

Editorial

Fetal diagnosis of congenital cardiac malformations—a challenge for physicians as well as parents

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FETAL ECHOCARDIOGRAPHY HAS GREATLY CONTRIBUTED to our improved knowledge and understanding of normal, as well as abnormal, fetal growth and development. With fetal scanning, it is possible not only to visualize the cardiac structures from the 16th week of development, but also by means of Doppler echocardiography to measure the velocity of flow. In this way, it is possible to derive important information about fetal conditions. When complex congenital heart diseases, or other severe congenital malformations including chromosomal abnormalities, are diagnosed during fetal life, ethical problems are produced not only for the physicians and specialists who are monitoring the pregnancy, but also for the parents of the fetus.

It seems to us that prevailing wisdom among those who specialize in this field is that information concerning the conditions diagnosed during fetal life should be presented to the mother, or the parents, in an objective and unambiguous fashion, with the prognosis being presented in the same clear way, giving information on the likely success of medical therapy, surgical intervention, the risks involved, and on the expected length and quality of life. On the basis of all this information, the parents will be able to make their own judgment concerning progress of the pregnancy, taking into account also the pertinent laws permitting fetal termination.

The role of the physician, then, is to present the precise diagnosis and to explain it in the most objective and understandable way. But is this attitude on the part of the physician appropriate and sufficient? From a formal, and a legal, point of view, such an approach will certainly prevent any potential legal actions against the doctor, a consideration which, at this time, is not irrelevant. But what about the social and moral position of the clinician? What responsibility does the physician have to the future of humanity, and how is this to be reconciled with the position of the physician as clinician, and researcher?

Some physicians in such circumstances have made progress which has contributed to making life more livable. If cases are excluded in which the prognosis is unequivocally fatal, should it be said then there is nothing to do, or should attempts be made whenever possible to improve the outcome for the afflicted fetus? Clinical activity is not a position of privilege, nor is it easy. It is a commitment. The clinician must assume commitment first of all with him or herself, with the realities in which he or she believes, but then particularly with the scientific world, and with humanity.

This commitment requires that everything possible is done to help the sick people to get better, to provide better living conditions, and by means of intelligence, solidarity and perseverance, to widen the frontiers of knowledge. There should be an ethic for the clinician

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which is beyond that of research alone. It has its own rigorous requirements. In our opinion, humanity rewards those who have dared and tried, but forgets those who have surrendered to “there’s nothing to do.”

The sick or malformed fetus is a human being. It may be that we must accept that the fetus will die, but we should not omit, because of inertia, convenience, expense, or fear, to make attempts to improve the condition of the fetus rather than abandoning it to death. The clinician must always fight disease, rather than abandoning the sick to their fate, passing by with indifference those who live and suffer. To work through one’s own endeavors, and to involve other colleagues in the battle to defeat disease, is the noblest task for the clinician. Such interventions might not be successful, but that does not mean that the attempt should not be made.

Within this frame, what does it mean to limit oneself simply to diagnosing the condition? Then to pass on the burden and the drama of the decision concerning life to the parents, often alone and desperate? In which decision should the parents be involved? In the easy one of interruption, or in the alternate one of seeking to preserve the fetus and then, whenever possible, starting treatment and repair?

The fetus, as well as the pregnant woman, is a person within the community of the family. In this respect, the family encompasses the groups, the cities, the world, those who live today, and those who will come tomorrow. We should not forget, therefore, that we also come from yesterday. We are the heirs, the beneficiaries of a previous humanity which dared on our behalf. How and what would be our lives today if others had not fought similar seemingly impossible battles on our behalf?

As clinicians, we must accept our responsibility to help others, and to seek to provide a more adequate service. When there are chances to cooperate in solving some human problems, to follow a pregnancy all along its course is not for using the fetus as an instrument, nor

for serving ambitions of science or the clinician. Our aim should be to assist the fetus as a patient that is also a person. We should then cooperate within the limits of our own responsibilities to produce the best possible conditions for future life.

Our own strongly held belief is that it is better to operate and work in the context of hope. Interruption removes the malformed fetus. It does not cure the underlying malformation within the fetus. Thus, removing the fetus does nothing to prevent the disease, and does nothing to help those who are thus affected. It is our belief that it is better for the clinician to treat the diseases and not to suppress the patients, seeking to help them overcome their suffering. The road to recovery and cure, if found for one patient, increases the hopes of others. More importantly, it gives to other physicians the reason to dare to treat with more confidence. The clinician or researcher should never give up! Even after death, by means of the autopsy, the clinician seeks to subtract from death the secrets it keeps within. The clinician must always be looking to the “not yet” of research.

Our aim is to develop a science which does not take refuge in the existing state of knowledge. We seek to encourage a society which perseveres in research, and which works to involve in its path not only the patients, but also the health organizations, the socio-political world and the families. Science is an essential component of society, and it makes use of society. Science realizes conditions of solidarity, and links ethics, politics and human well-being. We submit that the decision to be made by the pregnant mother carrying a malformed child should be a confrontation between her own needs, her own personal condition, and the needs of society.

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