low quality and value. Christopher Newell maintains that, "It is the lack of provision of necessary personal care services which provides the tragedy to be found within the incidence of disability in the community".

Too many doctors are keeping patients in ignorance and effectively making judgments for them

What role should a doctor play in giving advice in such a medically and ethically complex area? How should parents act when uncertainties are raised by chromosome analysis, particularly when it is difficult to predict from limited results what a child will actually be like?

Bioethics is a complex area attracting a wide range of opinion and is beyond the role of an

untrained doctor. Two of the major dilemmas for doctors working in prenatal diagnosis are striking a balance between full disclosure of information and causing inappropriate parental anxiety. Trained genetic counsellors advocate non-directive counselling; where results, risks and options should be presented as objectively as possible.

However, our experience indicates that the practice in the field is very different, particularly when the general practitioner is seen as the expert, and offers no discussion on the subject other than, "Don't worry about it. I can arrange an abortion for you next week".

This very mechanistic view results from the fact that the development of technology has outstripped the intellectual capacity of the medical profession to use the technology ethically. It also reflects a patronising view which many practitioners have toward their clients. They hold that it is best not to confuse ordinary people with too much detail.

Not so long ago the common advice given to parents after the birth of a child with a disability was to "forget this one" or "go home and start again". In fact, I still hear of instances where similar advice is being given. This approach looks only at the 'designer baby' or 'perfect product' and not at the overall quality of life of the child. I would suggest that there may be many designer babies in the world today, but there are no 'perfect products' - just ask any parent of a teenager!

The training of doctors needs to involve a greater emphasis on the ethical implications of the new

technology that they have at their fingertips.

It is time to abandon the cult of perfection and concentrate on allowing all people to develop to the limit of their ability. Genetic counselling must not just look at genetics but should seriously look at the situation of the whole child within the family setting. Parents cannot fully understand all the medical and long-term implications of such a diagnosis and are very vulnerable to external pressures during this traumatic period.

Messages given by doctors, counsellors and others are not value-free, but in fairness to the family it is important that information should be factual and that alternative options should be presented simply and honestly.

The fact that prospective mothers are often presented with no other option but termination does not consider the 14% of the population who oppose abortion in this situation. As a matter of principle, pressure groups or single-minded professionals should not be forcing people into making decisions with which they do not feel comfortable. Most importantly, parents should be supported in order that they can cope and adjust to information which can be quite emotionally burdensome.

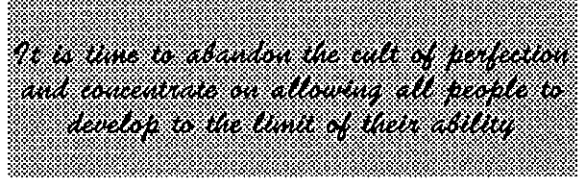
Parents' reactions to devastating news varies from denial, anger, guilt, frustration and self-pity. In this state, they cannot absorb all the news that they are hearing. Often they will only hear selected pieces of information. For these reasons they need continued support to help them reach a decision with which they can live.

In a study released last Sunday in the latest Australian Medical Association Journal, a study on low-birth weight neonates carried out in the 1980s shows that the survival rate has jumped from 52% to 80%. The number of low-birth neonates with severe disabilities has dropped from 13% to 4% over that period. The researcher contributed these figures to better medical practice and better educational and community support practices.

I mention this to illustrate how quickly progress has occurred in

this area. It is a pity that we have not managed to make the same progress in changing community and medical attitudes towards people with intellectual disabilities.

(References available on request)



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