

Ethical aspects of screening and diagnosing chromosomal and other abnormalities in the second trimester



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In this article I hope to encourage you to think about the ethics of your obstetric practice. I am not attempting to present the answer, but rather promote reflective thought. It is important that we, as members of the medical profession, act in an ethical manner in all of our practice.

However, in most situations there is no close ethical check on our practice and it is our own personal conscience which will determine how we act. In many areas there is no real debate as to what is appropriate ethically. When there are questions of what is ethically appropriate, it is useful to have thought about the issues beforehand. In screening and diagnosing chromosomal

and other abnormalities in the second trimester, there can be considerable difference of opinion as to what is ethical.

The second trimester covers the period from 14 to 26 weeks gestation when there is a huge change in the fetus. With current neonatal care available in Australia, the pregnancy develops from being non-viable into not only being viable by the end of the second trimester, but a baby born in a tertiary hospital in Australia in good condition, who would be likely to survive with a reasonable quality of life.

Screening tests in the second trimester include tests such as the triple test and the anatomy ultrasound. These can be followed up as necessary by diagnostic tests such as an amniocentesis. I do not propose to discuss specific screening programs or diagnostic tests here.

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Ethics can be said to be about 'what ought to be', a sense of what is right. Acting ethically involves acting in a morally correct manner. Deciding what is morally correct can be based on religious or secular beliefs and different people can reach different conclusions depending on their underlying beliefs. There is no way to definitely prove what the correct answer is.¹

In order to be able to decide on what the ethical approach is to a clinical situation you face, it is necessary to have a framework on which to base decisions. Unfortunately, this is not as simple as it sounds. There are several different ethical principles that can

be used to decide what is ethical, such as autonomy, beneficence and nonmaleficence, utilitarianism and justice.^{2,3} These different principles can lead to different conclusions as to what the ethical action is in some circumstances.

Autonomy literally means self-rule, as used in ethics it means that the individual is free to choose for themselves between different options. In the medical situation, this requires providing the patient with the information to enable them to make a decision. Hence, it is this ethical principle which supports the practice of informed consent. Respect for patient autonomy is what underlies the concept of the patient choosing whether or not to undergo a treatment.

Beneficence is doing or producing good and nonmaleficence is doing no harm or injury. They are slightly different, but for most purposes can be considered together. I think most of us would accept these principles as a basis of good medical practice. The basic tenant of 'first do no harm' is covered by this ethical principle.

The utilitarian approach means achieving the greatest good for the greatest number. In many cases, this principle will result in a different conclusion from the principle of autonomy.

Justice is a much more difficult issue. It involves giving what is due. In the medical setting, this is complicated by the need to allocate limited resources. Superficially, the principle of justice may be thought of as people in similar circumstances being offered similar treatment.³

I would like to highlight the ethical issues in two situations. The first ethical issue is whether a screening test should be undertaken. The principle of autonomy holds that the pregnant woman should decide. Does she want to have the test? There may be a number of possible reasons she does not want the test ranging from needle phobia to not wanting to know the result of the test. For example, a woman who has decided that she would not terminate her pregnancy for Down syndrome may not wish to have the triple test because it may cause a lot of unnecessary stress and worry. (If a screening test is undertaken and it comes back as a high risk of Down syndrome – say one in 100 – there is still a 99 per cent chance that there is no genetic abnormality, that is, in the case of a positive result the test is likely to be harmful to the woman.) To undertake a screening test of this nature without the informed consent of the mother is, in my view, paternalistic and very difficult to justify as ethical practice. Unfortunately, it can be considered to be a 'basic blood test' for pregnancy and can be ordered without

explanation along with other tests. The increased take-up of the first trimester screening for Down syndrome is helping to address this issue, as it is far harder for the busy doctor to order an ultrasound and blood test without explaining why it is being undertaken.

The second ethical issue I would like to highlight is more complex. It really relates to the moral standing of the fetus.¹ There are very strongly held conflicting views on this. If you consider that the fetus has rights, then deciding between the relative importance of the mother and the fetus in the ethical considerations is difficult. (If, on the other hand, you consider the rights of the fetus are completely subservient to those of the mother, then the ethical problem is simple.)

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In any decision relating to testing for abnormalities, the decision on whether to undertake a test is inextricably linked with what actions will follow from the results. Many of the pregnancies which are found to have a chromosomal or other abnormality are aborted. This is not always the case and sometimes identifying an abnormality results in the delivery occurring at a tertiary centre where appropriate neonatal care is readily available. The interests of the fetus in the latter case would clearly be to undertake the test.

The law provides a limit to how one can practice medicine. However, legal is not the same as ethical. The law can vary from jurisdiction to jurisdiction (for example, the law on termination of pregnancy). The law enacted in any one jurisdiction is a result of many influences on the law makers, for example, local history, religious beliefs, community norms, the action of pressure groups, etc. Thus the law cannot be used as a guide for what is ethical, as it is not consistent with the concept that ethics is about 'what ought to be'.

The real difficulty comes when one tries to decide what is best for the fetus if an abnormality is found. How do you evaluate quality of life and the effect of a disability on the rest of the family? Is there a difference if the fetus is viable? Who is the best person to make a decision for the fetus?

I believe each of us has to consider and answer the question as to what the ethical approach is. We should also accept that there will be others who have given the issue just as much careful thought, but because they have a different set of values, they may have reached a different conclusion. It is impossible to prove who is right.

References

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