THE PRICE OF PROGRESS

Is the increasing knowledge about fetal abnormality really providing a service to the mother? Soo Downe suggests it may be a double-edged weapon

THE rapid development of tests designed for use in pregnancy worries me. The debate surrounding the Human Embryology Bill has raised many questions about the importance of understanding embryotic development and, while I believe that improving our knowledge of the process of embryology and pregnancy is theoretically a good thing, I also feel that a sudden increase in such information without a concurrent increase in the knowledge of prevention and cure of abnormality is psychologically dangerous.

The recent experience of a friend highlights some of my concerns. The friend received the result of the routine alphafeto protein (AFP) test, undertaken at 16 weeks of pregnancy. She knew that if the result was high it could indicate that her unborn child suffered from spina bifida. She had considered the possibility of termination if this was the case. However, she was not aware that there was also interest at the time in low AFPs and their possible link to Down's syndrome.

The results proved to be low for the gestation of the pregnancy as determined by scan. She was devastated when told what this might indicate. She had to endure a week of waiting for the results of a further chromosome analysis, knowing she may still have to decide whether she would undergo an amniocentesis, risking a one per cent chance of miscarrying what was probably a normal baby.

The repeat chromosome analysis tests showed a reduced risk that the baby suffered from Down's syndrome, but did not rule out the possibility. In the meantime, she decided that she would not undergo a termination, whatever the results indicated.

She is left with both relief and doubt — and with a subtly changed relationship to her unborn baby.

My friend's experience convinced me more than ever that the psychological burden of suspected abnormality at this highly susceptible time of pregnancy is a heavy one to bear.

Barbara Katz Rothman's book, *The Tentative Pregnancy*, reinforces these views. She comments:

'It is often taken for granted that the more information doctors can obtain about what is going on inside a pregnant woman's body, the better; that any intervention to reduce the risk of the birth of a sub-standard baby must be beneficial; and that a women should submit, for the sake of her baby, to whatever tests and treatments are available'.

But it is the women and their families who have to make profound psychological and emotional decisions about the results: to terminate or not to terminate.

It is easy to see that congenital malformations that are severely limiting or immediately lethal could be deemed to be morally justified grounds for termination by most people. But what about conditions such as cystic fibrosis or cleft lip and palate?

Women are having to weigh up the economic, moral and psychological dilemma of terminating a wanted child on the basis of tests that are not 100% specific. What is more, some of the tests carry a concomitant risk of damaging a perfectly normal child.

A further problem is when the diagnosis predicts the death of a child some time in the future — for example, a diagnosis of Duchennes' muscular dystrophy. When is it reasonable to say that it will it not be justifiable to bring him/her into the world?

Rothman talked to a woman whose child died at the age of 10 after a long illness, and asked her whether she regretted having had the child. The women said no. Rothman then asked her whether, if she had been told before he was born that he would die that way, she would have continued with the pregnancy. The woman's response was: 'Where would the strength come from to bear a child that would die?'

There are undoubtedly very positive benefits for many people in the choices offered by modern medicine and in the advances to come. However, I feel that, as the nurses and midwives who may be faced with people having to make impossible decisions, or having to live with what in retrospect may have been the 'wrong' decision, we must begin to recognise that the power to choose life or death is a terrible one that carries profound psychological trauma. **NT**

REFERENCE

Katz Rothman, B. *The Tentative Pregnancy: Prenatal diagnosis and the future of motherhood.* London: Pandora, 1988.

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