

Editorial

Fetal diagnosis of congenital heart disease

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TECHNOLOGICAL ADVANCES WHICH IMPROVE PATIENT care often also raise new ethical problems. This is especially true of fetal echocardiography, a relatively new use of diagnostic ultrasound. Presumably as a result of this, Squarcia et al¹ have offered us their views concerning the moral and ethical issues raised by the use of this technique. While their commitment is admirable, a very careful analysis is required of their position. They begin with a factual, dispassionate discourse of the current status and role of physicians in fetal echocardiography. They then question this role and propose that physicians have a higher calling in their ethical responsibility to research, science and humanity. They exhort us to strive to do everything to save life and, even if this or a cure is not possible, to promote hope. Their arguments follow two main paths: first, that parents should not decide the fate of their fetus (and by inference their child) and, second, that physicians and patients have an obligation to humanity above that of the individual. Squarcia and his colleagues, therefore, seek to reverse the perceived trend for parental decision making or directive counselling which results in termination of the pregnancy. My response to their editorial is based on experience in performing over 3,000 fetal echocardiograms since 1979 and counselling the families.

The language used by the authors emphasizes their bias and their editorial proselytizes unnecessarily. Their description of the "burden and drama of the decision concerning life" for the parents reveals more than bias, and the contention that termination is the "easy decision" reveals a surprising lack of understanding of this agonizing decision with its long-term psychological trauma.

I live in a multicultural society in a secular state, as do most people for whom fetal echocardiography is available. No individual should seek to impose a set of beliefs or ethics on patients who are in a most vulnerable state, to persuade them to undertake a course of action which may not be in their best interest. The days are gone

when the doctor "knew best" and paternalistically protected the patients from unpleasant facts and painful decisions. Nowadays, patients rightly demand to make their own decisions. The role of the physician must be to provide non-directive counselling—that is, to provide the information necessary for parental decision making in an unbiased manner. This may be more difficult than realized, as bias may be subconscious. Physicians, unlike other health-care professionals, receive no formal training in counselling. Sometimes it appears that the family asks the physician to take over the decision. How many times have we been asked, "If it were your baby what would you do, doctor?" While this question expresses the parents' dilemma, it should not be interpreted as giving away the right to make the decision.

Squarcia and his co-authors exhort us to strive for an ethic that is higher than research alone—that is, an undefined humanity. The use of phrases such as "abandon it to death," or "passing by with indifference," denigrates those who do not share this view and who give a different form of care to ease suffering. Squarcia et al go on to state that we are the result of scientific battles fought for humanity. For them, it follows that we should battle on for the sake of the next generation; the experience gained in treating these patients may benefit subsequent patients. This argument is made with the disclaimer that this practice does not make use of the patient.

In their conclusions, the authors invoke an all-encompassing role for "science." They propose that the balance in the conflict between the needs of the mother and society be tilted toward society. Their reference to suffering is abstract. The reality is that those who suffer are the individual babies and also their families. While there is no doubt that medical progress has been made by those who sought innovative treatment, this is not an argument that justifies coercion or persuasion of patients to undertake a course of treatment or complex surgery. The basic premise made by Squarcia and his colleagues, claiming a right on behalf of humanity, has great potential danger. Much harm has been done in the name of a higher ideal, whether that ideal be religious,

political, scientific or medical. The first and overriding responsibility of any physician is to the welfare of the individual patient.

Irrespective of our personal beliefs, therefore, in prenatal counselling for fetal echocardiography, we must, first, inform, second, aid the parents to come to their own decision based on these facts, and third, be supportive of their decision. The counsellor should avoid imparting his or her own bias.

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Reference

1. Squarcia U. Fetal diagnosis of congenital cardiac malformations: a challenge for physicians as well as parents. *Cardiol Young* 1996; 6: 256-257.