OVERVIEW

This article cuts to a very tense and difficult point: Mothers are suing over poor prenatal care, claiming that if they’d known they were going to give birth to severely disabled children, they would have terminated their pregnancies. But legally, and morally, what does it mean to say that a child should not have existed?

Weil tells the story of Donna Branca and her child, A.J. Branca became pregnant with A.J. when she was 31 and the pregnancy did not go well. She bled during her first trimester, the fetus was strikingly small at the 20 week sonogram, and she did not gain much weight. Had she been only a few years older, entering a period in which pregnancies are treated more cautiously by medical professionals, her doctors might have suggested more rigorous tests for genetic disorders in the fetus.

A.J. is now 6 years-old, but, as a result of Wolf-Hirschhorn Syndrome, has the mental capacity of a 6 month-old. Looking back, Branca wishes she had pressed her doctors with more questions. After more complications – including evidence of gene duplication in the fetus, gene deletion in one chromosome, an early delivery, and a newborn A.J that measured 15 inches and weighed two and a half pounds – the ordeal prompted her to file a multimillion-dollar lawsuit against her obstetrician. Her contention is that the poor medical care deprived her of the right to abort her fetus.

Such a story, says Weil, “sheds an uncomfortable light on contemporary expectations about child-bearing and on how much control we believe we should have over the babies we give birth to.” Recent advances in prenatal technology, for example, have made it possible to detect major flaws in fetus health. A recent article in The New England Journal of Medicine details new noninvasive techniques for screening for Down syndrome in the first trimester – the assumption being that early testing can give parents the option of early pregnancy termination. The number of prenatal genetic tests jumped tenfold between 1993 and 2003. But there remain no clear
set of ethical guidelines for making the difficult decision to terminate. It seems the courts will decide questions such as the following:

- Should it be O.K to terminate a deaf child?
- What about a blind child?
- How mentally retarded is too mentally retarded?
- What if the child will develop a serious disease later in life?

At issue is the question of a ‘wrongful birth’ or termination of an otherwise ‘wanted pregnancy.’ And the assumption appears to be the prospect of a ‘medical necessity’ that can legitimize fetus terminations. But the courts are understandably hesitant to weigh in on this. In the 1966 case, Gleitman v. Cosgrove, the first significant wrongful-birth lawsuit involving a disabled child, the New Jersey Supreme Court stated that a court “cannot say what defects should prevent an embryo from being allowed life.” Of course, in 1973 Roe v. Wade established a woman’s right to terminate a pregnancy. But the moral quandary remains, and a few states refuse to accept wrongful-birth cases to pass through legislation or case law.

As a matter of bioethics that hits home with families and doctors alike, the quandary boils down to a question of whether technological possibilities translate into medical necessities (i.e. prenatal testing), and whether the findings of such tests can stand as valid reasons for fetus termination. More to the point: should disability lead to abortion? Weil herself wrestled with this question in a personal way, having learned that a fetus she was carrying was likely to be born with serious birth defects. She and her husband made the decision to abort.

According to David Wasserman and Adrienne Asch, university bioethicists, prenatal testing is morally suspect because the system leads people to reduce fetuses to a single trait: impairment. Moreover, is there already a bias toward termination within the medical establishment, and perhaps within a consumeristic approach to pregnancies on the part of parents? Then again, deciding to proceed with a pregnancy in which the child will have certain defects will certainly amount to a life of difficulty, cost, and suffering on the part of the child and their parents.

QUESTIONS FOR REFLECTION AND DISCUSSION
1. Have you or anyone you know faced a situation involving medically-warranted pregnancy termination?
2. How should patients be counseled when faced with such a difficult decision?
3. Should the life of a fetus be protected at all costs?
4. Should doctors press for more rigorous prenatal testing?
5. What is the role of technology in this story? Is technology complicating moral decisions, or helping them?

**IMPLICATIONS**

The author and her subject have shed a personal light on a situation that is complex and painful. Neither appear to have been rash ‘consumers’ in their view of troubled pregnancies. However, it is evident that the availability of new pre-natal testing technologies strengthens the assumption that future parents are entitled to make the ‘wise’ decision to abort. Critics of this practice and mindset make a sobering point. Once we begin to evaluate an existing fetus as a possible inconvenience (as true as this may be) we have already exchanged the devotion to life for the dictates of pragmatism.

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