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Obstetric Genetic Counseling for Lethal Anomalies

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by

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Part I: Principles

Much that is routine in obstetric genetic counseling and the obstetric management of babies with birth defects is inconsistent with the medical-moral teaching of the Catholic Church. A Catholic, pro-life alternative is needed.

Secular genetic counseling will be reviewed as a statement of the problem. In part I, inspired guidance from the Pope will then be gleaned from the Gospel of Life. In part II, actual cases of severe and lethal fetal anomalies will then be reviewed. From these difficult cases and the guidance of His Holiness, Pope John Paul II, a loving and compassionate approach will be synthesized, consistent with the teaching of Christ and the Catholic Church.

Secular genetic counseling begins when the physician establishes the diagnosis to the best of his ability. Clinical genetic diagnosis on neonatal children is one of the most difficult and demanding areas of medicine. At least with neonates, though, one can hold, touch, measure and examine the baby. Extending this approach to fetuses is more difficult because the clinical information is limited to ultrasound data. Since the fetus is at an earlier stage of development differentiating characteristics are also less developed.

Next, secular genetic counseling endeavors to explain the diagnosis, prognosis and therapy to a mother. The genetics of the disorder and its recurrence risk are explained. Reproductive options are then presented. Reproductive options include vaginal delivery at term, abortion and fetal euthanasia. Fetal euthanasia occurs when a fetus who cannot survive outside the womb is delivered after viability but before term. The maternal

patient chooses a course of action. The secular geneticist then supports whatever decision the family makes.

Can we develop a Catholic alternative? For treatable disorders, treatment is obviously the Catholic alternative. A more difficult situation arises if the fetus has a lethal anomaly. Since the appropriate Catholic management for treatable disorders is obvious, this paper will concern itself primarily with situations in which the fetus has a lethal anomaly. Secular obstetricians, geneticists and perinatologists have often recommended abortion in such cases. Is abortion good for lethal fetal anomalies? Is vaginal delivery at term good for lethal fetal anomalies?

In order to formulate a loving, caring, responsible and compassionate approach, inspired guidance will be gleaned from the teachings of Pope John Paul II. Some have suggested that offering mothers abortion in these cases is an act of compassion or even a moral imperative. If this were true, then His Holiness the Pope would be a diabolical apostle of cruelty. It should be self-evident that such a position is absurd. Closer scrutiny reveals that the Gospel of Life is in fact the Gospel of Love.

His Holiness states, "It is true that the decision to have an abortion is often tragic and painful for the mother, insofar as the decision to rid herself of the fruit of conception is not made for purely selfish reasons but out of a desire to protect certain important values, such as her own health or a decent standard of living for other members of the family. Sometimes it is feared that the child to be born would live in such conditions that it would be better if the birth did not take place. Nevertheless, these reasons and others like them, however serious and tragic, *can never justify the deliberate killing of an innocent human being* (*Evangelium Vitae*, p.58).

His Holiness states, "Given such unanimity in the doctrinal and disciplinary tradition of the Church, Paul VI was able to declare that this tradition is unchanged and unchangeable. Therefore, by the authority which Christ conferred upon Peter and his Successors, in communion with the Bishops – who on various occasions have condemned abortion and who in the aforementioned consultation albeit dispersed throughout the world, have shown unanimous agreement concerning this doctrine – *I declare that direct abortion, that is, abortion willed as an end or as a means, always constitutes a grave moral disorder,* since it is the deliberate killing of an innocent human being. This doctrine is based upon the natural law and upon the written word of God, it is transmitted by the Church's Tradition and taught by the ordinary and universal Magisterium. No circumstance, no purpose, no law whatsoever can ever make licit an act which is intrinsically illicit, since it is contrary to the law of God which is written in every human heart, knowable by reason itself and proclaimed by the Church." (*Evangelium Vitae*, p. 62).

This teaching is unambiguous. It does not contain "nuances". His Holiness seems to preemptively discourage creative rationalizations and semantic gymnastics. He seems to be saying that this teaching is to be obeyed rather than negotiated.

The Holy Father's teaching on euthanasia proceeds from the teaching on abortion in the direction of the Gospel of Love and Life. "Taking into account these distinctions, in harmony with the Magisterium of my Predecessors and in communion with the Bishops of the Catholic Church, *I confirm that euthanasia is a grave violation of the law of God,* since it is the deliberate and morally unacceptable killing of a human person. This doctrine is based upon the natural law and upon the written word of God, it is transmitted by the Church's Tradition and taught by the ordinary and universal Magisterium." (*Evangelium Vitae*, 65).

The Holy Father's teaching on euthanasia casts a great deal of light on the subject of abortion for fetal indication. Abortion for fetal indication is often advocated as a mercy killing for the benefit of the fetus or a mercy killing of the fetus for the benefit of the mother. His Holiness writes thus on the subject of euthanasia: "euthanasia must be called a false mercy, and indeed a "*disturbing perversion of mercy.*" "True compassion leads to sharing another's pain; it does not kill the person whose suffering we cannot bear. Moreover, the act of euthanasia appears all the more perverse if it is carried out by those, like relatives, who are supposed to treat a family member with patience and love, or by those, such as doctors, who by virtue of their specific profession are supposed to care for the sick even in the most painful terminal stages." (*Evangelium Vitae*, p. 66)

From here the Holy Father leads in the way of love. "Quite different from this [mercy killing] *is the way of love and true mercy*, which our common humanity calls for, and upon which faith in Christ the Redeemer, who died and rose again, sheds ever new light." (*Evangelium Vitae*, p. 67). "The request which arises from the human heart in the supreme concentration with suffering and death, especially when faced with the temptation to give up in utter desperation, is above all a request for companionship, sympathy and support in the time of trial. It is a plea for help to keep on hoping when all human hopes fail." As the Second Vatican Council reminds us: "It is in the face of death that the riddle of human existence becomes most acute." And yet "man rightly follows the institution of his heart when he abhors and repudiates the absolute ruin and total disappearance of his own person. Man rebels against death, because he bears in himself an eternal seed which cannot be reduced to mere matter." (*Gaudium et Spes*, 18; *Evangelium Vitae*, 67)

When a mother carries a baby with a lethal anomaly she also confronts suffering and death, the suffering her own, but the death of the baby. She too is faced with the temptation to give up in desperation. When

she looks ahead to the remainder of the pregnancy, the birth of the baby and subsequent death, the funeral, the subsequent pain, suffering and emptiness and the non-negotiable finality of it all, she recalls the suffering of Our Lord in the Agony in the Garden.

The gospels don't say that the devil was there in the garden of Gethsemane trying to tempt Jesus into passing up the cup of suffering. But we can hear the rejoinder to the temptation in Jesus' prayer: "Father, if you are willing, take this cup away from me; still not my will, but yours be done." (Luke 22:42). Here was the devil's greatest opportunity since the fall of Adam. The devil might have said: "Jesus, if you will sneak out of the garden before the soldiers come, I'll give you all the salvation you want and all the kingdoms of the world without any of the pain and suffering." Imagine how tempting a deal that would be, and yet how profoundly dishonest.

Whenever we make a deal with the devil, he always cheats us. If Christ had not paid for our salvation with his own suffering, then with what would he have paid for our salvation? With an IOU from the devil? Contemplate how much good would not have been done if Christ had not accepted the cup of suffering. If the mother and her baby can accept and endure their tragic suffering they will accomplish a great deal of good. Around many of these tragedies blessings from God often spring forth. Friends, relatives, staff often return to the Church or the sacraments; those with civil marriages may have their marriages blessed in the Church; anyone who is doing something he/she knows is wrong may reconsider when he/she comes face-to-face with eternity. Many are awed and inspired by the heroism of the mother and family.

For the rest of us our job is like that of the apostles; our job is to provide companionship, sympathy and support in time of trial. Our job is to share suffering with the aggrieved in time of the utter desperation. The Pope (*Evangelium Vitae*, p. 67) quotes St. Paul, "I rejoice in my suffering for your sake, and in my flesh I complete what is lacking in Christ's afflictions for the sake of his body, that is, the Church" (Col. 1:24).

The Pope gives guidance both as a society and as a health care system on how we should perform this ministry of the apostles in the garden. "There are still many *married couples,* with a general sense of responsibility, ready to accept children as 'the supreme gift of marriage.' Nor is there a lack of *families* which, over and above their service to life, are willing to accept abandoned children, boys and girls and teenagers in difficulty, handicapped persons, elderly men and women who have been left alone. Many *centers in support of life,* or similar institutions are sponsored by individuals or groups which, with admirable dedication and sacrifice offer moral and material support to mothers who are in difficulty and are tempted to have recourse to abortion. Increasingly, there are

appearing in many groups and in many places *groups of volunteers* prepared to offer hospitality to persons without a family who find themselves in conditions of particular distress or who need a supportive environment to help them overcome destructive habits and discover anew the meaning of life." (*Evangelium Vitae*, 26).

The Pope praises evangelists of the Gospel of Life. In this way he shows physicians how to proceed. "*Medical science*, thanks to the committed efforts of researchers and practitioners, continues in its efforts to discover ever more effective remedies: treatments which were once inconceivable but which now offer much promise for the future are today being developed for the unborn, the suffering and those in an acute or terminal stage of sickness. Various agencies and organizations are mobilizing their efforts to bring the benefits of the most advanced medicine to countries most afflicted by poverty and endemic diseases." (*Evangelium Vitae*, 26).

The inspired words of the Pope should guide us in developing methods to care for these patients. We need to bring true compassion, rather than false mercy, to the care of both maternal and fetal patients. Applying the Gospel of Life will help us to bring the healing touch of God's love to our patients. They will be healed, and they will realize that this approach is more beneficial for their families than compounding the impending death of a baby with the poisonous effects of abortion.

Part II: Practical

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 obstetrics 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 than 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".

Conclusion

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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