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The Ethics of Prenatal Genetic Testing: A Religious View

For most families, pregnancy is a time of great joy and wonder. Parents prepare for their new child wondering what their baby will be like: will it be a boy or a girl? How much will the baby weigh? Will the baby have Grandma Rose's blue eyes? But for some families, the nine months are not just spent debating which parent the baby will resemble. For parents who have genetic diseases and disorders, the questions are a lot harder: Will our baby have Down syndrome like cousin Sarah? Will our baby have Cystic Fibrosis? What happens if the baby has Huntington's disease like Grandpa Joe?

A huge advance that has resulted from the field of genomics is the ability to test children for genetic diseases and disorders prenatally. Even before implantation of a fetus, doctors and geneticists can determine if a child will have genetic diseases. Prenatal genetic testing and preimplantation genetic testing has been able to bring some peace of mind to parents who may be a carrier for a certain disorder.

Despite all the benefits that parents may receive from these tests, some opt not to receive prenatal genetic testing even if there is a risk for a genetic disorder. The reasoning for this decision varies from parents to parents, but it usually has a common theme. Many of these parents choose not to undergo prenatal genetic testing or preimplantation testing for personal moral, ethical, or religious reasons.

This paper will explore in a little more depth the ethical doctrine surrounding prenatal genetic testing in Catholicism. I hope to explore the church's view on the rights of an oocyte and fetus. The purposes of prenatal and preimplantation genetic testing will be explored and connected to the views of the church.

² PURPOSES OF PRENATAL GENETIC TESTING:

Before discussing the ethics and religious viewpoints surrounding prenatal genetic testing, the purposes of the testing must be identified. Many of the religious views are based on the motives behind testing.

If two parents are a carrier for a recessive genetic disease, one of their two alleles is mutated, but the phenotype of the disease is not present. This heterozygocity of two parents leads to a 25 percent chance that their child will receive both of the mutated genes, thus expressing and suffering from the disease. Parents who are carriers for genetic diseases chose prenatal or preimplantation genetic testing for a few reasons.

Instead of letting chance decide the genetic makeup of their baby, parents can choose to undergo in vitro fertilization to minimize the risk of having a baby with a genetic disorder. In this method of preimplantation genetic diagnosis (PGD), a doctor would remove eggs from a mother and fertilize them with the father's sperm. On the third day after fertilization, one or two cells from the blastomere are removed and analyzed. The most commonly used method for genetic testing on these cells is PCR. Geneticists can then determine whether each embryo will have the genetic disorder or not. The selected embryo is then implanted into the mother's uterus after day five. Extra embryos are then either frozen for possible further use or discarded.

But what would happen if two carriers for a genetic condition had already conceived a child? Through procedures such as amniocentesis, geneticists can determine if an embryo or fetus will have a genetic disorder or disease. If a child will have a genetic disorder, parents have the opportunity to respond in a few ways.

If parents discover that their baby will in fact have a genetic disease, they can chose to abort the baby. There are different motives cited for this choice. Some parents do not want to bring a child into the world who will only suffer. They believe it is unfair to the child and immoral to knowingly carry it to term with the knowledge of this future suffering. Another reason may be that parents cannot deal with the stress and pain of having a child with a genetic disorder; perhaps the stress is financial, social, familial, etc. Parents may not be able to afford Bernal having a child with a severe disorder, or they may not have the time. Some parents have even been cited as choosing to abort a fetus with a genetic disease because they believed it would be unfair to their existing children, since their new child would take an exorbitant amount of time, energy, and resources from the parents.

However, even after receiving the news that their baby will have a genetic disease, some parents choose to keep the baby. By choosing to receive prenatal genetic testing, parents are given the opportunity to have the knowledge of a future disease before the birth of the child. This gives parents an opportunity to prepare for the child—both psychologically and physically. Parents can learn more about the resources available for their baby and learn how they can best take care of their child. Parents are given the chance to make their baby's transition into the world as safe, healthy, and loving as possible with their child's genetic disease.

CATHOLIC PERSPECTIVE

The Catholic Church's view of prenatal and preimplantation genetic testing draws mostly from the doctrine of *Dignitas Personae*. This doctrine explains the dignity of human life; that everyone has inherent worth and dignity because they are made in the image of God himself. For this reason, every life should be valued and protected—from the moment of conception to the moment of natural death.

The Vatican states that, "The dignity of a person must be recognized in every human being from conception to natural death. This fundamental principle expresses *a great 'yes' to human life* and must be at the center of ethical reflection on biomedical research." (Congregation for the Doctrine of the Faith). It is upon this idea that a person has dignity from the moment of conception upon which the teachings on genetic testing are based.

Derived from the doctrine of Dignity of Human Life, the document *Instruction Dignitas Personae on Certain Bioethical Questions*" spells out the Catholic Church's stance on prenatal genetic engineering. It is a well-known fact that the Catholic Church is against abortion. Although the presence of a "soul" cannot be scientifically proven, the Church argues that conception is the first appearance of a human life, so the embryo must be a human person and therefore is entitled to the dignity of life. There is no human life purer and more innocent than an unborn child, and therefore it is a sin to destroy this life.

Because the Catholic Church stands in opposition to abortion, prenatal genetic testing with the end goal of an abortion is morally illicit. If a mother plans to abort a child that will inherit a genetic disease, the Church does not condone prenatal genetic testing. If, however, parents wish to know if their child will have a genetic disease so they can better prepare for their baby's arrival, then prenatal genetic testing is morally licit.

The Catholic Church's stance on preimplantation genetic testing is a bit more complex. First, the topic of in vitro fertilization must be explored. When a couple decides to undergo in vitro fertilization, many times, more oocytes are produced than can be implanted in a mother's uterus. These oocytes, or sometimes fetuses, are frozen to be saved in case the parents decide to have another child later, or sometimes for research or stem cell purposes. The Catholic church states that "the majority of embryos that are not used remain 'orphans.' Their parents do not ask for them and at times all trace of the parents is lost." (Congregation for the Doctrine of the Faith). For this reason, the Catholic faith has decided that "Cryopreservation is *incompatible with the respect owed to human embryos.*" Oocytes, which some claim have lesser rights than even an embryo, are still entitled to the same dignity of human life in the Catholic faith. For this reason, the cryopreservation of oocytes is also morally unacceptable.

Additionally, the church has spoken about the morality of performing genetic tests on embryos before implantation. The Catholic Church explains that Preimplantation diagnosis "is directed towards the qualitative selection and consequent destruction of embryos, which constitutes an act of abortion." The Catholic Church also frowns upon preimplantation genetic testing because it stems from a "eugenic" mentality, valuing healthy genes over embryos with genetic abnormalities. This mentality measures the value of life simply in terms of "normality," preserving the dignity of life only for embryos without genetic disabilities.

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The church stresses that it is important to grant dignity to each life, regardless of parent's desires, social conditions, level of development, disabilities, health, etc. The sick and disabled are not a separate part of humanity, they are a part of the human condition, affecting each and every person. For this reason, preimplantation genetic testing leads to reduced worth for individuals already living with genetic diseases and disorders. By valuing life simply based on healthy genes in the earliest forms of development, the mentality is extended to all humanity. It shows that society values healthy individuals more than the unhealthy. Take, for example, the fictional example provided by the movie *Gattaca*. In this movie, babies are produced in vitro, enabling the best genetic selection possible. Children born naturally, without selection of genes and therefore suffering from more genetic disabilities, do not have as much value in society and are disadvantaged when it comes to employment, marriage, friends, etc. While this example is rather extreme, it points out the moral dangers the Catholic Church identifies from choosing healthy genes over genetic disabilities; it places more value on healthy life, reducing the value of others. In the eyes of the Catholic Church, all people are entitled to this dignity and worth.

It is so important to recognize and understand the reasoning behind the Church's stance on preimplantation genetic testing and other bioethical issues, as well as the opinions of other faith traditions. With many people in our world turning to their faith in regards to health, it is so important for healthcare providers to be understanding and sensitive of a person's religious views and traditions. This knowledge enables providers to be able to provide the best treatment possible. Additionally, with the evolution and revolution of genetic medicine, it is important to evaluate advances and procedures ethically. Because sometimes even if something is possible, it may not be ethically sound—how far is too far?

Bibliography

- Anderson, Rebecca Rae. "Religious Traditions and Prenatal Genetic Counseling." Am J Med Genet C Semin Med Genet. 2009 February 15; 151C(1): 52–61. doi:10.1002/ajmg.c.30203. Accessed from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2819466/pdf/nihms85828.pdf>.
- Ekberg, Merryn. "Maximizing The Benefits And Minimizing The Risks Associated With Prenatal Genetic Testing." Health, Risk & Society 9.1 (2007): 67-81. Academic Search Premier. Web. 7 Dec. 2013.
- Bick, David P. and Eduardo C. Lau. "Preimplantation Genetic Diagnosis." *Pediatric Clinics of North America*. Vol 53, Issue 4. 2006. Accessed online from < http://www.mdconsult.com/das/article/body/432037882-2/jorg=journal&source=&sp=16353516&sid=0/N/541537/1.html?issn=0031-3955>.
- Congregation for the Doctrine of the Faith. *Instruction Dignitas Personae on Certain Bioethical Questions*. Vatican: 2008
- Congregation for the Doctrine of the Faith. *Instruction Dignitas Personae on respect for human life at its origins and for the dignity of procreation*. Vatican: 1987.

Drexel Medical School. *Spirituality and Religion in Medicine*. http://webcampus.drexelmed.edu/religion/module/genetics/perspectives.asp

- John Paul II. Encyclical Letter 'Veritas splendor' regarding certain fundamental questions of the Church's moral teaching. Vatican 1995.
- Markens, Susan. ""It Just Becomes Much More Complicated": Genetic Counselors' Views On Genetics And Prenatal Testing." *New Genetics & Society* 32.3 (2013): 302-321. *Academic Search Premier*. Web. 7 Dec. 2013.
- Milunsky, Aubrey. Genetic Disorders and the Fetus: Diagnosis, Prevention, and Treatment. Fifth Edition. 2004: John Hopkins University Press.