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Selective Abortion For Fetal Anomaly: The Perspective Of A Support Organization.



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Antenatal Results and Choices (ARC) is a UK charity that has been providing non-directive information and support to women and couples about prenatal testing and its consequences for more than 25 years. In that time we have had contact with thousands of expectant parents given a diagnosis of fetal anomaly and supported them through the difficult experience of ending what is most often a wanted pregnancy.

ARC has no agenda or investment in the decision women make after a prenatal diagnosis. We want to ensure that they are enabled to make the choice that is individually right for them: it is the women, and their partners, who have to live with the consequences. Our extensive contact with women and couples has given us insight into what they bring to their decision and the medical, cultural and political context that frames this complex experience. We can attest to the fact that in these complicated and often traumatic circumstances, women are capable of making the choices that are best for them and their families.

The legal context in the UK

In England, Scotland and Wales, abortion under 24 weeks' gestation is legal under Section 1 1(a) of the 1967 Abortion Act:

... when a pregnancy is terminated by a registered medical practitioner if two registered medical practitioners are of the opinion, formed in good faith — (a) that the pregnancy has not exceeded its twenty-fourth week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children of her family.

Terminations for fetal anomaly (TFA) are sanctioned (without gestational limit) through Section 1 (1) (d) of the Act, if:

... two registered medical practitioners are of the opinion, formed in good faith — (d) there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.

Neither 'substantial risk' nor 'seriously handicapped' is defined, which should enable doctors to consider the relevant factors in a particular case.

Although this legal ground extends beyond 24 weeks' gestation (the legal limit for most abortions), very few TFAs take place in the third trimester. There were fewer than 200 in 2013. ARC is aware that clinical practice in sanctioning post-24 week TFAs is variable. For example, some doctors will certify a third trimester termination after a late diagnosis of Down's syndrome and some will refuse.

The reality for a woman is that, after 24 weeks' gestation, it is her doctors' attitude to the potential outcome that holds sway. Before this point, under British law two doctors have to authorise the abortion, but the woman's views take precedent.

The medical context

All women in England, Scotland and Wales are offered screening tests in their pregnancy for Down's syndrome, sickle cell and thalassaemia, and structural fetal anomalies. Such

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testing is optional, and while the vast majority opt to have ultrasound scans, the uptake for Down's syndrome varies across the country, with an overall total of around 70 per cent of women opting in. Diagnosis of fetal anomaly continues to rise due to an increase in maternal age and the application of more sensitive testing technologies.

A recent major development in prenatal testing is the introduction of non-invasive prenatal testing for Down's syndrome (NIPT). This involves a maternal blood test from which circulating cell free fetal DNA is extracted for analysis. Without putting her pregnancy at risk a woman can get a 99 per cent accurate assessment of the chance of her baby having Down's syndrome. This is 10-15 per cent more accurate than standard screening tests.

NIPT is widely available in the private sector from 10 weeks' gestation and an evaluation study is underway to see how it might be implemented within the National Health Service (NHS). At the same time a new technique for detecting chromosomal anomalies is being introduced into practice. Known as array comparative genomic hybridization (arrayCGH),

this method is a hundred times more sensitive than conventional chromosome analysis. While this can improve the detection rate of genetic conditions, it will also pick up genetic copy number variants (CNVs) of unknown significance.

Concerns in the clinical community about relaying information of uncertain consequence are illustrated by this extract from a major UK research study into the prenatal application of arrayCGH:

The main risk is that arrayCGH will detect a significant number of CNVs with unknown or variable significance and that, in communicating these results to parents, we will increase the anxiety associated with prenatal testing. In some cases the inability to cope with the uncertainty of a CNV's significance could lead parents to choose to terminate a fetus potentially at low risk of adverse outcome. (1)

There is currently a debate within the genetics community as to whether arrayCGH should be narrowly targeted to avoid presenting what some ethicists have dubbed 'toxic' information to expectant parents. Others believe this restriction impinges on the woman's autonomy and her right to know as much as possible about any potential genetic anomalies affecting her fetus. The debate is likely to continue as scientists are on the cusp of being able to sequence the whole fetal genome within pregnancy.

While there are no easy answers here, prenatal tests revealing uncertain information are not a new phenomenon. Ultrasound scanning has been around for decades and can detect an ever-increasing number of unusual features in the developing fetus. However, doctors' ability to apply accurate prognosis has not kept pace.

All too often, fetal medicine specialists find themselves pointing out anomalous scan findings that may indicate potential disability but are unable to give the woman a clear picture of what it will mean for her child. Some women decide to end the pregnancy in this circumstance as they feel unable to manage the uncertainty ahead and the possibility of an adverse outcome. While we support such an autonomous decision, we also recognize the ethical load this places upon clinicians in the field.

With the very limited number of in utero treatments for fetal anomaly at their disposal, many fetal medicine specialists spend much of their clinical time giving expectant parents difficult news without being able to intervene medically to 'make things better'. At ARC we have maintained a close collaborative relationship with clinicians to help them to address both their own needs, and the needs of women in their care.

The cultural context: the spectre of eugenics

Prenatal diagnosis and subsequent abortion decisions have long been the subject of debate within the disability rights community. While many commentators identify as pro-choice, they worry that the provision of prenatal screening in order to facilitate reproductive decision-making promotes a negative attitude to those living with disability. To quote disability studies academic Adrienne Asch:

The focus of my concern here is not on the decision made by the pregnant woman or the woman and her partner. I focus on the view of life with disability that is communicated by society's efforts to develop prenatal testing and urge it on every pregnant woman. (2)

In the UK there has been focus on the abortion law as it applies to fetal anomaly, and some have suggested that the difference in time limit for the abortion of a 'healthy' fetus as opposed to one with potential disability is discriminatory. A group of anti-choice Members of Parliament (MPs) went so far as to instigate an enquiry that concluded:

Parliament should consider at the very least the two main options for removing those elements which a majority of witnesses believe are discriminatory – that is either reducing the upper time limit for abortions on the grounds of disability from birth to make it equal to the upper limit for able bodied babies or repealing Section 1(1)(d) altogether. (3)

These 'expressivist' arguments often resonate with pro-choice advocates. In this regard, it is worth quoting the well-known British disability rights campaigner and academic Dr Tom Shakespeare, who has achondroplasia (a form of dwarfism):

I conclude that prenatal diagnosis is not straightforwardly eugenic or discriminatory. We should be on hand to offer counselling, good quality information and support, but we should not venture to dictate where the duties of prospective parents may lie. Nor should we interpret a decision or termination of pregnancy as expressing disrespect or discrimination towards disabled people. Choices in pregnancy are painful and may be experienced as burdensome but they are not incompatible with disability rights. (4)

It is reassuring that in the UK, the introduction of national prenatal screening programs in the past 20 years has coincided with improvements in conditions for those living with disability with the introduction of legislation to promote inclusion and reduce discrimination. Thus the provision of prenatal diagnosis and the fact that most women confronted with serious fetal anomaly decide on termination is compatible with an empathetic and inclusive attitude to those living with impairment.

The political context of abortion: 'You are the person responsible for the loss; abortion suggests the baby is unwanted' (5)

Many women facing a diagnosis of fetal anomaly find that their stance on abortion in the abstract changes in the complex reality of what it means for their prospective child and their own future. We speak regularly to women on our helpline who define themselves as anti-abortion and are anxious to differentiate themselves from those who end pregnancies for non-medical reasons.

The fact that 'termination' is the term consistently used in this context illustrates the emphasis on the medical grounds and perhaps an attempt to avoid the stigma associated with 'abortion'.

Psychologically many women struggle to reconcile their concept of themselves as a mother carrying a desired baby with the decision to terminate:

I really thought after bonding with my baby and thinking the week before we found out the results that I would never dream of ending the pregnancy whatever the outcome. I researched the condition, and we just wouldn't know how poorly she would be until she grew up (if she lived that long). (6)

Such conflicted feelings can lead to what has been termed 'disenfranchised grief', where women do not feel they deserve sympathy from others or have the right to mourn their loss because it was self-inflicted.

The complicated grieving process in the aftermath of TFA can be exploited by those who wish to prove that abortion harms women. ARC is aware of 'crisis pregnancy centers' in the UK that are all too ready to exploit women's ambivalent feelings, by providing them with 'post abortion recovery programs' that aim to highlight the 'wrongness' of their decision and suggest that only through absolution will they find peace.

Final thoughts: Supporting women who terminate a pregnancy for fetal anomaly

In the midst of the context outlined above is an individual woman reeling from the intense shock inherent in the news of fetal anomaly. Suddenly her world is shattered as she is no longer expecting the healthy baby around whom she had built her hopes and expectations. In a state of emotional turmoil she has to negotiate a way forward that she knows will be life-changing.

[1] In the UK, the introduction of national prenatal screening programs in the past 20 years has coincided with improvements in conditions for those living with disability.

Some women take longer than others to come to a decision. It will always be painful; it will often feel almost impossible to envisage two apparently equally onerous potential outcomes. Our work at ARC and published evidence tells us, even in these extreme circumstances, that women are able to make the choices that are right for them and to live with these choices:

This was the most dreadful thing we have ever been through in our lives. The grief, the emotional pain and the shock were overpowering. But even through this truly terrible time we felt a sense of gratitude that we had the choice to end the pregnancy. We felt and still feel that we made the right decision for us, but also, importantly, for her. (7)

Expectant parents are best placed to decide what they can cope with and what they want their child to cope with, and should be able to depend on our unequivocal support and compassion for their choices.

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- (7) ARC Newsletter, August 2011: Woman who had TFA after diagnosis of spina bifida.

Jane Fisher joined Antenatal Results and Choices (ARC) in 2001 as Support Coordinator and became Director in 2004. ARC is a UK charity with a remit to provide non-directive information and support to parents throughout prenatal testing and when fetal anomaly is diagnosed. Help is offered for as long as is needed whatever decision is made about the future of the pregnancy. ARC also runs a well-established training program for health care professionals. As well as managing the charity, Ms Fisher is also involved in directly supporting anxious expectant and bereaved parents, training health care professionals, research, policy and media work. She represents service users on the UK National Screening Committee, Fetal Maternal and Child Health Group of the UK NSC and a number of its subgroups.



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