Practitioner perceptions of ethical issues in antenatal screening and testing

Associate of King’s College Programme
Department of Theology and Religious Studies
23rd November 2006

Clare Williams
King’s College London

Key Themes

1. Informed choice
   - Non directive approach
   - Information giving
   - Expansion of screening technologies

2. Fetal status
   - Fetal ‘pain’/distress
   - Fetal patienthood

‘Moral’ versus ‘Immoral’ A/N screening

- Voluntary decision and informed choice
- All options should be explained
- Individual decisions driven by personal values
- No overt coercion
- Time for deliberation
- No penalties if people decline terminations

Caplan 2000

Non-directive approach: restrict choice through offer of screening?

Midwife: ‘We have to offer screening because it’s individual choice and it’s there, but also, if you are offering these things, you are in a way implying that it’s better to have the perfect child if you see what I mean’

Manager: ‘I think if screening’s there they’ll have it in most cases, won’t they? They’ll take it, because it gives them that little bit of added reassurance, that little bit of comfort…people take what’s offered’.

Williams et al (2002a) Social Science & Medicine

Difficulties of ‘opting out’

Midwife: ‘I think society deems that everything should be perfect and I think a lot of women feel that if they have a handicapped child, if they didn’t have the screening, it’s almost as if to say, “Well, it’s your fault because you didn’t have screening”’.

Societal attitudes to disability

Midwife: ‘I think we’ve gone down the line where if you do have a child with Down’s, obviously you need extra support, but looking at the resources we’ve got in society, we may not be able to offer that support.’

Williams et al (2002a) Social Science & Medicine

Restriction on choice through the offer of screening?

Non Directive Counselling

Seeing screening as ‘normal’

Midwife: ‘we write pages in the notes about the fact they’ve refused a test, whereas if they have them we write little or nothing, so what are we saying to women? Was that person abnormal because they didn’t want testing, or are we just protecting ourselves?’

Women’s ‘best’ interests

Midwife: ‘You can easily force, not force them but channel them into the decision making process you feel is correct.’

Williams et al (2002a) Social Science & Medicine
Information Giving

How much information is needed?
Obstetrician: ‘the amount of time you’d need to give proper informed consent about what a scan can pick up, what the outcomes would be and what the management of these conditions is, it’s not feasible before you do a routine list…we can’t give patients informed consent’.

When to give information?
Paediatrician: ‘perhaps you need the information before you’re pregnant because when you’re pregnant or when an abnormality is found on the scan, that’s a really difficult time to try and explain the pros and cons of what a cleft palate means, what extra digits mean, the sorts of things you can see now [on scans]…and I worry that some people are making what turn out to be very foolish decisions’.

Expansion of A/N Screening

- Antenatal screening programmes tend to ‘creep’ in (HTA Review, 2000)
- Absorbed under rubric of routine care
- Seen to convey advantages associated with such care
- Consumer ‘demand’, reinforcing ‘need’ for service
- Expanded uses of tests also absorbed
- 70% detection rate; false positive no greater than 5% (NICE 2003)

Informed Choice?

‘Freedom of choice is proclaimed as a basic right, with a great deal of goodwill and good intentions…but on the other hand, there is the momentum of technology, and in gradual steps – albeit at first hardly noticable – the concept of responsibility changes its content; it is being expanded and adapted along with the increasing options of technology’.

‘Do ethics in the age of genetics mean that avoiding the birth of a handicapped child becomes the obligation of today’s responsible citizen?’

Beck-Gernshein, 2000

Fetal Status

1997, RCOG, ‘Fetal Awareness’
The Working Party concludes that it is not possible for the fetus to be aware of events before 26 weeks gestation. Because of the uncertainty that attends estimates of gestational age, it may be appropriate to consider providing some form of fetal analgesia or sedation for major intrauterine procedures performed at or after 24 weeks gestation.

1998, RCOG, ‘Law and Ethics re late TOP’
‘The obstetrician has a duty to protect the fetus from suffering pain in all terminations of pregnancy regardless of gestation…in late terminations for fetal abnormality, or in the interests of the mother, methods must be chosen to avoid the risk of fetal pain’.

1998, BMJ
‘In the 13 years since the 1st annual symposium of ‘The fetus as a patient’, diagnostic skills with fetal disease have improved enormously, but therapeutic approaches remain limited…Arguably, the most significant advance is that most professionals and parents consider the fetus as a separate individual and a potential patient in his or her own right’ (James: 1580)

1999, BJOG 3rd trimester abortion
‘It follows from the arguments we have presented here, based on virtues and ethical principles relevant to the concept of the fetus as a patient, that third trimester abortion should be restricted to pregnancies complicated by fetal anomalies in which either death or absence of cognitive developmental capacity is certain or near certain. Only in these cases should compassion for the pregnant woman be decisive. In all other cases integrity requires that doctors refuse requests for 3rd trimester abortion’. (Chervenak et al: 296)
With the technology of the late 20th C, a fetus is considered to be viable at 24 weeks gestation: after this point therefore the doctor has a duty of beneficence to the fetus, and should show it the intellectually disciplined compassion he affords to adults who are ill.

The fetus is currently treated as though it feels nothing, and is given no analgesia or anaesthesia for potentially painful interventions…given the anatomical evidence, it is possible that the fetus can feel pain from 20 weeks and is caused distress by interventions from as early as 15 or 16 weeks…in the UK, even frogs and fish are required by Act of Parliament to be protected by anaesthesia from possible suffering due to invasive procedures. Why not human beings? (Glover and Fiske)

Doctors cannot be expected to maintain a careful neutrality about whether the fetus survives or is destroyed. Health professionals cannot be expected to maintain an artificial equipoise between the options of life and death. Since Hippocrates, the practice of medicine in the West has always enshrined moral commitments that include a primary orientation to protect vulnerable life. This is one reason why raising the option of late feticide can cause such deep ambiguity and sense of ethical conflict amongst professionals (Wyatt, 2001: 19).

Doctors cannot be expected to maintain a careful neutrality about whether the fetus survives or is destroyed. Health professionals cannot be expected to maintain an artificial equipoise between the options of life and death. Since Hippocrates, the practice of medicine in the West has always enshrined moral commitments that include a primary orientation to protect vulnerable life. This is one reason why raising the option of late feticide can cause such deep ambiguity and sense of ethical conflict amongst professionals (Wyatt, 2001: 19).

Bioethics implicitly deals with uncertainty - fraught questions of value, belief and meaning that are as religious and metaphysical as they are medical and moral. What is life? What is death? When does a life begin? When does it end? What is a person? What is a child?. Is it better not to have been born at all than to have been born with a severe genetic defect? How vigorously should we intervene in the human condition to repair and improve ourselves? And when should we cease and desist? (Fox, 2000: 422).