

Genetics Testing and Prenatal Diagnosis

This is the second of six case studies, prepared by the staff of CHA's Theology and Ethics Department, scheduled to appear in Health Progress in 2003.

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*Should they take
a chance and
conceive a child?*

Nancy and Bill, recently married, want to begin a family. Both of their families have extensive histories of cystic fibrosis (CF), however. In fact, both partners have siblings with CF. In a conversation with a friend, Nancy expresses anxiety about having a child with CF. She is very intent on having a "normal" child and doesn't want "to be burdened with caring for a handicapped kid." If Nancy and Bill both carry the gene for CF, every child they conceive will have a 1 in 4 chance of inheriting both aberrant genes and getting the disease. There is also a 50-50 chance that any child of theirs will be a carrier of the aberrant gene. As a carrier, that person could pass the gene on to his or her offspring.

Nancy's friend encourages Nancy and Bill to go for testing. They decide to do so. From the tests, they learn that each of them carries the gene for CF. They are devastated.

They are also very confused. Given what they were told by the geneticist (and the risk therefore to a future child), they wonder whether they have a moral obligation *not* to conceive. Or should they take the chance (and possibly burden a child with this disease)? Or should they conceive and then undergo prenatal diagnosis to determine whether the unborn child has the mutation for CF. If the unborn child does have CF, there is the option of abortion. Bill is adamantly opposed to abortion, but Nancy thinks it is sometimes justified.

They decide to take the chance. They do conceive. Nancy goes for prenatal diagnosis (amniocentesis in this case). Her unborn child, the test shows, has inherited the CF gene from both parents and, hence, will get the disease.

QUESTIONS FOR DISCUSSION

Sponsors and Board Members

1. Does your facility (or do facilities in your system) have a genetics program that offers *carrier*

testing (i.e., testing of individuals to determine whether they are carriers of an aberrant gene that they could pass along to offspring)? If yes, how is this service provided in a way that reflects the value and belief commitments of Catholic health care and the mission of your organization? Are the assumptions that guide the provision of this service at all different from those of a secular facility? What is in place to support couples who receive a devastating diagnosis?

2. If this service is not provided, what are the reasons for this (e.g., insufficient volume, duplication of services, lack of resources)? Is there a possible "ministry opportunity" in beginning to provide the service (assuming that the need for it exists)? If yes, what values and beliefs would guide its development and characterize its provision?

3. Does your facility (or do facilities in your system) offer *prenatal diagnosis*? If yes, how is this service provided in a way that reflects the value and belief commitments of Catholic health care and the mission of your organization? Are the assumptions that guide the provision of this service at all different from those of a secular facility?

4. If the service is not provided, what are the reasons for this (e.g., no ob/gyn department, insufficient volume, duplication of services, belief that it is contrary to church teaching, belief that it is associated with or contributes to abortion)? Is there a "ministry opportunity" in beginning to provide the service (assuming that the need exists)? If yes, what values and beliefs would guide its development and characterize its provision?

Executive Teams

1. Does your facility (or do facilities in your system) have a genetics program that offers *carrier testing* (i.e., testing of individuals to determine whether they are carriers of an aberrant gene that they could pass along to offspring)? If yes, how is

this service provided in a way that reflects the values and belief commitments of Catholic health care and the mission of your organization? Are the assumptions that guide the provision of this service at all different from those of a secular facility? What is in place to provide support to couples who receive a devastating diagnosis?

2. If this service is not provided, what are the reasons for this (e.g., insufficient volume, duplication of services, lack of resources)? Is there a "ministry opportunity" in beginning to provide the service (assuming that the need for it exists)? If yes, what values and beliefs would guide its development and characterize its provision?

3. Does your facility (or do facilities in your system) offer *prenatal diagnosis*? If yes, how is this service provided in a way that reflects the value and belief commitments of Catholic health care and the mission of your organization? Are the assumptions that guide the provision of this service at all different from those of a secular facility? What messages are communicated to patients in the way the service is provided? What is in place to provide support to couples who receive a devastating diagnosis?

4. If the service is not provided, what are the reasons for this (e.g., no ob/gyn department, insufficient volume, duplication of services, belief that it is contrary to church teaching, belief that it is associated with or contributes to abortion)? Is there a "ministry opportunity" in beginning to provide the service (assuming that the need exists)? If yes, what values and beliefs would guide its development and characterize its provision?

5. If the service is provided, how do the physicians deal with the issue of abortion when discussing the option of prenatal diagnosis with a woman?

6. How do you (or how would you) ensure that women who undergo prenatal diagnosis are adequately counseled and counseled in a way that is consistent with Catholic values?

7. What are the ethical issues/concerns that you see in the case above, both explicit and implied, at the individual, organizational, and societal levels? How would you address them, in light of Catholic moral teaching and the value commitments of Catholic health care?

8. If either or both of these services are offered, who benefits from them? How does this square with our commitments to justice and to care of the poor?

Ethics Committees

1. If your facility does offer *carrier testing*, how does it, first, demonstrate the commitments

of Catholic health care and of the Catholic moral tradition, and, second, how does it ensure that women are adequately counseled and counseled in a manner consistent with the Catholic tradition? Has the ethics committee been involved in developing policies and procedures for carrier testing?

2. If your facility offers *prenatal diagnosis*, how does it demonstrate the commitments of Catholic health care and of the Catholic moral tradition and how does it ensure that women are adequately counseled and counseled in a manner consistent with the Catholic tradition? Has the ethics committee been involved in developing policies and procedures for prenatal diagnosis?

3. What values and beliefs do you think should characterize the provision of carrier testing and/or prenatal diagnosis in a Catholic health care facility?

4. What ethical issues/concerns do you see in the case above? Think about issues in the individual, organizational, and societal spheres, both explicit and implied. How would you address them in light of the Catholic moral tradition, the commitments of Catholic health care, and the mission of your organization?

5. Nancy and Bill wonder whether they have a moral obligation not to conceive. Might there be such an obligation in this case? In other cases? If not, why not? If so, why and under what circumstances?

6. What ethical challenges do you see in Catholic health care facilities' providing either or both of these services?

GUIDING ETHICAL PRINCIPLES

The following principles and norms are intended to provide some moral guidance to discussions around the questions above. They are not exhaustive of those that might be relevant to the case and the questions raised. They should, however, be of some help.

Ethical and Religious Directives Two of the *Ethical and Religious Directives for Catholic Health Care Services* apply here:

- "Genetic counseling may be provided in order to promote responsible parenthood and to prepare for the proper treatment and care of children with genetic defects, in accordance with Catholic moral teaching and the intrinsic rights and obligations of married couples regarding the transmission of life" (Directive 54).

- "Prenatal diagnosis is permitted when the procedure does not threaten the life or physical integrity of the unborn child or the mother and does not subject them to disproportionate risks;

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 “Prenatal diagnosis is not permitted when undertaken with the intention of aborting an unborn child with a serious defect.”

when the diagnosis can provide information to guide preventative care for the mother or pre- or postnatal care for the child; and when the parents, or at least the mother, give free and informed consent. Prenatal diagnosis is not permitted when undertaken with the intention of aborting an unborn child with a serious defect” (Directive 50).

*A Shared Statement of Identity for the Catholic Health Ministry*¹ reminds us that we must:

Promote and Defend Human Dignity Because each person is created in the image of God, each one is sacred and possesses inalienable worth, is social by nature, and finds fulfillment in and through community. Catholic health care, therefore, treats individuals—and their families and various communities—with profound respect and utmost regard.

Attend to the Whole Person Because each person is, in this life, an inseparable unity of body and spirit, Catholic health care responds to human need by addressing the physical, psychological, social, and spiritual dimensions of the person. [Because a person is a unity, he or she ought not be reduced to any one dimension.]

Promote the Common Good Because the health and well-being of each person is intimately related to the health and well-being of the broader community, Catholic health care promotes the “economic, political, and social conditions [that] ensure protection for the fundamental rights of all individuals and enable them to fulfill their common purpose and reach their common goals.”²

Act on Behalf of Justice Because justice is an essential component of the Gospel of Jesus, Catholic health care strives to create and sustain right relationships both within the ministry and with those served by the ministry. Toward this end, Catholic health care attends to basic human needs for all (including accessible and affordable health care) and seeks structures that enable the full participation of all in society, the equitable distribution of societal resources, and the contribution of all to the common good.

Care for Poor and Vulnerable Persons Because Jesus had a special affection for poor and vulnerable persons, Catholic health care “should distinguish itself by service to and advocacy for those people whose social condition puts them at the margins of society and makes them particularly vulnerable to discrimination” (Directive 3). Catholic health care is characterized by its efforts to alleviate the conditions that perpetuate the structures of poverty and vulnerability in society.

Principle of Responsible Parenthood “Married couples should regard it as their proper mission to transmit human life and to educate their children. . . . This involves the fulfillment of their role with a sense of human and Christian responsibility . . . it also involves a consideration of their own good and the good of their children already born or yet to come, an ability to read the signs of the times and of their own situation on the material and spiritual level, and, finally, an estimation of the good of the family, of society, and of the Church.”³

RESOURCES

Congregation for the Doctrine of the Faith, “Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation,” (March 10, 1987), Part I, no. 2.

Haring, Bernard, “Man’s Responsibility for the Genetic Heritage,” in *Ethics of Manipulation*, Seabury Press, New York City, 1975, pp. 161-172.

National Conference of Catholic Bishops/Science and Human Values Committee, “Critical Decisions: Genetic Testing and Its Implications,” *Origins*, vol. 25, May 2, 1996, pp. 769, 771-772.

O’Rourke, Kevin, “Genetic Screening and Counseling,” in *Healthcare Ethics: A Theological Analysis*, Georgetown University Press, Washington, DC, 1997, pp.323-331.

Parens, Eric, and Asch, Adrienne, “The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations,” *Hastings Center Report*, vol. 29, September-October 1999, pp. S1-S22.

Tauer, Carol, “Preventing the Transmission of Genetic Diseases,” *Chicago Studies*, vol. 33, November 1994, pp. 213-227.

NOTES

1. *A Shared Statement of Identity for the Catholic Health Ministry*, Catholic Health Association, St. Louis, 2001.
2. *Ethical and Religious Directives for Catholic Health Care Services*, U.S. Conference of Catholic Bishops, Washington, DC, 2001, Introduction to Part 1, pp. 8-9.
3. “Gaudium et Spes,” in Austin Flannery, ed., *Vatican Council II: The Conciliar and Post-Conciliar Documents*, St. Paul Editions, Boston, 1975, section 50, p. 953.

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