

Chapter

Dilemmas in current
practice: the fetus

4

Dilemmas in current practice: the fetus

Introduction

- 4.1 In this and the following two chapters we explore more fully dilemmas of decision making in fetal and neonatal medicine. We examine three stages during which decisions take place, beginning in this chapter with those made during pregnancy. In Chapter 5, we consider extremely premature babies born at the borderline of viability (up to 25 weeks and six days of gestation)¹ before turning in Chapter 6 to focus on babies whose condition has stabilised after resuscitation. Looking beyond, to the time if and when a baby leaves hospital, we discuss longer-term implications for healthcare, education and social welfare, which we consider up to early adulthood, in Chapter 7. As well as attempting to set out the issues that arise at each of these four stages, we use examples to develop our analysis of ethical and social issues and to highlight the legal implications.² It is not our intention to take a particular stance in the discussion of each of these examples, but to use the cases to illustrate the nature of the issues that can arise in critical care.
- 4.2 In fetal medicine³, improvements in technology, and greater understanding of how fetal development affects the future health of a child, have changed the way in which pregnancies are managed. Approximately 800,000 women become pregnant in England and Wales each year.⁴ During pregnancy, women are offered a range of tests, scans and screening procedures, often presented as part of a 'care pathway',⁵ which will inform them and the health professionals providing care about their health, the health of the developing baby and the progress of the pregnancy. Although screening will provide reassurance for most pregnant women, more than 35,000 per annum will be told that there is a risk that their unborn baby may have a serious abnormality.⁶ Approximately 5% of pregnant women who have blood tests for fetal abnormality will be asked if they wish to have additional diagnostic testing (see Box 4.1). In about 2% of those who are tested, the presence of a serious fetal abnormality will be confirmed and the woman will be asked how she would like to proceed.⁷ She is likely to want to discuss her options with her partner and perhaps other family members. The timing of routine scans is based on fetal development, which means that a woman may only become aware of a fetal abnormality after 20 weeks of gestation. She may need further time to consider the best course of action in her circumstances. Most commonly, the choices will be

¹ By convention, the number of weeks of gestation refers to the period from the first to the last day of that week. For example 'at 23 weeks' means from 23 weeks, 0 days to 23 weeks and six days of gestation (161–167 days of gestation).

² We use examples that are representative of what occurs in hospital. They are not based on actual clinical cases. In the discussion of each example, issues are highlighted, some of which were drawn to the attention of members of the Working Party during fact-finding meetings. We acknowledge that the choice of the issues that we discuss after each example may influence how the examples themselves are perceived by different readers, depending upon the reader's own worldview.

³ We use the term 'fetal medicine' to include surgery.

⁴ National Statistics (Summer 2006) *Population Trends No. 124*, Table 4.1.

⁵ The *National Service Framework Standard for Maternity Services*, which must be met by 2014, requires that each pregnant woman has an individual care pathway in order to ensure that all pregnant women receive the same high standard of care. The care pathway is intended to indicate a woman's progress through the variety of services available and explain how her care will be provided in particular circumstances. See Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 31 July 2006. For further information on genetic screening programmes, see also Nuffield Council on Bioethics (2006) *Genetic Screening: a Supplement to the 1993 Report by the Nuffield Council on Bioethics* (London: NCOB).

⁶ See the website of Antenatal Results and Choices, available at: <http://www.arc-uk.org/>, accessed on: 29 Aug 2006.

⁷ In addition, there will be a small number of false-negative test results. For further information, see the website of Antenatal Results and Choices, available at: <http://www.arc-uk.org/>, accessed on: 29 Aug 2006; and Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 31 July 2006.

whether she should accept that her child will have disabilities and continue with the pregnancy, agreeing to an early delivery if appropriate, or whether the pregnancy should be terminated.

Box 4.1: Antenatal screening programmes in the UK

The options for antenatal screening will be discussed with a pregnant woman by her doctor or midwife. Screening aims to identify pregnancies that are at high risk of congenital or genetic disorders and may be followed by confirmatory diagnostic testing. If there are fetal abnormalities, doctors will advise the woman of possible options. The development of screening programmes with high detection rates and a low incidence of false-positive test results that can be applied to all pregnant women has been given a high priority within the NHS. Conditions for which screening is routinely offered during pregnancy in the UK include Down's syndrome, fetal anomalies such as hydrocephalus or limb abnormalities, haemoglobinopathies (in certain localities), rhesus haemolytic disease (see Case 1) and Tay-Sachs disease (in some 'at-risk' populations).

For chromosome abnormalities, particularly Down's syndrome, screening is carried out by ultrasound (measurement of the nuchal translucency*) at 10–14 weeks of gestation and/or maternal blood analysis at 10–20 weeks of gestation. For other abnormalities, screening by ultrasound imaging is performed ('fetal anomaly scanning'), usually at about 20 weeks of gestation.† Pregnant women at high risk of specific fetal genetic diseases such as sickle cell disease and thalassaemia (both haemoglobinopathies) are offered a genetic test early in their pregnancy. If a woman is found to be carrying a genetic mutation responsible for either disorder, her partner may also be offered testing. If one or both of them are identified as carrying the trait, biochemical or genetic tests would be offered for the fetus.

If a high risk of a fetal abnormality is predicted or detected, fetal diagnostic tests are offered. Fetal material is obtained from samples of the placenta (chorionic villus sampling) or amniotic fluid (amniocentesis) or by direct fetal blood sampling. Each of these techniques carries a small risk (estimated at 1–2%) of miscarriage. The pregnant woman (and her partner) must be informed of this before deciding whether to undertake such a test.

* Nuchal translucency is an early ultrasound measure of the thickness of fluid at the nape of the fetal neck. An increased amount of fluid may indicate that the fetus has Down's syndrome or another chromosomal, structural or genetic abnormality.

† For further information, see Wald N and Leck (2000) *Antenatal and Neonatal Screening* (Oxford: Oxford University Press), pp 573; National Institute for Clinical Excellence (2003) *Antenatal Care: Routine care for the healthy pregnant woman* (London: NICE).

Clinical perspectives

Decisions about when to deliver a fetus

- 4.3 In parallel with advances in the detection of fetal abnormalities, there has been an improvement in identification of cases where the fetus is at high risk of dying in the womb or where early delivery is needed for other reasons. Early delivery may be necessary for the health of the pregnant woman because of intense bleeding, the development of complications of pregnancy which threaten her life, or because the fetus will be at risk if left in the womb. Decisions need to be made about which treatments should be given and when the baby should be delivered. However, the options for effective treatment with medicine or surgery are limited (see paragraphs 4.10–4.11). In addition, extreme prematurity creates its own problems (see Chapter 5).
- 4.4 The most common causes of premature birth are spontaneous preterm labour, preterm pre-labour rupture of membranes, and multiple pregnancy (see Table 4.1). Approximately 15–25% of premature births occur when a baby needs to be delivered early because of maternal or fetal complications during pregnancy.⁸ The most frequent complications are maternal hypertensive disorders such as pre-eclampsia, which can put both the woman and fetus at risk, and where the fetus is failing to grow *in utero* (fetal growth restriction) and showing signs of distress. The balance between the risk for the fetus of remaining in the womb and the risk of death and disability after premature delivery needs careful assessment.
- 4.5 When a pregnant woman is at risk of an imminent premature delivery, evidence from several clinical trials shows that a single course of steroids can help to prepare the fetal lungs for

⁸ Tucker J and McGuire W (2004) Epidemiology of preterm birth *Br Med J* **329**: 675–78.

Table 4.1: Causes of premature birth in Europe and North America

Cause of premature delivery	Frequency
Spontaneous preterm labour	31–50%
Multiple pregnancy and associated complications	12–28%
Preterm prelabour rupture of membranes	6–40%
Hypertensive disorders of pregnancy	12%
Intrauterine growth restriction	2–4%
Antepartum haemorrhage	6–9%
Miscellaneous – cervical incompetence, uterine malformation	8–9%

Source: These data are reprinted from Slattery MM and Morrison JJ (2002) Preterm delivery *Lancet* 360: 1489–97, with permission from Elsevier. The data are based on a number of studies in Europe and North America. The frequencies quoted indicate the proportion of premature births associated with each of the causes listed.

birth while causing no identifiable problems.⁹ The treatment helps to mimic the effects that occur naturally prior to delivery near full term. Steroids used in this way can reduce the risk of a premature baby dying, developing lung disease or brain injury, particularly if birth takes place 24 hours or more after a course of the medicine has been given.

- 4.6 A second intervention is to delay or arrest the onset of labour. The inhibition of contractions may be achieved by a variety of treatments. Delaying labour can benefit the fetus by allowing time for steroid treatment to be completed or for the woman to be transferred to a specialist hospital before she gives birth.¹⁰ However, some women experience adverse effects from medicines used to delay labour, and randomised trials have not demonstrated a clear benefit from their use.¹¹ Furthermore there is always the concern that delaying premature delivery could worsen the health of the woman and fetus if there is an underlying reason for the premature labour such as an infection or high blood pressure.¹² For example, chorioamnionitis, a bacterial infection of the two membranes of the placenta and the fluid around the baby, can lead to more serious maternal and fetal infections and increase the risk of other problems in the baby.
- 4.7 A better understanding of fetal health has been achieved with improved antenatal assessment. Fetal growth restriction is often caused by problems with the flow of blood through the placenta, resulting in insufficient nutrients reaching the fetus. Techniques that identify poor fetal growth and condition have improved markedly. Growth may be monitored, usually by standard and Doppler ultrasound imaging, and by recording fetal heart rhythms. A decision about early delivery is needed when there are clear signs that growth restriction is affecting fetal function, detected for example by changes in fetal behaviour, abnormal blood flow or a worsening heart trace. By the time that it is clear that the fetus will die, it may be too late to save the baby's life. Yet delivery beforehand, when there are only early signs of fetal compromise, may expose the baby to the complications of prematurity. The decision to deliver is finely balanced and different obstetricians faced with the same clinical situation may make different judgements.

⁹ Roberts D and Dalziel S (2006) Antenatal corticosteroids for accelerating fetal lung maturation for women at risk of preterm birth *The Cochrane Database of Systematic Reviews*, Issue 3.

¹⁰ Royal College of Obstetricians and Gynaecologists (2002) *Tocolytic Drugs for Women in Preterm Labour* (London: RCOG), available at: [http://www.rcog.org.uk/resources/Public/pdf/Tocolytic_Drugs_No1\(B\).pdf](http://www.rcog.org.uk/resources/Public/pdf/Tocolytic_Drugs_No1(B).pdf), accessed on: 3 Aug 2006.

¹¹ *Ibid.*

¹² Committee on Understanding Premature Birth and Assuring Health Outcomes (2006) *Preterm Birth: Causes, consequences and prevention*, Behrman RE and Stith Butler A (Editors) (Washington, DC: National Academies Press).

- 4.8 A recent trial randomly assigned pregnant women to early delivery or to deferred delivery if there was good evidence that a fetus was failing to thrive, as well as uncertainty over the best course of management (the Growth Restriction Intervention Trial, GRIT).¹³ The results showed that the overall death rates for fetuses or babies were not substantially different in the two groups. Early delivery produced more deaths on the neonatal unit whereas deferred delivery led to more deaths before birth. There were no differences in outcomes for survivors at two years of age.¹⁴
- 4.9 Dilemmas arise in the clinical management of multiple pregnancy (see paragraph 3.4) where there are significant complications or evidence that the health of one or more fetuses is being adversely affected. This may be because of an underlying abnormality, fetal growth restriction or brain injury. These complications may lead to spontaneous prematurity, and increased risks of malformation and cerebral palsy, the risks rising as the number of fetuses increases. The options for clinical management include treatment, where possible, or early delivery. Selective reduction of multiple pregnancy by fetocide is sometimes advised by doctors when the health of one or more fetuses is compromised.

Possibilities for fetal treatment¹⁵

- 4.10 A pregnant woman's options are usually limited when a condition affecting the health of the fetus(es) is identified through screening, as effective fetal treatments are available for only a small number of conditions. They include:

Ultrasound-guided procedures to obtain fetal blood samples or tissue to confirm diagnoses, or to give treatments such as transfusions.

Fetal blood transfusion if a fetus suffers from rhesus haemolytic disease, which can cause heart failure, the accumulation of fluid (hydrops), and eventual death. Transfusing blood that is compatible with the pregnant woman's blood group into the fetus can reverse the process and allow the pregnancy to progress normally.

Laser treatment by fetoscopy to correct a condition that occurs in identical twins where connections develop between the two fetal circulation systems through the placenta.¹⁶

Drainage tubes used to remove fluid that accumulates in unwanted places, especially around the fetal lungs or when the outflow of urine is blocked in the bladder. The tubes drain the accumulated fluid into the amniotic sac around the fetus. This procedure is simple to carry out and can allow the fetus to develop normally. The dilemma for doctors is whether the condition leading to the problem is reversible, or whether the damage done by the accumulating fluid, for example to the growth of the lung or kidney, is already too far advanced for the procedure to benefit the fetus.

Medicines given to a pregnant woman often cross the placenta and can be used to treat the fetus. For example, the use of digoxin or flecainide can be highly effective in preventing abnormal fetal cardiac rhythms. Untreated, this condition may be fatal. However, care must be taken to treat the fetus without producing unacceptable side effects in either the fetus or the woman.

¹³ Thornton JG, Hornbuckle J, Vail A, Spiegelhalter DJ and Levene M; GRIT study group (2004) Infant wellbeing at 2 years of age in the Growth Restriction Intervention Trial (GRIT): multicentred randomised controlled trial *Lancet* **364**: 513–20.

¹⁴ Research in this area is continuing.

¹⁵ Medical terms in this section are explained further in the Glossary.

¹⁶ Blood may flow preferentially in one direction in such cases and one fetus may fail to grow properly while the other suffers the consequences of excess circulating blood, placing both fetuses at risk of dying before birth or of developing cerebral palsy if they survive what is often very premature birth. Randomised trials have shown that using laser therapy to divide the blood vessels causing the 'twin-to-twin transfusion' can be more successful in treating this condition than other treatments. However, long-term outcomes are variable. For a review, see Harkness UF and Crombleholme TM (2005) Twin-twin transfusion syndrome: where do we go from here? *Semin Perinatol* **29**: 296–304.

Possibilities for fetal surgery

- 4.11 Open surgical operations to correct or lessen the impact of abnormalities of the fetus before birth are rare, although a number of attempts have been made over the past 20 years to repair conditions such as congenital diaphragmatic hernia or spina bifida.¹⁷ Procedures of this kind, which involve opening the pregnant woman's abdomen and uterus under general anaesthesia and partly exposing and operating on the fetus, must be considered experimental. Because the risks for the pregnant woman are high and the outcomes reported to date have been generally poor or worse than operations performed after birth, there are currently only a small number of centres in the USA that undertake open fetal surgery. Consistent with the recommendations of the Bristol inquiry,¹⁸ **the view of the Working Party is that new procedures in fetal surgery should be offered in the UK only within a protocol approved by a research ethics committee (REC).**
- 4.12 If there are no options for surgery or other treatments to treat a fetus with a serious abnormality, a woman faces a stark choice of whether to continue with her pregnancy or seek termination. For some conditions detected by testing, the outcome will be certain; examples would include anencephaly or renal agenesis. Doctors would be able to explain what is wrong with the fetus and how the baby would be affected. In other cases the outcome may be much more difficult to predict. The woman may prefer to wait for results of further tests if these are available and to defer the decision about whether or not to have a termination. If no further tests are possible, she may decide to continue her pregnancy in the knowledge that there is a risk of miscarriage, stillbirth or having a baby with health problems or disabilities. Alternatively, she may decide to terminate her pregnancy.

Late termination of pregnancy

- 4.13 In England, Scotland and Wales the Abortion Act 1967 specifies that termination of pregnancy beyond 24 weeks of gestation is only legal if either a fetus is at substantial risk of serious handicap or there is a risk of grave permanent injury to the life, or the physical or mental health of the woman.¹⁹ In England and Wales in 2004, 124 terminations were carried out after 24 weeks of gestation, out of a total of 185,415 (less than 0.1%).²⁰ Of these, 91 were for congenital malformations, 23 for chromosomal abnormalities and ten for other conditions, such as disorders related to gestation and growth. Some specialists in fetal medicine have reported that the absence of an absolute cut-off in law at 24 weeks has relieved the

¹⁷ A randomised clinical trial of fetal surgery for spina bifida is in progress in the USA. See US National Institutes of Health *Management of Myelomeningocele Study (MOMS)*, available at: <http://www.clinicaltrials.gov/show/NCT00060606>, accessed on: 20 Sept 2006. Preliminary data from the UK have recently been published on fetal surgery to correct severe congenital diaphragmatic hernia[0]. See Deprest J, Gratacos E, Nicolaides KH; FETO Task Group (2004) Fetoscopic tracheal occlusion (FETO) for severe congenital diaphragmatic hernia: evolution of a technique and preliminary results *Ultrasound Obstet Gynecol* **24**: 121–6.

¹⁸ The Bristol Royal Infirmary Inquiry (2001) *The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984–1995: Learning from Bristol*, available at: http://www.bristol-inquiry.org.uk/final_report/the_report.pdf, accessed on: 25 Sept 2006. The recommendation made was that "Before any new and hitherto untried invasive clinical procedure can be undertaken for the first time, the clinician involved should have to satisfy the relevant local research ethics committee that the procedure is justified and it is in the patient's interests to proceed. Each trust should have in place a system for ensuring that this process is complied with." In the UK the Interventional Procedures Programme at the National Institute for Health and Clinical Excellence (NICE) is responsible for assessing and publishing guidance on the safety and efficacy of new interventions, including fetal ones, when they are first used in the NHS in England, Scotland or Wales outside of a REC-approved protocol. The Programme defines interventions as procedures "used for diagnosis or treatment that involve incision, puncture, entry into a body cavity or the use of ionising, electromagnetic or acoustic energy". See: National Institute for Clinical Excellence (2004) *The Interventional Procedures Programme – Programme manual* (London: NICE).

¹⁹ Abortion Act 1967; Mason JK and Laurie GT (2005) *Mason and McCall Smith's Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press). See also Chapter 8. Note that although the Abortion Act applies to Scotland, differences in the law in Scotland meant that the Act did not significantly alter existing policy.

²⁰ Government Statistical Service (2005) *Abortion Statistics, England and Wales: 2004*, available at: <http://www.dh.gov.uk/assetRoot/04/11/75/74/04117574.pdf>, accessed on: 13 June 2006. Note that these figures do not include 8,764 abortions performed on women who were not resident in England or Wales.

pressure for hurried decision making in a small number of patients where further investigations, consultation and/or monitoring are necessary to help establish a prognosis, or where there are delays in access to screening. While the Abortion Act 1967 does not apply to Northern Ireland, recent court cases have ruled that terminations may be permitted in some exceptional circumstances where a woman's life or physical or mental wellbeing would be at risk.²¹ Fetal abnormality alone would not be a lawful ground for termination in Northern Ireland.

4.14 Late termination of pregnancy can be traumatic for the woman, her partner, relatives and companions and for healthcare professionals²², as she ends a previously wanted pregnancy and must go into labour and give birth. In addition, at 22 weeks of gestation, a fetus (even with a fatal condition) may show signs of activity at delivery (such as a heartbeat, gasp or reflex movements). The birth of a live child has to be registered as such, which parents and professionals may find distressing when it follows termination, especially when death also has to be registered shortly afterwards.²³ The Royal College of Obstetricians and Gynaecologists (RCOG) has developed guidelines that include the recommendation that feticide (causing the death of a fetus) be carried out before the initiation of labour in terminations after 21 weeks and six days of gestation to ensure that the fetus is not born alive.²⁴ The College is also issuing new guidance about the management of pre-viable fetuses of less than 21 weeks, six days of gestation. The recommended method of feticide is an injection of potassium chloride into the fetal heart²⁵ which stops the heartbeat. It is mostly regarded as a means of causing rapid death which does not require analgesia (see paragraph 4.19). Feticide pre-empts the possibility of dilemmas about whether a baby born alive after a termination should be resuscitated. Some parents have been reported to be relieved knowing that their fetus will not suffer during induced labour or be born alive, although in other accounts parents described the procedure as particularly distressing.²⁶ Interview studies with parents have found that when the procedure is handled sensitively, reactions to feticide appear not to dominate the experience of grief at the loss of a wanted baby.²⁷

4.15 Since 2002, clinicians in England and Wales have been required to report whether feticide was performed in terminations. In 2005, 31% (approximately 800) of the terminations that took place at 20 weeks of gestation onwards in England and Wales were reported as including feticide.²⁸ The Working Party was informed that there may be some variation between

²¹ Mason JK and Laurie GT (2005) *Mason and McCall Smith's Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press), p148.

²² Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 8 Aug 2006.

²³ McHaffie HE (2001) *Crucial Decisions at the Beginning of Life* (Abingdon: Radcliffe Medical Press), p197.

²⁴ Royal College of Obstetricians and Gynaecologists (1996) *Termination of Pregnancy for Fetal Abnormality in England, Wales and Scotland* (London: RCOG); Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 8 Aug 2006. Feticide is discussed in several other RCOG reports and statements. One of these, from 1998, recommends the use of feticide for late terminations of pregnancy after advising that obstetricians have a duty "to protect the fetus from suffering pain in all terminations of pregnancy regardless of gestation". Royal College of Obstetricians and Gynaecologists (1998) *Late Termination of Pregnancy for Fetal Abnormality* (London: RCOG).

²⁵ Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 8 Aug 2006.

²⁶ Statham H, Solomou W and Green JM (2001) Care in hospital for parents who terminated their pregnancy, in *When a Baby has an Abnormality: A study of parents' experiences* (Cambridge: Centre for Family Research, University of Cambridge), Chapter 6.

²⁷ Personal communication, Dr Ruth Graham, School of Geography, Politics and Sociology, University of Newcastle upon Tyne.

²⁸ This percentage may be an underestimate as routine recording only began in 2002 and the Government Statistical Service states that it is likely that feticide is still being under-reported. Government Statistical Service (2006) *Statistical Bulletin Abortion Statistics, England and Wales: 2005*, available at: <http://www.dh.gov.uk/assetRoot/04/13/68/59/04136859.pdf>, accessed on: 29 Aug 2006.

doctors on the types of condition for which feticide is offered. However, doctors would usually advise feticide where a fetus has or will develop serious abnormalities, but may live for some time without special assistance after birth, such as in the brain disorder microcephaly (usually only diagnosable very late in pregnancy). Feticide is not always considered necessary if a fetus has an unequivocally fatal condition and will die during or soon after birth.²⁹ It may also be very difficult for practical reasons, for example if the nearest fetal medicine unit is some distance away.³⁰ A minority of pregnant women do not wish to have feticide, whatever the diagnosis.³¹ They prefer to be able to hold their baby after birth and be together as a family, even if only for a short while, before the baby dies.³² The Working Party was advised that termination of pregnancy after 22 weeks without feticide was an issue of major concern for healthcare professionals in fetal medicine. In particular, they needed a greater understanding of the legal position.³³

- 4.16 This uncertainty over whether doctors are legally obliged to resuscitate any child with a serious condition who is born alive, including conditions incompatible with long-term survival, and regardless of the parents' wishes, was expressed to members of the Working Party in fact-finding meetings. Unease about this question could affect the advice that doctors provide about feticide. However, such concerns are ill-founded. There is no legal obligation to institute all possible steps to preserve life for any baby with serious abnormalities whose condition is such that it is not in his or her best interests to survive (see paragraph 8.8). Doctors should therefore feel able to respect the woman's wish if she chooses to decline feticide and not be obliged to press her to reconsider. What is essential in these circumstances however, is that there should be thorough discussions with the woman (and her partner if she wishes) about the likely outcomes, taking into account the circumstances of her case. It must be made clear that in the exceptional circumstances that a baby appears likely to live when the termination is for a non-fatal condition, neonatologists will institute treatment if they believe this to be in the best interests of the baby, having assessed his or her condition at birth. In Chapter 9 we offer some guidance for helping to decide what is in a baby's best interests. It is important that the woman should be given time to consider her decision and evaluate whether termination without feticide genuinely remains her wish. If so, she should agree a care plan in advance of the procedure that covers the possible outcomes.
- 4.17 Currently, national statistics do not include data on the extent to which feticide is offered to pregnant women. The BMA has observed that little is known about how parents make decisions following the diagnosis of severe fetal abnormality, including the kind of information and support they receive and how this affects their decision making.³⁴ Available data suggest that parents experience difficulties in deciding how to proceed after such a diagnosis, with two factors reported as being important for decision making. These are first, the impact of

²⁹ Statham H, Solomou W and Green JM (2006) Late termination of pregnancy for fetal abnormality: law, policy and decision-making in four English fetal medicine units *BJOG* (in press).

³⁰ Feticide may only be carried out in a fetal medicine unit. Royal College of Obstetricians and Gynaecologists (1998) *A Consideration of the Law and Ethics in relation to Late Termination of Pregnancy for Fetal Abnormality* (London: Royal College of Obstetricians and Gynaecologists).

³¹ A recent study reported that of 31 parents offered feticide for late termination of pregnancy, three declined; in two cases the baby had a lethal abnormality and the doctors advised that feticide was unnecessary and in the other, at 21 weeks of gestation (i.e. earlier than the limit above which feticide is advised by the RCOG), the parents decided against it. Statham H, Solomou W and Green JM (2002) Termination of pregnancy, in *When a Baby has an Abnormality: A study of parents' experiences* (Cambridge: Centre for Family Research), pp 56–106.

³² Personal communication at a fact-finding meeting of the Working Party.

³³ Personal communication from Professor Steve Robson, University of Newcastle upon Tyne.

³⁴ British Medical Association (2005) Diagnosing fetal abnormality, in *Abortion Time Limits – A briefing paper from the BMA*, available at: <http://www.bma.org.uk/ap.nsf/Content/AbortionTimeLimits~Factors~Diagnosing>, accessed on: 30 May 2006.

the abnormality on the child, on themselves and on other immediate family members (including children they wish to have in the future), and secondly, their prior attitudes and beliefs about termination. It has been suggested that parents tend not to focus on levels of risk and the options available in an objective way, but rather on their perception of their own ability to cope.³⁵ Decision making is made more complex when there is uncertainty over how seriously a child will be affected by any disability in the future.

- 4.18 The Confidential Enquiry into Maternal and Child Health (CEMACH) is currently (2006) undertaking a survey of terminations of pregnancy where a neonatal death was subsequently recorded. The survey will seek to determine the reasons for the termination of pregnancy, the method of termination and whether feticide was offered. Where possible, for terminations over 21 weeks, six days of gestation, the reasons for which feticide is not performed will be recorded, including when pregnant women declined. The Working Party supports the collection of these data for the insight they may give into current practice.

Fetal pain

- 4.19 The question of whether a fetus can feel pain is almost impossible to answer. For adults, pain involves consciousness, thought, memory and fear. In the fetus, a grimace, physical withdrawal, movement or release of stress hormones into the blood stream does not necessarily mean that pain has been consciously perceived. Scientists disagree as to when the fetus has sufficient neurological development to perceive pain and whether there might be particular characteristics of the fetal environment that inhibit conscious perception of pain *in utero*.³⁶ Even if the cerebral cortex (where pain and other sensations are perceived) is insufficiently developed before 26 weeks of pregnancy for the fetus to be conscious of pain,³⁷ there may be negative consequences from distress associated with invasive procedures which affect subsequent development. In a report on fetal pain, the RCOG suggested that the potential for it should be considered in procedures involving fetuses from 24 weeks of gestation onwards (after which it is possible that the fetus may experience pain), while bearing in mind the potential harm that analgesic drugs may cause.³⁸ The RCOG have recommended that fetal analgesia or sedation be considered for major intrauterine procedures, and (see paragraph 4.14) feticide or sedation be considered for late terminations of pregnancy.³⁹

Some examples⁴⁰

- 4.20 In the following paragraphs, we use two hypothetical examples to illustrate some of the issues that may arise when decisions affecting the survival of a child have to be made during pregnancy. The first case concerns a pregnancy where the fetus has rhesus haemolytic disease. The second concerns a woman who has been asked to decide whether to terminate her pregnancy because the fetus has a serious abnormality of brain development.

³⁵ Statham H (2002) Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences *Fetal Matern Med Rev* **13**: 213–47.

³⁶ See Anand KJ, Aranda JV, Berde CB *et al.* (2006) Summary proceedings from the neonatal pain-control group *Pediatrics* **117**: S9–22; Derbyshire SWG (2006) Can fetuses feel pain *Br Med J* **332**: 909–12; Mellor DJ, Diesch TJ, Gunn AJ and Bennet L (2005) The importance of 'awareness' for understanding fetal pain *Brain Res Rev* **49**: 455–71; Lee SJ, Ralston HJP, Drey EA, Partridge JC and Rosen MA (2005) Fetal pain: A systematic multidisciplinary review of the evidence *J Am Med Assoc* **294**: 947–54; Glover V and Fisk NM (1999) Fetal pain: implications for research and practice *Br J Obstet Gynaecol* **106**: 881–6.

³⁷ Royal College of Obstetricians and Gynaecologists (1997) *Fetal Awareness: Report of a working party* (London: RCOG Press).

³⁸ *Ibid.*

³⁹ Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 21 Nov 2005.

⁴⁰ See footnote 2.

Case 1: Sarah – a fetus at risk and a dilemma for the doctor**Sarah**

Sarah, who is pregnant for the second time, has a rhesus negative blood type. If she is pregnant with a rhesus positive fetus, antibodies in her blood may attack the fetus' blood cells. This will only occur if her blood has previously come into contact with rhesus positive blood, usually during the birth of a previous rhesus positive baby. Sarah's first child, who is now two years old, showed mild jaundice after birth but then recovered. In her second pregnancy, Sarah did not attend the antenatal clinic regularly although she had an ultrasound scan at 26 weeks. Her scan showed that the fetus had clear signs of rhesus haemolytic disease and anaemia caused by the incompatibility in blood groups. The skin and body tissues of the fetus showed an abnormal accumulation of fluid, caused by fetal heart failure.* Sarah's doctors now advise her that a fetal blood transfusion is urgently required. Without a transfusion, the fetus will die, but with a transfusion the survival rate for similar cases is 90%. Fetal transfusions are not without risk (1–2% risk of fetal mortality) and several would be needed. Sarah decides to refuse the treatment because she does not want to take this risk and 'everything was all right last time'. What should doctors do?

* Rodeck CH and Deans A (1999) Red cell alloimmunisation, in *Fetal Medicine: Basic sciences and clinical practice*, Rodeck CH and Whittle MJ (Editors) (Churchill Livingstone), p 785.

Moral status

- 4.21 As we have said, a presumption in favour of life is at the root of all medical care (see paragraph 2.36). Sarah's refusal of treatment for her unborn child with anti-rhesus antibodies is morally unacceptable to those for whom every possible measure should be taken to preserve life. We have described this position as an absolutist interpretation of the sanctity of life view (see paragraph 2.9). The pregnant woman might say that her refusal of the transfusion is because of the risk of death for the fetus. However, she has not appreciated the relative risks for the fetus of taking no action, as opposed to accepting the transfusion. In assuming that the outcome of the previous pregnancy will be replicated, she has not acknowledged that the risks are higher for a second pregnancy. For those who see the fetus as having a lower moral status than human life after birth, her refusal would be seen as a matter for her personal choice. A gradualist regards the fetus as gaining increasing moral status as their development progresses through the pregnancy. The fetus in Sarah's case has developed for 26 weeks of gestation and so is likely to be accorded significant status, although perhaps not the same status as a full-term baby. While there are several different approaches within consequentialism, one such view would be that the rightness or wrongness of the decision might be considered in terms of the balance between the anticipated benefits and burdens of the treatment. In this case, the risk:benefit ratio and expected outcomes would be in favour of treatment.
- 4.22 Even those who consider that the fetus has a moral status, and thus is entitled to treatment, would agree that this claim cannot be realised without involving the pregnant woman, since the treatment must pass through her body. The issue then becomes a matter of whether the claim of the fetus is such that we would be prepared to force Sarah into complying with the treatment against her wishes. To require her to undergo treatment would contravene the ethical principles of respect for patient autonomy and informed consent to treatment. As we have said, the view of the Working Party is that any attempt to save the life or to improve the health of the fetus *in utero* can be done only with the full consent of the pregnant woman (paragraphs 2.20 and 8.4).

Best interests

- 4.23 Those seeking to justify an intervention to treat the fetus, or encouragement of the pregnant woman to reconsider her position in discussion with the clinical team, are likely to appeal to the best interests of the fetus. As we observed, consideration of the various interests at stake requires an assessment of the weight that should be accorded to them. Here, the interest of the fetus to survive can be accorded considerable weight, whereas Sarah's interest to proceed as she thinks is best appears to be less important.

Conveying information

4.24 The example illustrates the importance of good communication.⁴¹ Sarah was concerned by the risk associated with fetal transfusion, but seemed to have overlooked the fact that the risk of the fetus dying in the absence of treatment was far greater. She may have wanted a totally 'natural' pregnancy and thought that the doctors wanted to interfere unnecessarily. Her lack of attendance at prenatal check-ups and completion of the ultrasound scan at 26 rather than 20 weeks are a cause for concern. Sarah's absence may be related to social or personal factors, a result of poor coordination within the health service or lack of information provided to her, or encouragement to attend. It is crucial that women in Sarah's position are given appropriate information to clarify the risks of not proceeding with treatment. Sarah should be able to ask questions as necessary and come to her own decision. She is likely to want to talk her dilemma through with her partner and perhaps friends or other family members and should be offered professional, emotional and spiritual support. This case also illustrates how perceptions of risk can vary and the difficulty of ensuring that the weight accorded to the different perspectives of all involved in the decision-making process are appropriately balanced. Some might consider that Sarah misinterpreted the information given to her and should follow the doctors' advice. However, the healthcare team would not claim to have special moral expertise on the matter. **The Working Party cannot overstate the importance of making decisions in partnership (see paragraphs 2.48 and 3.19) and ensuring that information is conveyed in a way that is appropriate to the understanding of the parents involved.** We note that the standards of the UK Government's National Service Framework (NSF) for Children, Young People and Maternity Services require that information be provided in different languages and mediums in order to meet the needs of different individuals, a policy that we support.⁴²

Legal issues

4.25 The position in English law is, in this case, straightforward. Sarah's decision is decisive (see paragraph 8.4). A pregnant woman does not have to take account of the father's wishes, should they differ, and she cannot be compelled to comply with the advice of her doctors, except if there is a question of her mental capacity. **While the requirements of the law are clear, the view of the Working Party is that doctors should make their best efforts to ensure that a woman is able to make an informed choice about her pregnancy.** This may require resort to more effective methods of communication to help her understand that the risks associated with a second pregnancy are much higher than for the first, and that the outcome without a transfusion would entail a high risk of fetal death.

Economic issues: antenatal screening

4.26 Sarah's dilemma has come to light through the application of antenatal screening. Clear economic arguments have been made in studies for some forms of routine screening for fetal infections or abnormalities.⁴³ However, such studies have tended to emphasise the potential of a fetus affected with abnormalities to incur future costs to the healthcare and other sectors of the economy, while not recognising that the fetus also has the potential to produce

⁴¹ Royal College of Physicians (1997) *Improving Communication between Doctors and Patients: A report of a working party* (London: RCP).

⁴² Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 31 July 2006.

⁴³ Lane B, Challen K, Harris HG and Harris R (2001) Existence and quality of written antenatal screening policies in the United Kingdom: postal survey *Br Med J* **322**: 22–3.

future benefits.⁴⁴ A consistent application of methods for economic evaluation would require adjustment to take account of such benefits, which cannot be measured purely in terms of resources. Such an approach is likely to counterbalance the economic argument against many forms of antenatal screening. **The Working Party believes that economic considerations should not be central in any discourse about the value of antenatal screening programmes that often result in termination of pregnancy in cases of serious abnormality.** We discuss the economic costs of saving babies born at the borderline of viability in Chapter 5.

Case 2: Theresa – a fetus at risk and a dilemma for the pregnant woman

Theresa

Theresa is an 18-year-old woman with an unplanned first pregnancy. She discovered that she was pregnant at 23 weeks and, after she had become used to the idea, was pleased. She has just found out after a series of tests that the fetus has severe hydrocephalus due to a mutation in a gene necessary for brain development.* In this condition, some areas of the brain fail to develop and the infant will have spastic paralysis with severe learning disorders. A scan at 26 weeks of gestation showed that there was too much amniotic fluid surrounding the fetus, a condition called polyhydramnios. This fluid was distending the uterus and threatened to precipitate labour. Theresa was advised that she should consider terminating her pregnancy now because the prospects for the fetus were so severe. If born alive, the child would have the combined problems of severe prematurity and a very abnormal brain, a combination of physical disability and serious learning disorders. The doctors would carry out feticide as the first part of the termination procedure. Theresa was very upset because she would no longer have the baby she hoped for. She agreed to the termination but was thinking of refusing feticide because she could not bear the idea.

* Weller S and Gartner (2001) Genetic and clinical aspects of X-linked hydrocephalus (L1 disease): Mutations in the L1CAM gene *J Hum Mutat* 18: 1–12.

Making a decision about ending the pregnancy

- 4.27 With severe hydrocephalus of this type, the baby would be unable to develop any higher brain functions, and when older would not be able to take part in human activities or form relationships. Children with less severe forms of the condition might be less seriously affected. In Theresa's case, the loss of brain function would result in a future for her baby in which no human experience or ability to relate to the outside world would be possible. Those who hold that there is a moral obligation to preserve life at all costs could not condone termination, nor the preceding feticide. Others, however, might contend that the doctors should try as far as possible to abide by professional guidelines, which would mean not agreeing to Theresa's preferences (see paragraph 4.16). Some might think that there could be very little benefit to the baby in being born alive, and might even maintain that to preserve his or her life once born would be inhumane.
- 4.28 In considering best interests, the dilemma is to decide whether the interests of the fetus or the newborn baby should have priority. Some people may prefer to prevent the possibility of pain if the fetus should be born alive and this would incline them to accept feticide. It could be argued, however, that using anaesthesia during a medical termination⁴⁵ to reduce pain is preferable, although the outcome would be the same. However, the latter carries more risk for the pregnant woman than feticide.

⁴⁴ For example, many of the economic evaluations measure and value benefits in terms of costs averted by the screening programmes i.e. the resource savings that follow: (i) the abortion of the affected fetus; (ii) the abortion of the affected fetus less the resource costs involved with respect to any 'replacement' child; or (iii) the treatment of affected women or children.

⁴⁵ A medical procedure is used for late terminations of pregnancy after 22 weeks. Surgical terminations would in any case be carried out under general anaesthesia, thus both the woman and the fetus would receive treatment for pain.

- 4.29 Theresa may or may not hold definite views about the rightness or wrongness of termination and/or feticide. As in Case 1, **the view of the Working Party is that, whatever the decision ultimately agreed, there is no moral justification to coerce a woman to permit the feticide and/or the termination of pregnancy** (see paragraph 2.20). It would also be illegal (see paragraph 8.4).
- 4.30 Whatever she decides, this is likely to be a disturbing experience for Theresa. Receiving a prenatal diagnosis, dealing with decision making, undergoing a termination and coping afterwards can be very distressing.⁴⁶ Psychological distress is reported to be high immediately after termination of pregnancy for fetal abnormality, with most women reporting acute grief.⁴⁷ The intensity of the distress lessens over time for most women, although studies have shown that some continue to show signs of psychological distress or express feelings of sadness, guilt or anger several years later. Theresa may, for example, have concerns stemming from a strong belief in the sanctity of life, such that taking any life is morally wrong (paragraph 2.9). She may feel pressured by the doctors and nurses and feel guilty or responsible at the prospect of agreeing to terminate her pregnancy. Theresa may also have great need for social support and counselling, given that she discovered her pregnancy at an advanced stage and appears not to have close support from family or friends. Psychological and spiritual assistance could also be of value to her.
- 4.31 If Theresa should agree to feticide, she will have to cope with the death of the fetus, just as she would have to do if the baby died after birth. The longer she delays her decision on termination, the more likely it is that the baby will be born alive and could survive into infancy. If Theresa should wish the pregnancy to continue, the doctors will decide upon the best time for delivery and again, the baby is likely to survive the birth. Her ability to cope will depend on her maturity, the level of support from others, and the way that information is presented to her. It may also depend on whether she had ever previously thought about feticide and her views on it, although research suggests that parents do sometimes change their mind once they find themselves in this situation.⁴⁸ She may find that her relatives have different views if she consults them, which may cause her concern if she derives her sense of morality from the attitudes and relationships within her family (see also paragraph 3.17). She may also be influenced by the outlook of others around her, who may hold, for example, strong religious or disability rights perspectives.⁴⁹ It should not be assumed that her relative youth makes her any less capable of making decisions.
- 4.32 In this situation, parents' decisions may also be associated with socio-demographic factors. A major study in the USA on decision making following a diagnosis of fetal abnormality has shown that a number of factors correlate with the decision to terminate.⁵⁰ In particular the likelihood of termination increased with severity of abnormality and with increasing maternal age. This research cites other studies in which educational level, racial origin and household income were also found to have an effect on decisions.
- 4.33 The doctors may be unclear whether they are entitled by law to agree with Theresa's request for termination without feticide and worry that if they do agree, they would be legally

⁴⁶ Statham H, Solomou W and Chitty L (2000) Prenatal diagnosis of fetal abnormality: psychological effects on women in low-risk pregnancies *Bailliere's Clin Obstet Gynaecol* 14: 731–47.

⁴⁷ Statham H (2002) Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences *Fet Mat Med Rev* 13: 213–47.

⁴⁸ *Ibid.*

⁴⁹ *Ibid.*

⁵⁰ Schechtman KB, Gray DL, Baty JD and Rothman SM (2002) Decision-making for termination of pregnancies with fetal anomalies: analysis of 53,000 pregnancies *Obstet Gynecol* 99: 216–22.

obliged to resuscitate the baby once born (see paragraph 4.16). They may also see a professional obligation to adhere to any local hospital guidelines and to the national guidance from the RCOG (see paragraph 4.14).⁵¹ They should clarify carefully with Theresa any issues about which she is worried and ensure that she has access to independent advice so that, for example, she can find out whether other women accept feticide in her situation. In practice, only a minority do not accept the offer of this procedure as part of a late termination.

4.34 This case also raises the issue of how the doctors perceive feticide. Recent research has shown that hospital consultants are acutely aware of both their clinical responsibility and personal involvement when carrying out feticide.⁵² They describe tolerating the procedure as a necessary part of their clinical practice and justify it for various reasons, for example to enable the parents to have 'options' available to them or to reduce suffering. It has been suggested that the emotional and personal implications for health professionals undertaking unpleasant tasks such as feticide are often not recognised and that there is a need for them to be studied.⁵³ If a doctor or other health professional has a conscientious objection to termination of pregnancy, they have the right under the Abortion Act 1967 to refuse to participate in such procedures⁵⁴ and refer the patient to another doctor.⁵⁵ This right of conscientious objection to participating in terminations is supported by the BMA.⁵⁶ However, research suggests that, while midwives involved in feticide felt that the right to object was genuinely available, consultants typically saw this right as theoretical.⁵⁷

Social perceptions of the fetus

4.35 In developed societies, people are exposed in their daily lives to powerful imagery that has increased awareness of many issues, including those related to medicine. Looking beyond this case, there are many conflicting perceptions of both the fetus⁵⁸ and the newborn baby that may affect the various parties involved in the decision-making process. For example, the image of a fetus has been used in anti-smoking campaigns. Medical imaging that visualises in three dimensions the detailed movements of the fetus inside the womb has also recently received press coverage. Such images may evoke perceptions that the fetus and the newborn baby are more similar in terms of development than in fact they are.⁵⁹ In contrast, there is greater awareness of the possibility that, in the future, scientists may be able to alter a child during development to improve his or her health, whether at the level of the gene, the pre-embryo, the embryo, the fetus or the baby. There has been speculation that the possibility of using fetal tissues in medical treatments⁶⁰ and the advent of prenatal testing to assess

⁵¹ Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 21 Nov 2005.

⁵² Graham R, Rankin J, Haimes E and Robson S (2006) Providing feticide: An exploration of health professional perspectives *J Obstet Gynaecol* **26** (Suppl. 1): S14–16; Graham R, Robson S, Rankin J and Haimes E (2005) *Living with Feticide: A case study in tolerance and tender care*, paper presented at British Sociological Association Medical Sociology Annual Conference, September 2005.

⁵³ Graham R (2006) Lacking compassion—sociological analysis of the medical profession *Soc Theory Health* **4**: 43–63.

⁵⁴ Although not in a situation when the termination is needed to save the life of or prevent severe permanent injury to the pregnant woman.

⁵⁵ Mason JK and Laurie GT (2005) *Mason and McCall Smith's Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press).

⁵⁶ British Medical Association (1999) *The Law and Ethics of Abortion*, available at: <http://www.bma.org.uk/ap.nsf/Content/abortion-objection>, accessed on: 29 Aug 2006.

⁵⁷ Graham R, Rankin J, Haimes E and Robson S (2006) Providing feticide: An exploration of health professional perspectives *J Obstet Gynaecol* **26** (Suppl. 1): S14–16.

⁵⁸ Williams C, Alderson P and Farsides B (2001) Conflicting perceptions of the fetus: person, patient, nobody, commodity *New Genet Soc* **20**: 225–38; Williams C (2005) Framing the fetus in medical work: rituals and practice *Soc Sci Med* **60**: 2085–95.

⁵⁹ Williams C, Alderson P and Farsides B (2001) Conflicting perceptions of the fetus: person, patient, nobody, commodity *New Genet Soc* **20**: 225–38.

⁶⁰ For example transplanting fetal brain cells into the brains of patients with Parkinson's disease; see Young E (2001) Think again *New Scientist*, available at: <http://www.newscientist.com/article.ns?id=dn507>, accessed on: 22 Sept 2006.

whether a fetus is viable may foster perceptions of the fetus as an 'expendable consumer object'.⁶¹ Furthermore, the availability of prenatal testing may mean that some women view their pregnancy as tentative and do not form attachments to the unborn child until they know the results of the tests.⁶²

Legal issues

4.36 Although what is meant by a substantial risk of 'serious handicap'⁶³ to the future child so as to justify termination after 24 weeks under the Abortion Act 1967 is not defined, this type of severe hydrocephalus would definitely lead to a 'serious handicap,' and a termination of Sarah's pregnancy at 26 weeks is therefore lawful. Feticide itself is lawful if the termination of the pregnancy comes within the provision of the Abortion Act. Both feticide and the termination procedure would involve invasion of Theresa's body and therefore, under the law, require her consent. Should a termination be performed without feticide and a baby with serious health problems is born alive, there is not necessarily any obligation that the baby should be ventilated or admitted to neonatal intensive care if using all possible means to sustain his or her life is not in his or her best interests (see paragraph 8.8). The law would thus allow the doctors to act on Theresa's wishes and provide palliative care until the baby dies. Having concluded our consideration of dilemmas arising during pregnancy, we turn our attention in the next chapter to critical care at the borderline of viability.

⁶¹ Williams C, Alderson P and Farsides B (2001) Conflicting perceptions of the fetus: person, patient, nobody, commodity *New Genet Soc* 20: 225–38.

⁶² Statham H, Solomou W and Chitty L (2000) Prenatal diagnosis of fetal abnormality: psychological effects on women in low-risk pregnancies *Bailliere's Clin Obstet Gynaecol* 14: 731–47.

⁶³ The term 'handicap' is taken from the wording of the Abortion Act 1967.