Legal and Ethical Issues Associated with Chromosomal Abnormalities

CASE:

Martha Lawrence was nervous about going to the human genetics unit at the hospital. Her physician referred her because she was unexpectedly pregnant at age 41, and at that age she was at risk for having a child with a chromosomal abnormality, especially Down syndrome. She was 18 weeks pregnant, which would not leave much time if she wanted to have an abortion, considering it takes 7-14 days to get the results of an amniocentesis procedure. Women older than age 35 have a much higher risk of having a child with a chromosomal abnormality than younger women.

Martha previously had two normal pregnancies; her children are now 13 and 17. The genetic counselor, Dr. Gould, suggested that Martha have amniocentesis to examine the fetal chromosomes.

In discussing the results of the test, Dr. Gould said that the fetus did not have an extra copy of chromosome 21 and therefore did not have Down syndrome. But the analysis did show the presence of an extra Y chromosome (XYY instead of XY), a condition called Jacobs syndrome. This condition is fairly common; each day in the United States, five to ten boys are born with an XYY set of chromosomes.

In the U.S. legal system, Martha Lawrence would have an option to sue Dr. Gould if she were not offered amniocentesis and later gave birth to a child with a genetic disorder. There are two possible legal scenarios: a wrongful-birth suit or a wrongful-life suit. Both types of lawsuits are based on the idea that the birth or the life of the child is wrong because of either the action or the inaction of the physician or genetic counselor.

The table below explains the differences between the two legal actions:

In a Wrongful-Birth Case	In a Wrongful-Life Case
The parents sue the physician.	The child sues the physician.
The parents argue that because the physician's inaction did not make it possible for them to take a prenatal test, they could not make an informed decision as to whether they should have the baby.	The child argues that because of inadequate advice by the physician, he or she was born into a life of pain and suffering.
This type of case relies on *Roe v. Wade*, the case that legally allowed abortion in the United States, because the mother must say that if she had known that the child had this condition, she would have aborted it.	This type of case also relies on *Roe v. Wade* for similar reasons.
Reasons for such suits include the following: The physician neglected to tell the parents of the test or the risk of having such a child; the physician or lab mixed up the results, did the test incorrectly, or did the wrong test; or the physician deliberately chose not to tell the parents.	Reasons for such suits are the same as for wrongful-birth suits.

The outcomes in these types of cases are based on two questions:

1. Could a diagnosis of this condition have been made in time to have an abortion?
2. Was the condition serious enough that a reasonable person would have had an abortion?

Most courts of law allow wrongful-birth suits for two reasons: *Roe v. Wade* gave a woman an alternative to birth (abortion), and physicians have extensive medical malpractice insurance, so financial compensation is often not a problem. However, only five states allow wrongful-life suits, because courts are uncomfortable declaring that someone should never have been born. An example of a wrongful-life suit is examined in "Spotlight on Law: *Becker v. Schwartz*" below.

Wrongful-life and wrongful-birth suits are different from malpractice suits, because in these cases the physician has done nothing to cause the injury (the birth defect). In malpractice suits, the physician is accused of malpractice ("bad" practice), because he or she caused the damage to the patient.

Some other types of cases have evolved from these types of lawsuits:

- *Wrongful conception*: when birth control methods (surgical or chemical) don't work
- *Wrongful pregnancy*: when an abortion isn't completed and the mother has medical problems

Martha Lawrence may want to read about some of the interesting legal aspects of the XYY karyotype. Early investigations found that people with the XYY karyotype have a tendency toward aggressive behavior associated with the presence of an extra Y chromosome. In effect, this may mean that some forms of violent behavior are genetically determined. In fact, the XYY karyotype has been used on several occasions as a legal defense (unsuccessfully, so far) in criminal trials (see, for example, *People v. Tanner*, 13 Cal.App. 3d [1970]).

The question asked in these trials and the subsequent studies of children with the XYY karyotype is: Can we find a direct link between the XYY condition and criminal behavior? Using today's science, there doesn't seem to be strong evidence to support such a link. In fact, most males with the XYY karyotype lead socially normal lives.

In the United States, long-term studies of the relationship between antisocial behavior and the XYY karyotype were discontinued. Researchers feared that identifying children with potential behavioral problems might lead parents to treat them differently and result in behavioral problems as a self-fulfilling prophecy. The uncertainty surrounding the XYY condition illustrates Dr. Gould's dilemma about Martha Lawrence's case and may make Martha's decision all the more difficult.

The following case is an example of the type of lawsuit Ms. Lawrence's child might file if Dr. Gould fails to tell Ms. Lawrence about the XYY condition: a wrongful-life case.

Delores Becker got pregnant at age 37. Her physician, who treated her for her entire pregnancy, did not tell her about amniocentesis and her increased risk of having a child with Down syndrome. Her son was born with Down syndrome. Even though it was 1978, amniocentesis was being used.

The Beckers filed a wrongful-life suit on behalf of their son, and the resulting case, *Becker v. Schwartz*, was eventually heard by the New York Court of Appeals. Delores Becker testified that if she had been informed of her son's condition, she would have had an abortion. As a result of her physician's failures, she did not learn of her son's mental disability until after he was born.

The court dismissed the complaint, holding that no one has the right to be born free of disease. A $2,500 settlement was reached, and the baby was given up for adoption. Some attorneys analyzing the case later thought that the Beckers could have received more money if they had gone to an even higher court.

From: Yashon, Ronnee K., and Michael R. Cummings. *Human Genetics and Society*. 2. Belmont, CA: Brooks/Cole Cengage Learning, 2012. 65-67.