



Susceptibility Testing for Children

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

Holy Toledo Hospital has a genetics program that gets most of its referrals through the obstetrics service. Recently it has begun recruiting practitioners of general internal medicine and family medicine, thereby giving continuing education units to physicians who attend lectures about new possibilities in genetic testing for a variety of conditions.

Janice Miller, MD, a family practice physician, has attended these lectures and found them fascinating. She has begun to incorporate what she has learned into her practice. Dr. Miller, who considers herself to be a very ethical physician, spends time making her patients aware of the risks, benefits, and alternatives not only of treatments but also of diagnostic tests. One kind of diagnostic test seems to her utterly benign. It is a simple blood test that can predict predisposition to certain diseases. Dr. Miller knows that most people can keep healthy with early detection and intervention, lifestyle changes, and ongoing surveillance. Believing that such information is a patient's right, she encourages testing whenever the test is sensitive enough and specific enough to generate reliable information for the patient involved.

Dr. Miller, however, is stumped in the case of a particular patient. Billy Jones is 13 years old and as hale and hearty as they come. Dr. Miller has known Billy since birth and has treated him for childhood cuts and scrapes, a simple fracture of the arm that occurred in a tree-climbing incident, and lice. Billy is an active child, growing to be a big boy like his older brother and many of the men in his family.

His mother recently made an appointment for a September physical examination for him. Over the phone, she tipped her hand. She told Dr. Miller that her father and uncle died at age 55

and 53 respectively, each after a decade of deterioration with early-onset Alzheimer's disease (AD). There is some suspicion that her paternal grandfather, who also died young and had a reputation for craziness, may also have had AD. Mrs. Jones has done her homework. She knows there is a familial form of Alzheimer's disease, characterized by early onset, responsible for somewhere around 5 percent of all AD cases. She also knows that Alzheimer's of this type is associated with four different genetic mutations and that if a person has one of those four, a mutation in the ApoE4 gene, the likelihood of getting AD increases dramatically if the person has also sustained a head injury earlier in life.

Mrs. Jones is prepared to demand the genetic test that will show whether Billy carries a mutation of this gene. Dr. Miller's own research finds the test to be quite reliable. If Billy does carry the mutation, Mrs. Jones says, it's piano lessons for him, not the football tryouts he has his heart set on. She admits she is not sure whether their health insurance will pay for this test, but she doesn't care. If she has to, she will pay for Billy's genetic test out of her own pocket.

QUESTIONS FOR THE BOARD

Does the board receive regular reports on new and ethically challenging programs such as programs in genetic testing? Do these reports include only financial information—or do they also inform the board about how the program is developing, how it is being marketed, and the kind of education it makes available for providers and consumers?

Is Dr. Miller's dilemma hers alone (a physician's only), or is it appropriate for policy consideration? If it is appropriate for policy consideration, at what level should the policy be made? The board? Executive management? The medical

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*Should a
13-year-old be
tested for the
Alzheimer's
gene?*

staff? The genetics department or program?

How would Dr. Miller's dilemma come to the attention of the board—or would it? If it did, to what or whom would the board appeal in order to make a principled decision about whether such testing should or shouldn't be allowed at Holy Toledo? Is there relevant guidance in the *Ethical and Religious Directives for Catholic Health Care Services*? In other sources of Catholic teaching?

QUESTIONS FOR EXECUTIVE MANAGEMENT

Is Dr. Miller's dilemma hers alone (a physician's only), or is it appropriate for policy consideration? If so, where should a policy be developed? Should Holy Toledo Hospital offer testing for susceptibility to genetic diseases for which there is no treatment?

Should Dr. Miller's dilemma be brought to the attention of executive management at Holy Toledo Hospital? If so, why and how?

How does Dr. Miller's dilemma relate to the mission of a Catholic hospital such as Holy Toledo? Or does it not relate to that mission?

If you were a nurse executive, CEO, chief medical officer, or another member of the management team, and Dr. Miller brought this dilemma to you, what would you advise her to do? What would *you* do, if you were in her shoes?

QUESTIONS FOR THE ETHICS COMMITTEE

Imagine that Dr. Miller has, before keeping her appointment with Mrs. Jones and Billy, brought this case to the ethics committee. How would you, if you were a committee member, analyze the presence or absence of informed consent? Autonomy? Beneficence? Are there legal issues you would be concerned about? Spiritual concerns? What would you recommend to Dr. Miller?

If your executive management team asked you

to prepare a draft of a policy for the board's consideration about testing for early-onset diseases for which there is no effective treatment, what would your recommended policy include? Would it distinguish between minors and adults? If so, why?

To what sources would you appeal for justification for your draft policy? Catholic teaching? Secular sources, such as the President's Commission reports?

What role should the ethics committee play in developing educational programs for clinicians about the ethics of genetic testing and treatment?

What role should the ethics committee play in providing education for the broader local community concerning the ethics of genetic testing and treatment?

GUIDING ETHICAL PRINCIPLES

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

Promote and Defend Human Dignity Because each person is created in the image of God, each is sacred and possesses inalienable worth; each 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 (see Directive 23).

- **Beneficence** Our decisions and actions should contribute to the well-being of others.

- **Nonmaleficence** Our decisions and actions should not harm others.

- **Informed consent** When making decisions about possible treatments, individuals should have adequate information about the risks, bur-

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RESOURCES

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Wertz, Dorothy, "Genetic Testing for Children and Adolescents: Who Decides?" *JAMA*, September 21, 1994, pp. 875-881.

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playground came to me.
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all my rules.
And my mom just never
stopped smiling.

This is the day we all got to
forget I was sick.

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WISH KID MOLLY, AGE 6

REFLECTIONS

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The Mass allowed us to reaffirm our solidarity with the sick.

exists to bring the Lord to the sick—to people such as those who came to the basilica of the National Shrine of the Immaculate Conception seeking the church's healing ministry. The Mass allowed us to reaffirm our solidarity with the sick and renew our pledge to work on their behalf, from the tireless efforts of the nurses and other caregivers in our hospitals and clinics, to our advocacy efforts on behalf of those whose voices are often not heard, or even worse, ignored.

It is true that, in every nation in the Americas, Catholic health care must continually struggle with the question of its own identity in an increasingly secular world. The World Day of the Sick celebrated our resolve not to let that struggle interfere with our mission and duty to affirm Catholic, human values within the health care systems of all societies. Globalization in Catholic health care challenges us in the United States to see our mission and ministry in a broader context. It challenges us to affirm our solidarity with Catholic health care in every nation in continuing the healing ministry of the church. It challenges us, as Bishop John Ricard of the Diocese of Pensacola-Tallahassee, FL, said at the World Day of the Sick, to be a "positive example of globalization, promoting an authentic culture of solidarity, life, and the ethic of service." □

CASES IN GENETICS

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Each person is an inseparable unity of body and spirit.

dens, and benefits of the treatment; about treatment alternatives (including no treatment); and should make the decision freely, that is, without force, coercion, or manipulation (see Directives 26, 27, 28).

• *Best interests* When a person is unable to make treatment decisions for him- or herself and has had no opportunity to express his or her values and preferences, those making decisions for that person should base those decisions on the person's "best interests," that is, what will most likely contribute to his or her well-being, considering the person as a whole (see Directive 33).

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 his or her physical, psychological, social, and spiritual dimensions. Because of the unity that *people are, they ought not be* reduced to any one dimension (see Directive 33).

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 it. 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. □

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