the cradle of the womb

From personal experience, Dr Josephine Treloar asks some probing questions about ante-natal screening tests

I am a GP and mother who has experienced at first hand the desire of ante-natal services to screen out and destroy babies they consider unwanted. They are so keen they will actually screen without the consent or even knowledge of the mother. As Christians we are bound to be concerned about such moves. The joyful time of pregnancy can be harsh and dangerous. Mothers need all the support and knowledge they can get, to withstand some of the destructive pressures now inbuilt within ante-natal care.

Current public policy is increasingly designed to minimise expenditure on the care of the mentally or physically handicapped[1], and the main legal way at present is to prevent them being born alive. The dragnet is designed to be as comprehensive as possible and enrols all parents in screening, even though many of them really only want to see their baby and confirm their dates. Although there are many good obstetricians and midwives who provide excellent care for mothers and their unborn, they are working within a system where if a baby is born with an abnormality which could have been detected (and the baby aborted) they are open to law suits for 'wrongful life'. A court in Britain has already awarded substantial damages to one mother who gave birth to a Down's syndrome child undiagnosed before birth[2].

Tests currently performed

1. Alpha feto-protein

The AFP test has been around for many years as a non-specific marker for conditions such as spina bifida. More recently it has been used in combination with some other blood tests and maternal age to produce a clearer assessment of the mother's 'risk' of carrying a baby with Down's syndrome. Usually performed at about 16 weeks' gestation, with minimal explanation to, and consent from, many mothers, an abnormal result would be followed either by a detailed ultrasound or by amniocentesis. Obviously, more complex investigations usually require more informed consent from the mother, but by now these mothers are very much on the 'seek and destroy' conveyor belt. They are often out of their depth and terrified. I have seen women carried along by the enthusiasm of doctors and midwives and it is hard for them to stand up to pressure in these situations.

2. Nuchal translucency

An additional ultrasound test is being performed in many areas on all mothers at 11-13 weeks to pick up many who show signs of Down's syndrome. It leads on to amniocentesis. Nuchal translucency is however, a remarkably 'soft' sign, associated with a variety of chromosomal defects as well as structural anomalies such as renal dysplasia and exomphalos. When used for population screening only 5% of positive tests are associated with trisomy 21[3]. Nuchal translucency will usually detect for elimination up to 70% of live children with Down's syndrome[4]. All this is done for a condition associated with hardship for parents, but where Down's children are so often specially happy and loved.

3. Amniocentesis

Amniocentesis involves removing fluid from the amniotic sac with a needle and syringe, usually under ultrasound guidance. It can be performed from 11 weeks (after the last period) but because of 'unacceptably high losses' is usually only performed after 16 weeks. The miscarriage rate is 1%, rising to 2% in excess of natural loss when performed as early as 11 weeks (1% of established 16 week pregnancies is actually a very high rate of loss)[5]. Amniocentesis was fairly disastrous for one older mother I knew who had achieved her first pregnancy, was badgered into the test by the registrar, and subsequently lost her baby. Rarer side effects are the formation of silky fibrous bands across the amniotic sac and around which the baby can wrap fingers, toes and even limbs and thus be born without them.

4. Chorion villus sampling

CVS, usually performed from 11 to 14 weeks, aspirates placental tissue for testing, takes 2-3 weeks for a result and causes 1-2% fetal loss.

5. Obstetric ultrasound

Knowledge about gestation can be invaluable if intervention is required for the benefit of mother and/or baby, especially when deciding when to deliver babies around 23-28 weeks. A baby with spina bifida, treatable heart problem or an abdominal wall defect will undoubtedly fare better if delivered in an appropriate unit with specialist paediatric care.

Predictive validity of prenatal diagnosis

Many assume that amniocentesis is the 'gold standard' which gives 100% diagnostic certainty. One interesting report from Denmark questions this statement. Denmark is the only country whose national cytogenetic laboratory follows up testing by analysing the genetics of the baby born, or miscarried, or aborted. They found that one third of babies diagnosed as being chromosomally abnormal with Turner's syndrome who were not aborted, turned out to be normal[6]. Perhaps mosaicism has a part to play in the cause of this[7]. Whatever the reason for this finding, even chromosomal abnormalities on amniocentesis do not mean the child will have the chromosomal syndrome.

Fetal medicine centres

Intrauterine fetal surgery is also able to offer benefits. For example urinary tract obstruction can be treated to save renal function. These more simple procedures have a fetal loss of 8-10% which may sometimes be justifiable. More complex surgical operations which are done between 24 and 30 weeks involve a Caesarean-like delivery, operating on the baby and then returning him/her to the womb. This involves a fetal loss of up to 50% and also has risks for the mother. These latter interventions are still rare and experimental[8]. The centres are high technology specialised places where babies' lives can be saved, but nonetheless hearing the 21 week scan described as an 'anomaly scan', rather than a 'well-being scan' raises concern about the motives of such centres. Reading their literature, I fear they may select out more babies than they save. Much of their expertise was gained by practising on pregnancies due for abortion. Mothers should be well informed if they need to use their services.

Psychological effects of screening

Modern medicine has many benefits and we are fortunate, in wealthy countries, to have access to such care. Such opportunities have their problems as well. Some people may want comprehensive knowledge to prepare themselves for the birth of a child with an abnormality, even though there is rarely any significant medical benefit to be gained. On the other hand the distress and disruption of normal pregnancy by worry is widely recognised. Amniocentesis results take two (worrying) weeks to return. Scans may be happy events, may be worrying, or may be devastating. It does not take much imagination to consider how this affects the unconditional love of parenthood.

'Soft' ultrasonographic markers have been suggested to do more harm than good[9]. Parents undergo testing for reassurance that everything is alright. Doctors screen for abnormality. Medical success in detecting abnormalities leads to severe distress and many have questioned the sense of such tests[10,11]. Worries can be persistent and can damage parental relationships long after birth[12]. An abnormal early scan of a baby with severe structural abnormalities will obviously produce great distress. I have seen a mother in a scan room put in this position. Sometimes interpretation errors occur with the result that normal babies are aborted. Worst case scenarios are often presented along with comments such as 'you must think of the rest of the family'.

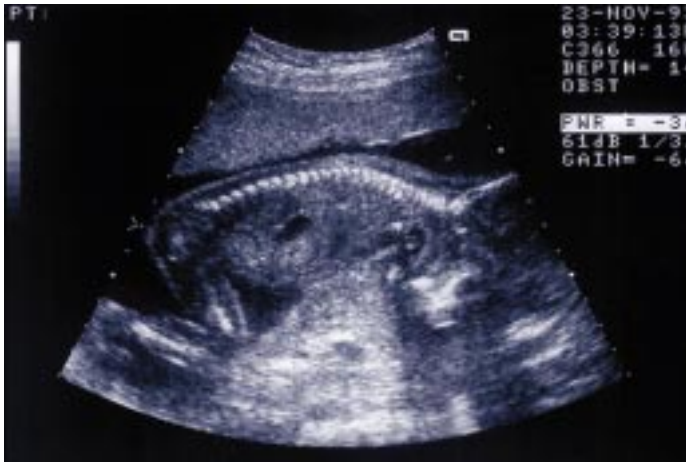
The majority of severely abnormal babies miscarry by the end of the second six months. Kelly[13] has beautifully described how precious short lives can be. 'To me my baby was lovely' said a mother who 24 hours earlier had given birth to a baby with multiple abnormalities and who died 20 minutes after birth. My clinical experience too has suggested that continuing to birth may have great benefits. Women aborting abnormal babies appear to suffer even more than others.

When parents have a disabled child there can sometimes be a sense of embarrassment at the perceived imperfections in the child. How much more so when ante-natal technology claims to be able to spare them such problems? We must remember that children are individuals in their own right who might one day be embarrassed about their own parents. There is no test predictive of adolescent problems or the many other difficulties that parents and children face.

Personal experiences

Perhaps examples from my own experience would be helpful. I trained as a doctor at King's College Hospital which has for many years been in the forefront of ultrasound investigation and research to decrease fetal mortality. As a result, I have been able to understand all the investigations and stages of my pregnancies.

In one pregnancy, during which I had threatened to miscarry several times in the first three months, I was told by the obstetrician that I should have the AFP test. I replied I did not want it. She understood why but still felt the need to press the point. In the end I said she could do it if she wanted to, on condition



Ultrasound scan of Gregory John Treloar

that I was not to know the result - I had had enough stress by then! She actually realised that the test was probably unnecessary and unreasonable and may well have given a false positive result because of the previous problems.

In a more recent pregnancy, I was probably one of those investigated in a large multi-centre study to pick up signs of Down's syndrome using ultrasound. I was following the progress of the scan when I noticed the ultrasonographer was spending a lot of time viewing round the back of the baby's head. 'I'm just measuring fluid around the back of the neck' was the not unreasonable response to my question. It was only after the birth of my baby that I was fully informed of what was being studied. I got my answer from the obstetric registrar whom I met in the car park as we were leaving hospital! Realising how close I had unwittingly been to receiving rather non-specific and entirely unconsented information has made me extremely wary of ever attending for an ultrasound test prior to the time when the information gained is of use regarding the baby's well-being.

As a medical student I saw another woman who had spina bifida herself as a child, pressed to have detailed scans of her baby to look for any possible anomaly even though it would not have affected the delivery and even though the mother would not have considered an abortion.

One woman asked me if, by refusing scans, she was really being irresponsible and denying her baby the best chances of being

born healthy. In a previous pregnancy she had lived through the traumas of two-weekly detailed scans at a fetal medicine centre to which she had to travel from mid-pregnancy. This had been a practical hardship as she still had to care for the family but was also a massive disturbance to her serenity. The tests had not made any difference to the management of the pregnancy. The obstetric registrar felt that she should go through this process again and when she refused wrote in huge red felt pen on the front of her notes to the effect that she had refused medical advice and was highly irresponsible. These were the notes she had to endure everyone seeing each time she attended for care - a gross infringement to personal liberty and autonomy. She did have a detailed scan later on with a view to plan for delivery but it would be fascinating to know, had she been in a position to press the registrar, exactly what, other than a process leading to abortion, she was refusing.

I know of many women who now fear ante-natal care. They are afraid that doctors will do tests which will show an anomaly and then press them to have an abortion. These fears are not irrational, but are based upon the experience of earlier pregnancies. Most women simply trust the system, go along, and get swept away when an anomaly is found. Even good Christian women who are against abortion seem to be highly vulnerable to this effect.

The moral nature of ante-natal information

Many would say that ante-natal information is morally neutral and that imparting such information is simply giving parents knowledge upon which they can base their own decisions. In other words, the doctor performing such tests does not become morally part of an abortion if such follows from the test. In one sense this is indeed true. The 'smoking gun' is seen at the time of abortion and not during ante-natal testing. On the other hand tests which serve no purpose other than enabling the destruction of handicapped children may be seen as loading that gun.

The distress and worry which follow on from an abnormal result can be used to propel vulnerable people towards decisions which they would never otherwise have considered. The mere availability of such information appears to have conferred, for many, a duty to have the tests and abort the abnormal babies. Too often I have heard people using financial and emotional arguments to criticise those who opt to keep a baby despite knowing there is handicap. Many talk of the reassurance that normal tests can provide for parents. In fact this is probably a deception. Scans can never identify normality. They can only detect or fail to detect anomaly. The effort that goes into aborting abnormal babies generates a conditionality about pregnancy which implies and persuades mothers that disabled children are less human than others.

Morally therefore, ante-natal testing which is purely for finding anomalies may be illicit. Indeed such tests may be the preparatory work for promoting abortion. As usual knowledge is a mixed blessing.

What should we do?

We cannot ignore the tragedies that are currently occurring as a result of ante-natal screening. There is a real need to support mothers in pregnancy. They are often alone as they deal with these issues on a personal level and need to know of the risks and issues associated with ante-natal testing. They also need to know where to get support and help. We must ensure there are good, well informed pro-life Christian obstetricians and GPs to whom such women can turn for help. We need to be able to do so with the support of a deep faith and spirituality which clearly understands the humanness of the unborn child as well as the humanity of the mother, especially the mother in distress.

Since ancient times men and women have sought to discern their future. Thomas a Kempis, in his 14th century *The Imitation of Christ*, encapsulates the unnecessary disturbance of serenity we undergo by unnecessary enquiry into future conditions for which there is currently neither a moral nor effective remedy:

'What doth solicitude about future accidents bring thee, but only sorrow upon sorrow? Sufficient for the day is the evil thereof (Matt. vi, 34). It is a vain and unprofitable thing to conceive either grief or joy for future things which perhaps will never happen . . . For he (the devil) careth not whether it be with things true or false that he deludeth and deceiveth thee; whether he overthrow thee with the love of things present or the fear of things to come. Let not therefore thy heart be troubled, and let it not fear.'

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References

1. Shackley P, McGuire A, Boyd P A, Dennis J, Fitchett M, Kay J, Roche M, Wood P. An economic appraisal of alternative prenatal screening programmes for Down's syndrome. *Journal of Public Health Medicine* 15(2): 175-84. 1993
2. Dyer C. MOD settles over Down's syndrome child. *British Medical Journal* 314: 1368. 1997
3. Makrydinas G, Colis D. Nuchal Translucency. *Lancet* 350: 1630-1. 1997
4. Hyett J A, Sebire N J, Snijders R J, Nicolaides K H. Intrauterine lethality of trisomy 21 fetuses with increased nuchal translucency thickness. *Ultrasound in Obstetrics and Gynaecology* 7(2): 101-3. 1996
5. Salvesen D R, Goble O. Early amniocentesis and fetal nuchal translucency in women requesting karyotyping for advanced maternal age. *Prenatal Diagnosis* 15(10): 971-4. 1995
6. Gravholt C H, Juul S, Naerra R W, Hansen J. Prenatal and postnatal prevalence of Turner's syndrome: a registry study. *British Medical Journal* 312: 16-21. 1996
7. Johnson A, Wapner R J. Mosaicism: implications for postnatal outcome. *Current Opinion in Obstetrics & Gynaecology* 9(2): 126-35. 1997
8. Kimber C, Spitz L, Cushieri A. Current state of ante-natal in utero surgical interventions. *Archives of Diseases in Childhood* 76: F134-F139. 1997
9. Whittle M. Ultrasonographic markers of fetal chromosomal defects. *British Medical Journal* 314: 918. 1997
10. Bunn A, Joannou G, Forrest K, Rea R. Serum screening for Down's syndrome. *British Medical Journal* 312: 974. 1996
11. Warner D. Testing for Down's syndrome causes too much stress. *British Medical Journal* 312: 379. 1996
12. Mason G, Baillie. Counselling should be provided before parents are told of presence of ultrasonographic markers of fetal abnormality. B*ritish Medical Journal* 315: 189-90. 1997
13. Kelly J. A difficult delivery. *Lancet* 335: 861. 1990