

OBSTETRIC GENETIC COUNSELING FOR LETHAL ANOMALIES.
PART II: PRACTICAL APPLICATION

by
Paddy Jim Baggot MD

And

M. G. Baggot MD

A number of cases were previously reviewed which had been used to justify partial-birth abortion (Baggot, 1998). These were predominantly cases where abortion was used as a compassionate and medically necessary response to a fetus with a birth defect. In considering these cases, significant physical complications can arise from abortion, including uterine perforation, hemorrhage, hysterectomy and possible maternal mortality. Procedural risks rise with advancing gestation. Post-abortion complications such as infertility, miscarriage, premature labor and ectopic pregnancy have previously been reviewed by Hilgers (1972). Post-abortion psychological sequelae have been reviewed by Rue (1994), and Ney (1994). The previous article (Baggot, 1998) indicated that, even in cases selected to manifest the strongest possible so-called medical justification for fetally-indicated abortion, there was in fact no medical necessity for abortion. The lack of such medical justification among patients who claimed that they would never have an abortion, but were forced into it by the situation, calls attention to the need for wider availability of pro-life perinatologist services.

There is also a need for Catholic pro-life services in the area of obstetric genetics. This point will be briefly made in reference to one of the more commonly diagnosed syndromes. One of the twenty-five most common malformation patterns is the VACTERL association. The acronym stands for : Vertebral, Anal, Cardiac, TE fistula, Renal and Limb anomalies. Children with VACTERL association generally have several but not all of the malformations in the pattern. Due to the presence of multiple malformations they are often mistakenly assumed to have chromosome abnormalities and therefore mental retardation. Usually they have neither. Presuming the child to have a worse prognosis the he/she really does, caregivers may unknowingly give up on the baby. This disorder illustrates the importance of establishing a correct diagnosis.

For the pro-choice geneticist, the rights and personhood of the fetus or embryo can be neglected. The pro-choice geneticist devotes his/her considerable efforts to prevent birth defects. These exertions often far exceed the paltry remuneration given to geneticists in today's health care system. While we may feel that from a Catholic perspective the pro-choice geneticist is perhaps unfortunately misguided about the dignity of life beginning from conception, we can at least legitimately admire the unselfish dedication and devotion of geneticists, who often devote more than a day to a single patient. In their zeal to prevent birth defects, the possibility of mental retardation may figure largely in their view of the problem. The pro-life Catholic obstetric geneticist on the other hand takes the inviolable personhood and dignity of the human embryo from conception as a given. Since he/she sees no legitimate indication for abortion in any situation. He may be less pessimistic and see a baby's cup as being half full rather than half empty.

In VACTERL association intelligence is usually, although not always, normal. Some of the birth defects are surgically correctable. Some birth defects may not require therapy. Some may be seen as the physical manifestation of a particular child's individuality. The presence of a birth defect can be a profound cross, but so is the loss of a spouse in divorce, the loss of a child's life in an accident, or the loss of one's job as a result of an economic upheaval. None of these is a legitimate reason for suicide. While euthanasia or abortion might seem compassionate, they are really false mercies.

From the Catholic perspective we need to explain the diagnosis, prognosis and therapy, if any. We must also review the genetics and recurrence risk. Fear of the unknown is a great burden of suffering when one's child has one or more birth defects. Accurate explanation of the situation removes the fear of the unknown. It is an important and considerable act of charity.

The Catholic perspective greatly simplifies consideration of "reproductive options." A Catholic geneticist can perform a great service by allaying the parents' unreasonable fears and helping them to accept their child with his own uniqueness and individuality. He may have a unique and individual appearance. He may have a unique and individual vocation and he may require a unique and individual sort of love from his parents. Other children have unique and individual appearances and unique and individual vocations and require unique and individual sorts of love as well; they just are not quite as unique. Guiding the parents away from despair and abortion, and toward hope and acceptance, the pro-life geneticist can prevent a disaster which would be unforgettable. Most geneticists rarely save a life. The Catholic pro-life geneticist, however, can save lives.

If providing abortion were truly compassionate, then not providing it might be cruel. If abortion is actually harmful, then providing this "choice" is not helpful. It then becomes more like giving your drunk friend his gun so he can commit suicide. It is indeed his gun, and he may have a legal right to use it on himself. It is not compassionate, though, to give him this "choice".

The purpose of this article is to present the accounts of mothers who did not take the "choice" of abortion. If abortion were truly compassionate, they could say how profoundly wrong they were not to choose abortion. Instead, they testified in Congress that they made the right choice, and why. This is their story.

PARENTAL TESTIMONY ON CLINICAL CASES

The following cases entered the public domain as congressional testimony. These couples testified before Congress concerning the ban on Partial Birth Abortion. They recounted their own experiences with their babies who had severe or lethal anomalies. Their message is that despite the birth defects of their babies, it was good that they did not have an abortion. They illustrate true compassion for their children rather than false mercy. They also illustrate that even babies who have lethal anomalies and are severely retarded can love, can be loved, and can contribute their own unique vocation to our society. They illustrate that helping the parents to care for their babies is not harmful to the parents, but in fact compassionate.

Denise and Andrew M.

The fetus was diagnosed with having a body stalk anomaly, such that the abdominal organs were outside the child's body. Possible complications justifying abortion included: 1.)

The child would not live. 2.) The delivery would be “horrendous.” 3.) The pain of watching the child suffer would be too great. “We took many beautiful pictures of him. We never had any regrets about carrying Gerard to term, giving birth to him and loving him till he died naturally. In fact, it is the event I am most proud of in my life.” (French, J.W., 1996).

Teresa and William H.

Gave birth to a child with Trisomy 5P on two separate occasions, Elizabeth and Mary Ann (who had hydrocephalus). “Our Creator sent us these children and we were privileged to love and care for them. What a tremendous loss to all of us who know them to terminate their lives because they were not physically perfect.” “She could not speak, but she knew us. She lived two and a half years. We clearly saw how many lives she touched when over two hundred people attended her memorial Mass.” (French, J.W. 1996).

Margaret S.

Her fetus was diagnosed with Trisomy 18. This was complicated by a large abdominal defect. The child lived 45 minutes after birth. Margaret has had five children subsequently. This case provides a telling counterpoint to one of the cases which was used to justify partial-birth abortion (Baggot, 1998). In that case the mother subsequently had five miscarriages, presumably as a result of cervical incompetence due to procedure-related trauma. “Our lives are richer for having carried Calvin. We can live our lives without doubts or second thoughts that we did the right thing.” (French, J.W. 1996).

Whitney and Bruce G.

The doctor told the mother the baby had a large abdominal defect and other anomalies. Possible prognosis given by the doctor was stillbirth, a newborn death, or a possible survival after extensive surgeries. “My fear is that under this emotional strain many parents do choose this option that can be so easily taken as a means of sparing themselves and their children from the pain that lies ahead.” (French, J.W. 1996). The patient chose full term delivery. The child underwent three extensive operations after birth and was on a respirator for six weeks. Further complications included: placement of a gastrostomy tube for feeding and a chest tube for pneumothorax. There was bleeding into the liver and into the brain which necessitated a total of eight blood transfusions. “Watching his pain and suffering was unbearable, but the courage and strength of our child was miraculous. We are now blessed by his presence with us every minute of our lives.” Some have not understood the last sentence accurately. The child survived and did well subsequently.

This last case raises a subtle but profound issue. We all know babies and children who did much better than we expected. The mother who chooses abortion can never really know in a definitive way that the baby would not have done better than he/she was predicted to do. The only definitive way to know the baby’s true potential is to help him achieve it. This leaves the mother who chooses abortion with the potential for poisonous self-doubts and self-recriminations. It should not be surprising then that abortion for fetal indication is so psychologically harmful to the mother (Rue, 1994; Ney, 1994).

CONCLUSION: A CATHOLIC PRO-LIFE APPROACH TO GENETIC AND CONGENITAL DISORDERS

Delivery at term is not only right, it is beneficial to families. Abortion is not only wrong, it is harmful to the mother physically, psychologically and spiritually. The mother and baby are not opponents, but a family. The best management is what is best for both. You can't help a mother by harming her child.

Catholic pro-life obstetric genetic counseling should be factual and comprehensive. The goal is to treat the fear of the unknown with its specific antidote: knowledge. The Catholic pro-life obstetric geneticist should be honest with the patient about his beliefs and goals (pro-choice geneticists should be honest about their beliefs, agenda and goals as well). The Catholic pro-life doctor should care about the baby and bear in mind his or her responsibility to the baby just as the mother cares about the baby and bears in mind her responsibility to the baby. Doctors should honestly discuss the complications of abortion and not gloss over or minimize them. Other treatment measures may be unnecessary but the Catholic pro-life doctor should be keen to develop new experimental treatments if possible. In cases where no treatment is possible, the doctor and all who care for the mother and baby should share their suffering with compassion, sympathy, understanding and support in the time of trial

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