

To the Editors

It was with great expectations that I turned to the Special Article *Reflection on the Past, Present, and Future of Pediatric Cardiology* by J.I.E. Hoffman.¹ The composite graphs of the natural history, and of surgical outcomes, were very revealing. I congratulate the author on the extensive effort needed to assemble so clear a picture for each individual defect. It was, however, sobering to note that, although we have achieved much, we still have a very long way to go before our patients can expect a reasonably "normal" span of life.

If healthful survival of its patients is to be a goal of pediatric cardiology, one must wonder whether the predicted "success" in the projects now being investigated will get us there? Homografts, conduits, myocardial protection, putting a small fetus on cardiopulmonary bypass or performing a fetal transplantation (perhaps with a pig heart into a human child), raise a nightmarish specter in which one searches in vain for justifications based on human values or social responsibilities. Have we not felt the anguish of parents who witness the suffering and disability of their child and who, over and over again, ask WHAT THEY CAN DO TO HAVE A NORMAL BABY? ? ! [sic]

In 1958, at the Third Congress of Cardiology, Dr. Ignacio Chavez, founder of the National Institute of Cardiology, Mexico City, delivered a compelling call for humanism to counterbalance the technologic transformation of medicine which would dehumanize the patient, the physician, and eventually Medicine. His words were unequivocal:

"A physician who lacks humanistic culture may be a great technician in his craft, may be a learned man in his science but in all else he cannot be but a barbarian, wholly ignorant of that which gives human understanding and sets the values of the moral world. And that, in a cardiologist, is unforgivable."²

Those of us who were young then did not think that this could happen. We, like Dr. Chavez, felt that:

"...we would not know what to do with such a medicine, transmuted and dehumanized, converted into a philosopher's stone."²

Yet, 36 years later, we hear the similar words of W.A. Silverman in his special article *Overtreatment of Neonates*:

"The dramatic increase in technical power in

neonatal medicine has made possible an unprecedented form of extremism—When the fulfillment of an eager team's dream of 'rescue' brings about the real-life enactment of a family's worst nightmare, something momentous has happened to the unwritten rules of common decency."

WHERE ARE WE GOING ??? AND WHY ??? [sic]

How can prevention be dismissed as "having little impact on the total incidence of congenital heart disease"? In fact, preventive measures have already had a notable effect when applied case by case, group, and region by region. Journals and books are replete with promising reports. Geneticists and teratologists have already attained a remarkable understanding of the origins and mechanisms of developmental deviations. Epidemiological studies in Europe and in America are identifying risk factors and a increasing potential for preventive interventions.^{4,5} Shall we not link the etiologic investigations of congenital heart disease with those of the rest of the embryo? Shall we not be inspired by the prevention of neural tube defects by so simple a measure as good nutrition? Should we not turn every stone possible to investigate the teratogenic effects of maternal diabetes, and to protect women and men from the reproductive toxins they encounter in their work and their lifestyles?

"Preventing many birth defects is an attainable goal. What is needed now is the will and resources to find the causes of birth defects and then actually to do what it takes to prevent them."⁶

Let a new generation of pediatric cardiologists become pioneers in these endeavors.

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Methinks the lady doth protest too much, and with hyperbole more suited to an advertising campaign than to scientific reasoning.

Everyone will agree with Dr. Ferencz that prevention is the ultimate goal for congenital heart disease, as emphasized in my article, but in practice prevention has limited applicability. Other than rubella immunization, and the avoidance by pregnant women of cardiac teratogenic drugs like lithium, retinoic acid and alcohol, there is little we can do to prevent most congenital heart disease. That is why I spent about two-thirds of the discussion of the future of pediatric cardiology referring to new molecular and cellular findings that might at some future time improve our ability to prevent these diseases.

Nevertheless, we have to deal with problems that now exist; we do not have the luxury of postponing the treatment of people who have serious cardiac problems just because we cannot yet prevent them. The remainder of the discussion about the future concerned things that are now being done or are on the drawing board. I have difficulty understanding why Dr. Ferencz regards some of these as "nightmarish specters." Why does she regard with horror the notion of improved myocardial protection for procedures now being done? We now put in homografts which give people many years of good health, but sooner or later fail, so that there is every incentive to trying to make them better. We put in conduits to reconstruct right ventricular outflow tracts, but have to change them if they get too small or become occluded. Surely it is useful to the patients and their families for someone to develop a conduit on a stent that can be expanded as the child grows (this is now being tested) so that there will be need for fewer reoperations. Does Dr. Ferencz really believe that saving a baby's life by doing an arterial switch for complete transposition has "no justification based on human values or social responsibilities"?

Advances in human treatment have often been won with great difficulty. Children with leukemia had a terrible prognosis before therapy was started. Then, in the early days, the therapy was painful and often ineffective, and many of us, including me, wondered why we should put people through that misery. Today, however, the results are much improved, even though the

treatment is still unpleasant, and many parents and children are enjoying their lives despite the uncertainties that the future may hold. I doubt if cardiology is any different.

There is a great difference between heroic (and unwarranted) therapy and that therapy that is "high tech" but works well. At present, attempts to save a 400 gm, 24-week gestation fetus lead to pain for all concerned, and almost certainly to a delayed and unpleasant death. Most of us would not condone the attempt. However, the same technology is being used to save the life and health of a 1000g fetus, who will probably lead a normal life. Furthermore, there was a time when those 1000 gm babies did not survive because the necessary research into cardiopulmonary, neurologic, and metabolic function had not been done.

When I wrote about the prospects of fetal cardiac surgery and neonatal xenotransplantation, I was referring to possibilities that might not only save lives in the immediate future, but lead to better and longer quality of life. Thus if it were possible to open up *in utero* an atretic aortic valve so that the left ventricle could develop, or an atretic tricuspid valve so that the right ventricle could develop, then after birth the child could have a two ventricle repair rather than a one ventricle repair or a transplant, and that might confer a great benefit on all the family. Or if fetal or neonatal tolerance to cardiac xenografts became a reality, then a cardiac transplant might lead to a normal healthy life, free from the need for immunosuppression. Obviously, I am assuming that the end result of the technique will be a satisfactory result, and for many of the suggestions that I made this may not be true. The decision to use them or not, however, will need to be made on their value, not whether they are or are not "high tech."

Finally, I would like to assure Dr. Ferencz that, as a practicing pediatric cardiologist, I (and the vast majority of my clinical colleagues) have great empathy with our patients and their parents. I have from time to time advised that therapy should not be started or should be withdrawn when this was clearly in everyone's interest. Most of my clinical colleagues have great humanity and empathy, and use their technical knowledge for the benefit of their patients, and not to "bring about the enactment of a family's worst nightmare..." Unfortunately, sometimes things do turn out badly, but this certainly happens less often today than it used to.

I have gone back to Dr. Chavez's lecture, and nowhere there do I find any disapproval of advances in science. His concern was humanism, by which he meant a broad knowledge of philosophy and the arts; he did not deal with humanitarianism. My interpretation of his words are that he was concerned in the main with narrow specialization and the tendency to favor basic over clinical research. He wrote, when referring to