

Editorial

Ethics of fetal echocardiography

Elliot A. Shinebourne and Julene S. Carvalho

THE EDITORIAL OF SQUARCIA AND COLLEAGUES WILL strike a sympathetic chord with many pediatric cardiologists and fetal echocardiographers. Others may disagree with the contention that some fetal echocardiographers, having diagnosed an abnormality, leave their patients with agonizing decisions they never wanted. Pregnant women may feel pressurized into considering or having a termination of pregnancy for fetal abnormality. Squarcia et al's paper is deeply felt, but some of the ethical issues raised merit further discussion. In addition, the final statement that whether a woman decides to have an abortion because of a fetal heart defect should depend in part on the needs of society is, in our view, ethically dubious.

Informed consent

Since the Second World War, informed consent has been a prerequisite of acceptance of medical investigation or treatment. In the editorial of Squarcia et al¹ and the commentaries by Allen² and Sandor,³ it is assumed that the diagnosis of a serious cardiac abnormality made by fetal echocardiography may produce an ethical dilemma for both patient and physician. No mention is made, however, as to whether informed consent is either needed or obtained to the study. Certainly the woman consented to a scan, but was she informed? Did she know the possible implications of finding an abnormality? Many women are told, or believe that the scan is carried out "to confirm that the baby is all right." They do not realize or are not informed in advance of the down side of the coin—what is to happen if the baby is not all right? This highlights the difference between a fetal echocardiogram carried out at the request of the woman, typically because she has had a previously affected child, or that carried out as part of a screening program. The need for informed consent prior not only to the fetal echocardiogram but also to a routine obstetric scan has also discussed by Chervernak and McCullough.⁴

Who is the patient? Fetal and maternal rights

The accompanying article does not always define who is the patient being discussed. Do Squarcia et al¹ mean the pregnant women, her fetus with congenital heart disease, or both? A discussion of maternal versus fetal rights inevitably leads to a conflict since the perceived rights of one, for instance the mother choosing a termination of pregnancy, may conflict with those of the other the fetus, who will not have a life if pregnancy is terminated. We prefer the language philosophy and practical expression of duties rather than rights. This inherently recognizes a hierarchy of duties, in this case both to the mother and fetus. Against this background there are few circumstances, maternal drug abuse being one possible exception, where the duty of care is equal or greater to the fetus than the mother. In the law of the United Kingdom, this is also recognized in the 1967 Abortion Act. If the pregnant woman's life, physical or mental health would be permanently damaged, termination can be carried out at any time during pregnancy. Below 24 weeks of gestation termination can be carried out if "the continuance of the pregnancy would involve risk to the physical or mental health of the pregnant women, or that of her children, greater than if the pregnancy were terminated." Squarcia et al¹ are also concerned about the responsibility of the physician "to the future of humanity." Apart from the fact that neither the future nor humanity are the patient, many atrocities have been committed in the name of the good of mankind (cleansing society of the handicapped, gypsies, Jews, and so on). Treating "humanity" or "the future of mankind" always has the danger of treating the individual as a means rather than an end. This danger was clearly articulated by Kant in his categorical imperatives: "One must always act in such a way that you treat humanity whether in your own person or in the person of any other never simply as a means but always at the same time as an end."⁵

Information, directive and non-directive counselling

Squarcia et al¹ comment that the prevailing wisdom

among those who specialize in the field is that information concerning the conditions diagnosed during fetal life should be presented to the mother or parents in an objective and unambiguous fashion, with information provided on the likely success of treatment, the risks involved, and on the expected length and quality of life. On the basis of all this information they contend that the parents will be able to make their own judgement... Squarcia et al¹ however, go on to imply that the passing on of the burden and drama of the decision concerning life to the parents who are often alone and desperate, may be irresponsible. Sandor³ in his accompanying commentary states clearly his strongly antipaternalistic view that only the parents have the right to make the decision, the role of the physician being to provide non-directive counselling, that is to provide the information necessary for parental decision making in an unbiased manner. But Sandor³ acknowledges that this may be difficult, as bias may be subconscious. Allan² in her accompanying commentary states "I have had the opportunity to follow the children of the continuing pregnancies and the families of those parents who chose to interrupt." In Allan's view "the suffering involved in the continuing pregnancies was many times greater than in the group who did not have a termination." This is her personal view, although the experience of others may be different. What Allan² does appear to imply, however, is that because of her personal experience, while honest information must be given to parents, she has adopted a more directive role in counselling than her previously non-directive stance.

Anthony Storr, in his book *Music and the Mind*⁶ notes that linguistic analysts distinguish prosodic features of speech from syntactic: stress, pitch, volume, emphasis and any other features conveying emotional significance as opposed to grammatical structure or literal meaning. He notes that there are many similarities between prosodic communication and music. Infants respond to the rhythm, pitch, intensity and tone of the mother's voice, all of which are part of music. The intrinsic prosodic component of language inevitably influences communication. As Sandor³ comments, bias in counselling may be unconscious. We would argue it is inevitable. We believe the ethical way to deal with this in counselling is to acknowledge that, however hard one tries, counselling will contain a directive component. This being the case, the bias of the fetal cardiologist, as far as he or she can recognize it, should be expressed. The pediatric cardiologist, not the patient, has prior experience of congenital heart defects and their knowledge is not symmetrical. While only the parent, the pregnant woman, can decide what it means to her to have a fetus with a heart anomaly, it is the physician who gives her crucial information which will assist her to make her judgement.

Information or facts can be presented in different ways. In counselling a family whose child has congenital heart disease, saying there is a 10% surgical mortality may be experienced as worse than a 90% success rate, yet the facts are the same. Prior experiences of the family will also influence how the information is received, for instance knowing a family whose child has had successful surgery may encourage proceeding with the pregnancy while knowing a child who has died may have the opposite effect.

Why undertake termination of pregnancy for congenital heart disease?

The decision to choose termination of pregnancy for a fetal cardiac anomaly in practice is usually social rather than medical, even though many families and doctors might wish or believe it to be the reverse. For it to be a medical choice, the quality of life of the fetus when born would have to be so distressing that death were preferable. This is not really so. The major consequences of congenital heart disease are breathlessness and cyanosis, both of which can usually be ameliorated. Even if the anomaly cannot be corrected, a short life expectancy is, for many, the most compelling reason for termination, although the distress produced is principally that of the parents rather than the child. Most people, if asked about their own life, would prefer some life even if short to no life at all.⁷ Most congenital heart disease does not cause such a dreadful existence for the patient. But, if a series of operations or other procedures is necessary to preserve life, and the quality of that life is poor and of short duration, then an abortion may be carried out to spare suffering in the fetus when born. Hypoplastic left heart syndrome arguably exemplifies such a condition, but most hearts with a univentricular atrioventricular connection (double inlet ventricle, tricuspid atresia) do not.

Conclusions

The pregnant woman, not society, is having the baby with congenital heart disease, and she should decide whether or not to elect for an abortion. The physician has a greater duty of care to the woman than to the fetus. The implications of finding an abnormality should be discussed prior to any obstetric scan so that the woman's consent to the procedure is adequately informed. Full information about a fetal heart anomaly should be given as objectively as possible, including natural history and prognosis with treatment, but the way this information is given will influence its reception.

As counselling involves language, there will always be a tendency for the counsellor to influence the family one way or the other. The directive component of counsel-

ling should not become oppressive so that a woman feels pressurized to have a termination. But neither should she feel abandoned in seeking assistance with her decision. Finally, no objective data exists on whether the long term effects on a woman are greater if she continues with a pregnancy and the infant dies after birth with or without a surgery compared with elective termination of pregnancy in the second or third trimester. Here is an area for further research.

*Royal Brompton Hospital
Queen Charlotte's Hospital for Women
National Heart and Lung Institute
Imperial College School of Medicine
London
United Kingdom*

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