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Perinatal Hospice: A Response to Partial Birth Abortion for Infants with Congenital Defects

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ABSTRACT: This article discusses decisions involving whether to terminate late-term pregnancies when fetal anomalies have been detected. Partial-birth abortion performed on fetuses with chromosomal abnormalities, while performed under the guise of reducing suffering, threatens the best interests of the mother and infant. An alternative for parents faced with the decision to terminate their pregnancy is perinatal hospice. Perinatal hospice recognizes the value of bringing these infants to term by treating them as beings conceived with a tangible future. This alternative is preferred because of post-termination psychological distress and because biblical teachings emphasize the dignity and worth of each fetus. Perinatal hospice supports parents through their grief when their infant dies and maximizes the opportunity for authentic mourning.

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The congressional debate over "partial birth" abortion—or "dilatation and extraction," as termed by its proponents—has received much press.¹ The procedure is performed on late term infants and involves manipulating the infant in the womb to a breech presentation, extracting the infant to the shoulders, trapping the skull, then suctioning out the brain and collapsing the skull before completing removal of the infant's body. Proponents have maintained that most of these were performed for congenital defects or to save the life of the mother.² However, in congressional hearings it has been estimated that more than 30,000 may be performed each year, and as many as 80% of these may be "elective."³ More recently, a well-known abortion provider and activist has acknowledged "that the vast majority of these abortions are performed in the 20-plus week range on healthy fetuses and healthy mothers."⁴ This is corroborated by other providers who admit that only a fraction of the thousands of procedures they have performed annually are for fetal anomalies or to save the life of the mother.⁵

However, even if public opinion prevails in banning the procedure for "healthy" pregnancies,⁶ congenital defects severe enough to cause death still affect roughly 0.5-1% of all live births,⁷ or about 30,000-50,000 births

¹See Diane M. Gianelli, *Shock-Tactic Ads Target Late-Term Abortion Procedure*, AM. MED. NEWS, July 5, 1993, at 3, 15-16 [hereinafter Gianelli, *Ads Target Late-Term Abortion*]; Diane M. Gianelli, *Outlawing Abortion Method: Veto-Proof Majority in House Votes to Prohibit Late-Term Procedure*, AM. MED. NEWS, Nov. 20, 1995, at 3, 27.

²Diane M. Gianelli, *Medicine Adds to Debate on Late-Term Abortion: Abortion Rights Leader Urges End to 'Half truths'*, AM. MED. NEWS, Mar. 3, 1997, at 3, 28-29.

³Testimony before the House Judiciary Committee referring to taped and transcribed interviews conducted by reporters from *American Medical News* with Martin Haskell, M.D. and James T. McMahon, M.D. (figures provided by Dr. Haskell, cited from direct transcripts of the interviews). Excerpts from these interviews can be found in Gianelli, *Ads Target Late-Term Abortion*, *supra* note 1.

⁴Gianelli, *supra* note 2, at 28.

⁵*Id.* On those rare occasions when pregnancy truly poses a threat to the mother's life at gestational ages when partial birth abortions are typically performed, immediate delivery of the fetus with vigorous supportive care would result in survival of many fetuses. See Edward J. Wolf et al., *Do Survival and Morbidity of Very-Low-Birth-Weight Infants Vary According to the Primary Pregnancy Complication that Results in Preterm Delivery?* 169 AM. J. OBSTETRICS & GYNECOLOGY 1233 (1993); Walter J. Morales & Thomas Talley, *Premature Rupture of Membranes at < 25 Weeks: A Management Dilemma*, 168 AM. J. OBSTETRICS & GYNECOLOGY 503 (1993).

⁶Gianelli, *supra* note 2, at 29. See also Diane M. Gianelli, *Medicine Adds to Debate on Late Term Abortion: ACOG Draws Fire for Saying Procedure 'May' be Best Option for Some*, AM. MED. NEWS, Mar. 3, 1997, at 3, 27-28 (documenting opposition to the procedure from a group of obstetricians within the American College of Obstetrics and Gynecology).

⁷N. P. Kuleshov, *Chromosome Anomalies of Infants Dying During the Perinatal Period and Premature Newborn*, 31 HUM. GENETICS 151 (1976); Rhona Bauld et al., *Chromosome Studies*

annually in the United States alone. Many of these infants die *in utero*, and most with severe chromosomal abnormalities (i.e., trisomy 13 or 18) who do survive to birth will die shortly thereafter.⁸ Partial birth abortion—like intrauterine lethal injection—is intended to ensure that those infants who survive to late pregnancy will not be born alive,⁹ thus avoiding the grim prospect of prolonging suffering at birth when law and society recognize and protect the infant as a person.¹⁰

While this approach appears to have the benefit of reducing human suffering, we believe it actually threatens the best interests of both mother and infant. The following case will illustrate the hidden dangers of early termination upon detecting fetal anomalies when eager anticipation is abruptly turned into disillusionment and anguish. A twenty-five year old woman, Gravida 3, Para 1, Ab 1, presented at twenty-two weeks of gestation with the question of how to manage the remainder of her pregnancy after sonography revealed findings suggestive of trisomy 13 and the diagnosis was confirmed by amniocentesis. Because hospital policy allowed for termination of pregnancy only if “pregnancy would endanger a woman’s life,” her obstetrician sought assistance from the hospital ethics committee, which met *ad hoc* to recommend whether to approve or disapprove termination of the pregnancy. The patient was not present at the meeting. The obstetrician did not know the circumstances of the patient’s previous abortion at four weeks of gestation. While there was no evidence of any impending danger to the mother’s life, the obstetrician asserted that a decision *not* to terminate the pregnancy would be detrimental to her mental state. Further discussion unmasked concern that this would be further aggravated if the parents were forced to bear the expense of the procedure at a different institution where health care costs would not be “covered.” Notwithstanding the vigorously stated moral and legal concerns of the hospital chaplain and attorney, the committee voted 7 to 2 in favor of administrative approval to terminate the pregnancy.

How much can an obstetrician in such cases “read into” parents’ preferences? Would the committee have been justified in seeking more information regarding the previous pregnancies and the parents’ feelings

in *Investigation of Stillbirths and Neonatal Deaths*, 49 ARCHIVES DISEASE CHILDHOOD 782 (1974).

⁸Bonnie J. Baty et al., *Natural History of Trisomy 18 and Trisomy 13: I. Growth, Physical Assessment, Medical Histories, Survival, and Recurrence Risk. II. Psychomotor Development*, 49 AM. J. MED. GENETICS 175-88, 189-94 (1994); Jonathan P. Wyllie et al., *Natural History of Trisomy 13*, 71 ARCHIVES DISEASE CHILDHOOD 343 (1994).

⁹Joan Callahan, *Ensuring a Stillborn: The Ethics of Fetal Lethal Injection in Late Abortion*, 6 J. CLINICAL ETHICS 254 (1995).

¹⁰*Id.* at 254, 258-60.

about termination? Were the potential adverse consequences of pregnancy termination openly discussed? Did the committee consider all the relevant options? We argue that the committee in this case reached premature closure in the decision and failed to pursue the best interests of either the parents or the fetus.

Providers involved in prenatal and perinatal care should critically evaluate the basis for their own approach to decisionmaking when fetal anomalies are detected and be ready to challenge and correct the potentially flawed reasoning behind early termination. The unexplained suffering in such cases raises key questions of meaning that all too often remain unexplored. We find that these issues are openly addressed by the Old Testament wisdom literature, which warns of the danger of attempts to discover meaning or mitigate suffering when driven by a categorical, unreflective insistence upon the right of self-determination.¹¹

Building on this wisdom perspective, we argue that there are significant pitfalls associated with early termination of pregnancy for fetal anomalies. What is needed is an approach to decisionmaking that offers these anguishing parents an opportunity for meaning. Perinatal hospice can provide this opportunity by emphasizing the value of bearing infants afflicted with severe congenital anomalies by treating them as beings conceived with a tangible future, even if destined for a soon death. This approach provides the time and resources needed to realize that future by supporting the family and infant through the ambivalence and anguish associated with bringing the pregnancy to term.

The Flawed Justification for Partial Birth Abortion

The "Right" of Self-Determination

The most prevalent rationale used to justify abortion in general is that of preserving the presumed "right" of *self-determination* or *autonomous choice*. The pitfalls of too readily acceding to external preferences in settings fraught with intense emotions, ambiguity, and uncertainty have been previously examined from the wisdom perspective.¹² So pervasive is this presumption in reproductive decisions, however, that it usually goes unchallenged in discussions such as that held by the ethics committee in the case presentation. This was evidenced by the unchallenged allusion to

¹¹See James S. Reitman, *The Structure and Unity of Ecclesiastes*, 154 *BIBLIOTHECA SACRA* 297-319 (July-Sept. 1997).

¹²See James S. Reitman, *The Debate on Assisted Suicide—Redefining Morally Appropriate Care for People with Intractable Suffering*, 11 *ISSUES IN LAW & MED.* 299 (1995) [hereinafter Reitman, *Debate on Assisted Suicide*]; James S. Reitman, *The Dilemma of "Medical Futility": A "Wisdom Model" for Decisionmaking*, 12 *ISSUES IN LAW & MED.* 231 (1996) [hereinafter Reitman, *Dilemma of Medical Futility*].

the parents' "preferences." The right of self-determination in reproductive decisions has been enshrined by recent developments in American jurisprudence, especially in the protection of maternal "liberty interests" by the doctrinal cloaks of "privacy" and "pluralism."

Privacy and the Problem of Informed Consent. While *Roe* found that a pregnant woman's decision to terminate her pregnancy was protected by a right to privacy which the Court derived from the "liberty" provision of the Due Process Clause of the Fourteenth Amendment, this right was not found to be absolute—it was qualified by "the state interests as to protection of health, medical standards, and prenatal life."¹³ This holding was reaffirmed by *Casey*,¹⁴ however, a subtle change in the argument was made necessary by the rapid development of the doctrine of informed consent, which has evolved into a duty required of providers to guarantee true liberty in medical decisions,¹⁵ including abortion.¹⁶ It was eventually recognized that too strict an adherence to the right of privacy would jeopardize a truly informed decision.¹⁷

Unfortunately a similar level of attention has not been focused on what information a woman bearing a congenitally defective fetus needs to know in order to make an "informed" decision. Studies assessing the predictors of disordered mourning following perinatal loss are fraught with significant methodological weaknesses that limit conclusions about the psychological sequelae in these cases, whether due to stillbirth¹⁸ or to

¹³*Roe v. Wade*, 410 U.S. 113, 155 (1973).

¹⁴*Planned Parenthood v. Casey*, 505 U.S. 833 (1992).

¹⁵See, e.g., JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (1984).

¹⁶This resulted in successive revisions to abortion jurisprudence in a line of cases beginning with *Planned Parenthood v. Danforth*, 428 U.S. 52 (1976) and continuing with *Akron v. Akron Center for Reproductive Health*, 462 U.S. 416 (1983); *Planned Parenthood Ass'n of Kansas City Mo., Inc. v. Ashcroft*, 462 U.S. 476 (1983); *Webster v. Reproductive Health Services*, 492 U.S. 490 (1989); and, ultimately, *Casey*, 505 U.S. 833. See also Bo Schambelan, *Postscript, in ROE V. WADE: THE COMPLETE TEXT OF THE OFFICIAL U.S. SUPREME COURT DECISION 101-116* (1992).

¹⁷This potential problem of privacy is addressed in the following citation from *Casey*:

Though the woman has a right to choose to terminate or continue her pregnancy before viability, it does not at all follow that the State is prohibited from *taking steps to ensure that this choice is thoughtful and informed*. Even in the earliest stages of pregnancy, the State may enact rules and regulations designed to encourage her to know that there are philosophic and social arguments of great weight that can be brought to bear in favor of continuing the pregnancy to full term and that there are procedures and institutions to allow adoption of unwanted children as well as a certain degree of state assistance if the mother chooses to raise the child herself.

Casey, 505 U.S. at 872 (emphasis added).

¹⁸Charles H. Zeanah, *Adaptation Following Perinatal Loss: A Critical Review*, 28 J. AM. ACAD. CHILD ADOLESCENT PSYCHIATRY 467, 476 (1989) (lamenting "the lack of clarity and

abortion for fetal anomalies.¹⁹ However, the results of recent research in this area have provided cause for concern.

While review of studies of psychological complications within two years of therapeutic abortion reveals a frequency of adverse sequelae averaging only about 10%,²⁰ a disproportionate number of these were found to be related to therapeutic abortion for fetal abnormalities.²¹ A recent case-control study evaluating the grief responses of women who terminated their pregnancies for fetal anomalies concluded that "[w]omen who terminate pregnancies for fetal anomalies experience grief as intense as those who experience spontaneous perinatal loss, and they may require similar clinical management. Diagnosis of a fetal anomaly and subsequent termination may be associated with psychological morbidity."²² Psychological stress three months after delivery for fetal anomalies has been found to be significantly greater for women whose pregnancies were terminated between twenty-four and thirty-four weeks of gestation than those who delivered after thirty-four weeks.²³ When disordered mourning beyond early grief reactions is studied, it "seems to be related to lack of or problematic social support and significant life stresses in pregnancy. . . . The marital relationship may be especially important."²⁴

These data should be quite arresting to the obstetrician who has assumed that early termination of such pregnancies should result in a relief

uniformity about what comprises disordered mourning, the generally small sample sizes in the relevant studies, the nonuniformity of variables examined as predictors, and the nonreporting of all of the variables found not to be predictive."). See also Charles H. Zeanah et al., *Initial Adaptation in Mothers and Fathers Following Perinatal Loss*, 16 *INFANT MENTAL HEALTH* J. 80 (1995).

¹⁹Charles H. Zeanah et al., *Do Women Grieve After Terminating Pregnancies Because of Fetal Anomalies? A Controlled Investigation*, 82 *OBSTETRICS & GYNECOLOGY* 270 (1993) ("[T]here are numerous problems with studies on this topic, including use of unvalidated measures and failure to include measures specific to pregnancy or infant loss. Further, most previous studies have been retrospective, with assessments at variable times following the loss, and none used a comparison group other than the patient herself or an unmatched group who did not experience loss." (citations omitted)).

²⁰G. Zolese & C.V.R. Blacker, *The Psychological Complications of Therapeutic Abortion*, 160 *BRIT. J. PSYCHIATRY* 742 (1992).

²¹*Id.* at 747.

²²Zeanah, *supra* note 19. A previous uncontrolled study indicated that 77% of such women experienced an acute grief reaction and 46% remained symptomatic six months after termination; some required psychiatric support. See also J. Lloyd & K.M. Laurence, *Sequelae and Support after Termination of Pregnancy for Fetal Malformation*, 290 *BRIT. MED. J.* 907 (1985).

²³J.A.M. Hunfeld et al., *Emotional Reactions in Women in Late Pregnancy (24 weeks or longer) Following the Ultrasound Diagnosis of a Severe or Lethal Fetal Malformation*, 13 *PRENATAL DIAGNOSIS* 603, 609 (1993).

²⁴Zeanah, *A Critical Review*, *supra* note 18, at 476 (citations omitted).

of anguish comparable to the termination of normal pregnancies in which the child is not wanted.²⁵ This suggests that in the case we presented earlier, the obstetrician and members of the committee that voted for termination were either unaware of this important information or thought it unnecessary to discuss these risks with the parents in order to satisfy the requisites of fully informed consent. Only recently is the complexity of this problem being recognized.

It is possible that primary care physicians face important structural barriers to the full utilization of opportunities in the consultation to assist the process of considered, autonomous decision-making. For example, time considerations may exert pressure on clinicians to focus more or less exclusively on the presenting problem and its quick solution rather than deliberately broadening the consultation to explore relevant psychosocial aspects of decisions. Because the procedure is so common, some clinicians may regard termination as fairly routine and thus underestimate its impact for some women.²⁶

Despite the necessity to satisfy certain criteria before a pregnancy is legally terminated, some patients, families, and physicians may consider that primary care physicians' efforts at providing a structure within which the pregnant woman can explore ambivalence and alternatives constitute meddling in the exercise of a personal right. Patients can bypass their primary care physician, however, and go directly to an abortion provider without the primary care physician's knowledge.²⁷

The problem of inadequate informed consent regarding the potential long-term psychological sequelae of elective termination—including partial birth abortion—mandates the serious discussion of other alternatives with these patients. There are, however, other barriers to the consideration of these alternatives.

Pluralism and the Problem of Conscience. Notwithstanding its recognition of the importance of informed consent, *Casey* gave no ground on the fundamental holding of liberty in decisions on abortion.²⁸ However,

²⁵See Teri Reisser, *Personal Characteristics as Predictors of Post-Abortion Emotional Distress* 24 (Dec. 1994) (M. thesis, California Lutheran University) ("One might reasonably assume that if a woman is aborting because of a suspected fetal anomaly, her post-abortion adjustment would be easier because she could rationalize the medical necessity of the procedure. Contrary to this line of thinking, the literature unanimously demonstrates that women who have had abortions for fetal malformation experience more severe psychological trauma than those who abort in general" (citations omitted)).

²⁶Chris Butler, *Late Psychological Sequelae of Abortion: Questions from a Primary Care Perspective*, 43 J. FAM. PRAC. 396, 398 (1996)(citations omitted).

²⁷*Id.* at 399.

²⁸This was still the overarching and determinative concern in the outcome. See *Casey*, 505 U.S. at 844 ("Liberty finds no refuge in a jurisprudence of doubt.").

the Court subtly redefined the notion of liberty in a way that belies an increasingly unquestioned societal presumption: "At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life."²⁹ The hidden yet widely accepted premise of this definition is that our society is characterized by an irreducible moral pluralism, and this presumption has increasingly insinuated itself into discussions of ethical decisionmaking, including decisions concerning abortion.³⁰

Key to this presumption is the denial that certain elements of moral awareness are common to all humans.³¹ Without a common moral ground on which to base such decisions, it is argued, mutual tolerance is the only feasible way to maintain a "peaceable" society.³² This argument is seriously flawed.³³ From the wisdom perspective each of us possesses a conscience which confers some level of awareness of transcendent purpose in life.³⁴ Moreover, we remain accountable for this awareness, which extends to decisions concerning the appropriate timing of life and death.

[A] wise man's heart discerns both time and judgment,
 Because for every matter there is time and judgment,
 Though the misery of man increases greatly.
 For he does not know what will happen;
 So who can tell him when it will occur?
 No one has power over the spirit to retain the spirit,
 And no one has power in the day of death.³⁵

Humans are aware of some transcendent order and design to human destiny even though they cannot discern the content of the future. They know that even amid severe affliction they do not retain the prerogative of determining the timing of life and death yet they all too commonly presume

²⁹*Id.* at 851.

³⁰See e.g., H. TRISTRAM ENGELHARDT JR., *THE FOUNDATIONS OF BIOETHICS* 239-87 (2d ed. 1996).

³¹*Id.* at 42-45.

³²*Id.* at 239-87 (insisting that autonomous choice and the correlative duty of permissive respect for others, i.e., tolerance, are the only values that can muster consensus for a secular morality and should therefore predominate in all such decisions).

³³See Stanley Hauerwas, *Not All Peace is Peace: Why Christians Cannot Make Peace with Engelhardt's Peace*, in *READING ENGELHARDT* 17 (Brendan Minogue, ed., 1997). A fuller exposition of the flaws of empirical and philosophical pluralism is undertaken by D.A. CARSON, *THE GAGGING OF GOD: CHRISTIANITY CONFRONTS PLURALISM* (1996).

³⁴See *Ecclesiastes* 3:10-11 (New International Version, unless otherwise indicated) ("I have seen the burden God has laid on men. He has made everything beautiful in its time. He has also set eternity in the hearts of men; yet they cannot fathom what God has done from beginning to end").

³⁵*Ecclesiastes* 8:5b-8a (New King James).

to exercise that prerogative, as evidenced in decisions to electively terminate pregnancy. Don Marquis has offered a simple yet extraordinary secular argument that accords fully with this wisdom.

When I am killed, I am deprived both of what I now value which would have been part of my future personal life, but also what I would come to value. Therefore, when I die, I am deprived of all of the value of my future. Inflicting this loss on me is ultimately what makes killing me wrong. This being the case, it would seem that what makes killing any adult human being *prima facie* seriously wrong is the loss of his or her future.³⁶

The claim that the primary wrong-making feature of a killing is the loss to the victim of the value of its future accounts for the wrongness of killing young children and infants directly. . . . [I]t meshes with a *central intuition concerning what makes killing wrong*.

[This] claim . . . has obvious consequences for the ethics of abortion. The future of a standard fetus includes a set of experiences, projects, activities, and such which are identical with the futures of adult human beings and are identical with the futures of young children. Since the reason that is sufficient to explain why it is wrong to kill human beings after the time of birth is a reason that also applies to fetuses, it follows that abortion is *prima facie* seriously morally wrong.

. . . The category that is morally central to this analysis is the category of having a valuable future like ours; it is not the category of personhood.³⁷

The higher frequency of grief reactions observed among women who terminate their pregnancies for fetal anomalies³⁸ may well be explained by the operation of such "intuition" in these decisions: The mother who anticipates a shared future with a "standard" fetus, yet chooses to terminate her pregnancy when she finds that her fetus is defective, can expect to experience deep ambivalence from two powerful but opposing emotional drives: the compulsion to relieve the anguish of a pregnancy that projects a sense of personal failure, and the dread of participating in the premature termination of her infant's "future,"³⁹ however brief and bittersweet that future might have been.

The strong influence of conscience among these women is attested by the experience of clinicians whom they have consulted for help in resolving

³⁶Don Marquis, *Why Abortion is Immoral*, 86 J. PHIL. 183, 190 (1989).

³⁷*Id.* at 192 (emphasis added).

³⁸See *supra* note 22.

³⁹The powerful influence of existential dread that can be associated with the loss of such a perceived future is explored by Reitman, *Dilemma of Medical Futility*, *supra* note 12, at 243-46.

the psychological sequelae of such termination. Irving Leon tellingly admits that he had been "inclined to want my clients . . . to view these terminations as potential rather than actual babies, believing that would soften both their grief and guilt . . ." ⁴⁰ yet "[m]any of the women I worked with demonstrated the importance of recognizing their child's existence and the guilt over feeling they had denied them just that by the decision to terminate." ⁴¹

[A]ttaching to the fetus as a real child clearly complicated the meanings and feelings behind the decision to terminate. Simply and bluntly put, many women described their action as murder, justifiable and excusable to be sure, but murder no less. This helps to explain the usually profound guilt that follows this loss, exceeding, at least in my clinical experience, that resulting from spontaneous perinatal loss. ⁴²

Rather than viewing these guilt reactions as disordered, the wisdom perspective would suggest that they are rooted in normally operating conscience. Leon's description of specific manifestations of such guilt in his patients ⁴³ is remarkably similar to that of post-abortion counselors confronted with cases of women who have self-referred—often years later—after having aborted normal pregnancies. ⁴⁴ The guilt reactions that come to clinical attention may represent only a small proportion of those that otherwise remain "successfully" repressed for years. ⁴⁵

Relief of Suffering—the Real Agenda Behind "Liberty"

If we grant that most women who are pregnant with congenitally defective infants are at least subconsciously aware that the infants they bear each have an existence and a future, then a more compelling need besides liberty must certainly be driving most decisions to abort. Indeed, careful examination of the *Roe-Casey* precedents reveals the more subtle conviction underlying the liberty/privacy holding.

This right of privacy . . . is broad enough to encompass a woman's decision whether or not to terminate her pregnancy. The detriment that the State would impose upon the pregnant woman by denying this choice altogether is apparent. Specific and direct harm medically diagnosable even in early pregnancy may be involved. Maternity, or additional offspring, may force upon the woman a distressful life and

⁴⁰Irving G. Leon, *Pregnancy Termination Due to Fetal Anomaly: Clinical Considerations*, 16 *INFANT MENTAL HEALTH J.* 112, 120 (1995).

⁴¹*Id.* at 119 (emphasis added).

⁴²*Id.*

⁴³*Id.*

⁴⁴See TERI REISSER & PAUL REISSER, *HELP FOR THE POST-ABORTION WOMAN* 35-45 (1994).

⁴⁵*Id.*

future. Psychological harm may be imminent. Mental and physical health may be taxed by child care. There is also the distress, for all concerned, associated with the unwanted child, and there is the problem of bringing a child into a family already unable, psychologically and otherwise, to care for it. In other cases . . . the additional difficulties and continuing stigma of unwed motherhood may be involved.⁴⁶

[T]he liberty of the woman is at stake in a sense unique to the human condition and so unique to the law. The mother who carries a child to full term is subject to anxieties, to physical constraints, to pain that only she must bear. That these sacrifices have from the beginning of the human race been endured by woman with a pride that ennobles her in the eyes of others and gives to the infant a bond of love cannot alone be grounds for the State to insist she make the sacrifice. Her suffering is too intimate and personal for the State to insist, without more, upon its own vision of the woman's role, however dominant that vision has been in the course of our history and our culture.⁴⁷

The arguments hinge upon the conviction that any suffering that is deemed unpalatable by patient or care provider must be eliminated.⁴⁸ The claim of liberty has thus been driven by a deeper commitment to avoid suffering at all cost. This reflects the natural emotional response to unwarranted suffering that makes abortion seem reasonable for both mother and infant:

I saw the tears of the oppressed—
 and they have no comforter;
 power was on the side of their oppressors—
 and they have no comforter.
 And I declared that the dead,
 who had already died,
 are happier than the living,
 who are still alive.
 But better than both
 is he who has not yet been,
 who has not seen the evil
 that is done under the sun.⁴⁹

By expressing the sentiment that some suffering is worse than death, the passage reflects the all too prevalent justification for ending the life of a

⁴⁶Roe, 410 U.S. at 153.

⁴⁷Casey, 505 U.S. at 852.

⁴⁸Cf. Reitman, *Debate on Assisted Suicide*, *supra* note 12, at 308-9.

⁴⁹Ecclesiastes 4:1b-3.

preborn infant overwhelmed by the "oppression" of congenital anomalies.⁵⁰ As a patient who is terminally ill naturally fears pain and being abandoned to the full assault of suffering,⁵¹ so does the family of a terminally ill fetus dread being abandoned or subjected to prolonged anguish before death finally ensues.⁵²

This rationale may also underlie the more subtle "professional judgment" of the genetics consultant or obstetrician who recommends abortion in the "best interests" of mother and fetus, as in the case presented above. By subtly insinuating that the infant will suffer less if it is destroyed,⁵³ prenatal counseling—even that which is purportedly "non-directive"—may thus reinforce a societal expectation to "terminate" the pregnancy and move on.⁵⁴ This is curious logic indeed from the viewpoint of the fetus (who will never know any other alternative), but it follows naturally from the perspective of suffering-avoidance portrayed above. Surely most of the professionals whose counsel is imbued with this attitude about the suffering of the fetus would not themselves prefer to be dead, simply because others predicted that "they would eventually die anyway," their lives would be "too painful to live," or they would suffer moral harm by narrowing their range of choices.⁵⁵ On the contrary, the future of the

⁵⁰Hauerwas' perception of the societal unease that attends the prospect of a *mentally* handicapped child applies equally well to the prenatal detection of *any* congenital anomaly:

I suspect that at least part of the reason it seems so obvious that we ought to prevent retardation is the conviction that we ought to prevent suffering. No one should will that an animal should suffer gratuitously. No one should will that a child should endure an illness. No one should will that another person should suffer from hunger. No one should will that a child should be born retarded. That suffering should be avoided is a belief as deep as any we have. That someone born retarded suffers is obvious. Therefore if we believe we ought to prevent suffering, it seems we ought to prevent retardation.

STANLEY HAUERWAS, *SUFFERING PRESENCE: THEOLOGICAL REFLECTIONS ON MEDICINE, THE MENTALLY HANDICAPPED, AND THE CHURCH* 164 (1986); Cf. MARTIN S. PERNICK, *THE BLACK STORK: EUGENICS AND THE DEATH OF "DEFECTIVE" BABIES IN AMERICAN MEDICINE AND MOTION PICTURES SINCE 1915* (1996).

⁵¹Betty Ferrell et al., *The Experience of Pain and Perceptions of Quality of Life: Validation of a Conceptual Model*, 7 *HOSPICE J.* 9 (1991); Betty Ferrell et al., *Family Factors Influencing Cancer Pain Management*, 67 *POSTGRADUATE MED. J.* 5-64 (Supp. 2 1991); L. J. Muzzin et al., *The Experience of Cancer*, 38 *SOC. SCI. MED.* 1201 (1994).

⁵²HAUERWAS, *supra* note 50, at 189-210. See also the relevant discussion of the subtle pitfalls of family decisionmaking surrounding the birth of handicapped infants in James Bopp, Jr. & Richard E. Coleson, *A Critique of Family Members as Proxy Decisionmakers Without Legal Limits*, 12 *ISSUES IN LAW & MED.* 133, 140-56 (1996).

⁵³See e.g., Callahan, *supra* note 9.

⁵⁴HAUERWAS, *supra* note 50, at 211-17; Bopp & Coleson, *supra* note 52.

⁵⁵See, e.g., Dena Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, *HASTINGS CENTER REP.*, Mar./Apr. 1997, at 7.

fetus and its suffering is largely inscrutable and thus lends itself to an entirely different approach.

A Better Standard for Decisionmaking: The Wisdom Perspective

"Personhood" and Distinctive Human Life

Debates over the "personhood" of the fetus have shed little light on the morality of decisions that touch upon the value and welfare of the fetus.⁵⁶ Arguments attempting to establish a threshold for personhood at certain stages of gestation merely beg the question of what value we may assign to the human life that exists at any point along the continuum of development. If instead we focus on the distinctive humanity of the fetus, even legal briefs submitted before the 1973 *Roe v. Wade* decision acknowledged that human life begins at conception,⁵⁷ a view strongly attested by the wisdom perspective:

My frame was not hidden from you
when I was made in the secret place.
When I was woven together in the depths of the earth,
your eyes saw my unformed body.
All the days ordained for me
were written in your book
before one of them came to be.⁵⁸

But can we assume that *all* infants are fashioned with the same deliberate intent and particularity? Would this be a legitimate reason to defer the inevitable demise of infants afflicted with severe congenital anomalies and thereby only prolong parental anguish?

The Image of God and Divine Prerogative

Biblical wisdom establishes the image of God as the basis for human dignity and worth.⁵⁹ But does it follow that the divine prerogative to determine such distinctive value also applies to the brief life of a child with anencephaly or trisomy 13? Since it is evident that preborn human life is equally imbued with God's image, great worth also attaches to the humanity

⁵⁶See e.g., *Respect for Persons and Their Agency*, in ON MORAL MEDICINE 273-304 (Stephen E. Lammers & Allen Verhey eds., 1987); ENGELHARDT, *The Context of Health Care: Persons, Possessions, and States*, in FOUNDATIONS OF BIOETHICS, *supra* note 30, at 135-54; P. Goube de Laforest, *An International Workshop: Life Sciences and the Concept of Person—Impact of Individual Opinions on the Respect for Human Personhood*, 12 ETHICS & MED. 10 (1996).

⁵⁷Brief Amicus Curiae of Certain Physicians, Professors, and Fellows of the American College of Obstetrics and Gynecology in Support of Appellees, *Roe v. Wade*, 410 U.S. 113 (1973) (No. 70-18).

⁵⁸*Psalms* 139:15-16.

⁵⁹See *Genesis* 4:9; 9:5-6; *James* 3:9.

of each fetus.⁶⁰ It is mere naturalistic presumption to assume that there exists some threshold of congenital defectiveness beyond which the birth of such an infant has no conceivable value: "Who gives man his mouth? Who makes him deaf or mute? Who gives him sight or makes him blind? Is it not I, the Lord?"⁶¹

If every infant is created with value, it follows that each one is also created with a distinctive purpose—regardless of physical characteristics or chromosomal complement—even if we cannot discern that purpose beforehand: "As you do not know the path of the wind,/ or how a body is formed in a mother's womb,/ so you cannot understand the work of God,/ the Maker of all things."⁶² Realizing how little is known about divine prerogative in fetal development should enjoin those in the moral community of the fetus to give due consideration to its created nature and inscrutable purpose.

The real problem with partial birth abortion is that it is based on the false presumption that parents have the capacity and full authority to determine which infants shall live, how long, and with what "quality of life." The vicarious suffering of parents and physicians does not justify an assault on the fetus, for there is no way to predict before birth what good may come of a child's life, however brief.⁶³ It is not their place to dictate the parameters of continued existence and preempt purposes that cannot be known ahead of time.⁶⁴ Consequently, we remain accountable for wise stewardship over such life and should not presume to destroy it as long as a future for that infant can still be realized.⁶⁵

⁶⁰Evidence for this conclusion can be adduced from *Psalm 139*, *supra* note 58; *Jeremiah 1:5*, *Genesis 1:26-27*; *Luke 1:39-44* (citing the *in utero* reaction of John the Baptist to the voice of Mary, the mother of the preborn Christ).

⁶¹*Exodus 4:11*. See also *John 9:3* (Specific biblical instances of such divine prerogative include the case of the man born blind "so that the work of God might be displayed in his life").

⁶²*Ecclesiastes 11:5*.

⁶³See *Ecclesiastes 6:12* ("For who knows what is good for a man in life, during the few and meaningless days he passes through like a shadow? Who can tell him what will happen...?"). See also Bethany Spielman, *Certainty and Agnosticism about Lethal Injection in Late Abortion*, 6 J. CLINICAL ETHICS 270 (1995).

⁶⁴See *supra* notes 35-37 and accompanying text.

⁶⁵This assertion is the moral foundation of *Exodus 21:22-25*. While scholars have tried to prove that the "life for life" provision specified in this passage applies only to the mother and not the fetus (see, e.g., Robert N. Congdon, *Exodus 21:22-25 and the Abortion Debate*, 146 BIBLIOTHECA SACRA 132 (1989)), the most cogent and exegetically consistent understanding is that the death in view is of either the mother or the fetus. See, e.g., JOHN S. FEINBERG & PAUL D. FEINBERG, *ETHICS FOR A BRAVE NEW WORLD* 63-65 (1993).

The Limits of Life and the "Opportunity" of Mourning

There are and always will be parents who, in spite of their suffering, choose not to destroy their unborn children with even severe anomalies.⁶⁶ There is wisdom to support this approach: We all share an essential kinship with each of these infants. Each of us carries the elements of physical imperfection that ultimately dictate the common, inescapable legacy of mankind—death.⁶⁷ While each of us is allotted a particular period of time to live,⁶⁸ we cannot determine in advance how long it will be.⁶⁹ Perinatal death presents an occasion to acknowledge and mourn our collective mortality and to contemplate the potential value and purpose of all life.

Even though this purpose—the "work of God"—cannot be seen ahead of time,⁷⁰ the wisdom perspective provides ample grounds for the hope of realizing such meaning. Despair over the prospect of suffering and death often leads to the discovery of new meaning in life, even when it is deformed and all too brief: "It is better to go to a house of mourning/ than to go to a house of feasting,/ for death is the destiny of every man;/ the living should take this to heart."⁷¹ Such authentic mourning⁷² can transform one's initial response to overwhelming suffering⁷³ into the conviction that "Anyone who is among the living has hope—even a live dog is better off than a

⁶⁶Victoria A. Vincent et al., *Pregnancy Termination Because of Chromosomal Abnormalities: A Study of 26,950 Amniocenteses in the Southeast*, 84 S. MED. J. 1210 (1991); Marlon S. Verp et al., *Parental Decision Following Prenatal Diagnosis of Fetal Chromosome Abnormality*, 29 AM. J. MED. GENETICS 613 (1988); Arie Drugan et al., *Determinants of Parental Decisions to Abort for Chromosome Abnormalities*, 10 PRENATAL DIAGNOSIS 483 (1990).

⁶⁷Ecclesiastes 3:19-21; 9:2-3; see also 1 Corinthians 15:48; Romans 5:12ff.

⁶⁸See Ecclesiastes 3:1-2a ("There is a time for everything,/ and a season for every activity under heaven:/ a time to be born and a time to die").

⁶⁹Ecclesiastes 9:11-12.

⁷⁰Ecclesiastes 8:16-17. Cf. *supra* notes 34, 62.

⁷¹Ecclesiastes 7:2.

⁷²The sense intended for "mourning" in Ecclesiastes is reviewed *supra* note 11, at 306-7. Furthermore, Zeanah gives a clinically useful description of the relationships among *grief*, *mourning*, and *bereavement*.

[G]rief refers to all of the painful affects associated with loss of an infant, such as sadness, anger, guilt, shame, and anxiety. . . . [M]ourning . . . refers to a complex interplay of all the psychological processes that are triggered by the loss. This includes biological reactions, behavioral reactions, and cognitive and defensive operations related to the loss. Therefore, . . . mourning is the total psychological experience of the bereaved individual with respect to the loss. Mourning is considered to be the process by which an individual resolves a loss, that is, accepts the reality of a change in the external world and reorganizes and reorients his or her . . . world accordingly. . . . Bereavement refers to the period of time during which mourning is largely unresolved.

Zeanah, *A Critical Review*, *supra* note 18, at 467-68.

⁷³See *supra* note 49 and accompanying text.

dead lion!"⁷⁴ The example of a loving and supportive delivery of a newborn with trisomy 18 with multiple anomalies who succumbs moments after birth illustrates this opportunity to "take to heart" the implications of mortality and transform the dread and grief of this experience into new meaning.⁷⁵

On the other hand, valid concerns over artificially prolonging the biological existence of infants born with truly marginal conditions like anencephaly warrant exercising wise judgment over reasonable limits of supportive care for these terminally ill infants.⁷⁶ Such decisions are still taken with care and respect for the image of God and the lost future represented in that infant. As the trajectory of the dying child's life emerges over time, parents ultimately gain the wisdom to discern when it is "time to die."⁷⁷ The need for a sensitivity and flexibility capable of adapting to the individual needs of different parents and family is increasingly reflected in the evolving standard of care for families facing perinatal loss.⁷⁸ How do we best incorporate these priorities to support parents through the grief and dread entailed in the dying process and maximize the opportunity for authentic mourning? Perinatal hospice provides just this setting.

The Advantage of Perinatal Hospice

Since federal law restricts the funding of stateside abortions to situations in which the life of the mother is truly at risk, military medicine provides a unique environment for obstetrics/gynecology and neonatology. Even with complications like maternal pulmonary hypertension, the provision of an abortion generally requires agreement among at least three obstetricians (including, if possible, a maternal-fetal-medicine (MFM) specialist) that the pregnancy truly poses a significant threat to maternal

⁷⁴Ecclesiastes 9:4.

⁷⁵By going through the birth and "premature" death of a long-awaited infant, many couples have overcome their dread with faith and love to be blessed far beyond their expectations. See, e.g., James H. Pence, *A Road Not Chosen*, in DALLAS THEOLOGICAL SEMINARY'S KINDRED SPIRIT, Aug., 1996 at 4.

⁷⁶While supporters of the sanctity-of-life principle have historically denied any significant role for quality-of-life criteria, cases such as "Baby K" raise legitimate questions about what should be considered "futile therapy." See Reitman, *Dilemma of Medical Futlity*, *supra* note 12, at 231-255). To blindly apply any and all possible life prolonging therapy when it becomes obvious that it is time to let go is also to risk presuming on divine prerogative. Cf. *supra* notes 35, 62 and accompanying text. See also, Jerome R. Wernow, *Saying the Unsaid: Quality of Life Criteria in a Sanctity of Life Position*, in BIOETHICS AND THE FUTURE OF MEDICINE: A CHRISTIAN APPRAISAL 93-111 (John F. Kilner et al., eds. 1995).

⁷⁷See *supra* note 68; cf. Reitman, *Dilemma of Medical Futlity*, *supra* note 12, at 256-64.

⁷⁸Zeanah, *A Critical Review*, *supra* note 18; Irving G. Leon, *Perinatal Loss: Choreographing Grief on the Obstetric Unit*, 62 AM. J. ORTHOPSYCHIATRY 7 (1992); Irving G. Leon, *Perinatal Loss: A Critique of Current Hospital Practices*, 31 CLINICAL PEDIATRICS 366 (1992).

life. When this condition is not met, many military parents do not choose to procure an abortion outside the system. While this choice may involve financial considerations—a second or third trimester abortion may be costly, often requiring prior payment—it should nevertheless raise substantial concerns about the embarrassing ease with which abortions can be procured under *Roe-Casey* for the “health” of the mother.

Under these circumstances parents expecting infants with congenital anomalies are given the opportunity to consider the alternative of perinatal hospice. Perinatal hospice coordinates the combined efforts of obstetricians, MFM physicians, neonatologists, anesthesia providers, labor and delivery nurses, neonatal intensive care nurses, chaplains/pastors, and social workers. The main burden of effort for physicians consists in antepartum counseling and preparation. Parents are first given the fetal diagnosis and expected prognosis during extensive counseling with MFM specialists, who participate in ultrasound evaluation, amniocentesis (if desired), birth planning, and ongoing medical management in the antepartum, intrapartum, and postpartum periods. Parents see the baby on ultrasound and are allowed to begin grieving.

The ultimate success of perinatal hospice depends on the patience, sensitivity, and sense of interdependence of nurses at the bedside, as well as their willingness to facilitate the mourning process.⁷⁹ Extensive support is provided in labor through encouragement by the nursing staff and pain relief administered by the anesthesia service. Labor management is conducted as in other labors with the exception of fetal heart rate monitoring in lethal fetal conditions like anencephaly or trisomy 13 or 18, where an abnormal pattern is expected.⁸⁰ Method of delivery is based on obstetrical indications and the infant is presented immediately to the parents to share the baby's remaining life.

Many of these infants are stillborn, but some may live for minutes to days. Most birth defects are not nearly as grotesque at birth as parents may imagine;⁸¹ non-anomalous features of the baby, such as cute hands and feet or soft skin, are pointed out. The parents are allowed to stay in the delivery

⁷⁹The rich dynamics of perinatal hospice is described in detail in a wonderful collection of narratives from Vanderbilt University Medical Center. See Andrew Todd, *1 JOURNEY OF THE HEART: STORIES OF GRIEF AS TOLD BY NURSES IN THE NICU* (2d ed. 1995). (Copies can be obtained directly from Mr. Todd at Vanderbilt University Medical Center, AAA-1200 MCN, VUMC, 1221 Second Ave. S., Nashville, TN 37232-2410.)

⁸⁰Toshihiko Terao et al., *Neurologic Control of Fetal Heart Rate in 20 Cases of Anencephalic Fetuses*, 149 AM. J. OBSTETRICS & GYNECOLOGY 201 (1984); Thomas J. Garite et al., *Fetal Heart Rate Patterns and Fetal Distress in Fetuses with Congenital Anomalies*, 53 OBSTETRICS & GYNECOLOGY 716 (1979).

⁸¹Todd, *supra* note 79, at 238.

suite with the child as long as they wish.⁸² Comfort measures are emphasized to the family—the infant is kept warm and cuddled, and some may even be able to feed. Neonatologists provide additional comfort measures as needed. We encourage dressing and naming the baby, taking pictures of the baby, and, if desired, holding of the baby by all family members, including children.⁸³ If the parents are feeling overwhelmed, those infants who survive for longer periods may be kept comfortable in the nursery during the postpartum period.

This supportive environment has been offered on our antenatal service since 1989. Contrary to the expectations of those who favor early termination, the response has been overwhelmingly positive.⁸⁴ We are convinced that most parents instinctively recognize that their infant has a "future-like-ours,"⁸⁵ however brief that future may be. When parents permit God to determine their paths and allow life to run its course they are much more content; they can more freely experience and mourn the bittersweet birth and all-too-soon departure of their awaited child. Grief lessens as time passes, and they can rest secure in the knowledge that they did not dismember or destroy their baby.

Conclusion

Physicians and nurses committed to authentic care can provide a genuine alternative to the horrific destruction wrought by partial birth abortion. They may refer to physicians who advise their patients of the life-affirming choice to bear and comfort their terminally ill fetuses. Perinatal hospice and the wisdom perspective provide a "better way" than merely hastening death. Since this choice is undoubtedly facilitated when such care is fully "covered," we assert that even in nonmilitary settings financial concerns should not preclude offering this option. Physicians and hospitals can foster the establishment of perinatal hospice by being willing to waive or adjust fees, or by helping to set up payment plans.

When provided with this support, most parents will choose to bring their infants with congenital anomalies to term. Parents are given the opportunity to genuinely mourn our common fallibility and mortality and acknowledge the sovereign prerogative of God as Creator over each individual life. While they mourn the premature loss of that life they come

⁸²Ingela Rådestad et al., *Psychological Complications after Stillbirth—Influence of Memories and Immediate Management: Population Based Study*, 312 *BRIT. MED. J.* 1505 (1996).

⁸³Todd, *supra* note 79, at Appendix B.

⁸⁴Out of 20 cases of fatal anomalies detected in our experience at Madigan Army Medical Center, only one family opted to pursue early termination.

⁸⁵See *supra* notes 34-37 and accompanying text.

to rejoice in the confidence that God delights in cultivating joy out of the sorrow that so characterizes our earthly existence.⁸⁶

⁸⁶*Ecclesiastes 11:7-12:1*. See also Reitman, *Dilemma of Medical Futility*, *supra* note 12, at 255-56, for an exposition of the implications of this passage for wise and joyful stewardship under similar circumstances of so-called medical futility.