

Genetics and Confidentiality

This is the first 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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Tom is
devastated by
the results
of the
Alzheimer's
test.

A colleague of yours at the neighboring community hospital (your major competitor) tells you of the following incident.

Tom, a 29-year-old man who is engaged to be married, came to the Alzheimer's program to be tested for the presence of a gene that causes early-onset Alzheimer's disease. (The community hospital has recently begun to offer more and more genetic testing, especially prenatally, for various types of cancer and for Alzheimer's). Two of Tom's siblings and several aunts and uncles on his father's side developed Alzheimer's in their mid-to-late 30s. Tom's results were positive.

The neurologist discussed the implications of the results with Tom. He is devastated. The neurologist strongly recommended that Tom inform his fiancée of the test results; Tom adamantly refused. He also told the neurologist that he doesn't want anything about the test to be entered into his medical record. He was, he said, about to apply for a job as an occupational therapist (he had just received an advanced degree) at the community hospital's adjoining long-term care facility, which has a large Alzheimer's unit. He feared that the information about his genetic status might undermine his chances of being hired for the position. The neurologist informed Tom that nothing could be done to alter his medical record.

Tom applied for the job, was given an interview, and ultimately offered employment on condition that he receive a favorable medical report. Tom underwent the usual physical. Two weeks later, he received a letter informing him that a conditional offer of employment had been revoked for medical reasons.

Your colleague has learned that Tom was denied employment because of the results of the genetic test. The community hospital (which is

self-insured) feared that Tom would eventually not be able to perform his job and was also greatly concerned about increased disability and health care costs.

QUESTIONS FOR DISCUSSION

Sponsors and Board Members

1. Your competitor is clearly trying to create a niche for itself in the area of genetic testing. The community hospital is even beginning to do some low-key marketing, especially for prenatal testing and testing for various types of cancer. How is your organization going to position itself vis-à-vis your competitor—that is, what is your organization going to do about genetic testing, taking into account both market considerations and, especially, mission considerations?

Executive Teams

1. Same as question No. 1 above.
2. How would your organization handle the kind of situation described in the case above as it concerns employment? How would you handle it as it concerns insurance coverage? Do you have any policies to guide such decisions? How knowledgeable are key decision makers in your organization about such issues?
3. If the neurologist were a member of your medical staff, what would you expect him or her to do in regard to Tom's refusal to inform his fiancée of the test results?
4. What would you suggest as morally justifiable approaches to the issues in this case? What are your reasons for suggesting such approaches? How might your organization's mission and values have a bearing on the issues?

Ethics Committees

1. What would you identify as the key ethical issues in the case?

2. What would you suggest as a morally justifiable approach to the issues and for what reasons?

3. Does your organization have policies that would provide guidance for this type of situation? If so, do you think those policies are adequate? If not, and if you were charged with developing such policies, what might they look like?

GUIDING ETHICAL PRINCIPLES

These values/principles drawn from the Catholic tradition should provide some guidance in addressing the issues in the case above. They will not provide easy or quick resolutions, but they will highlight critical considerations. Other values/principles may also be relevant. Surely an organization's own mission and values will have some bearing on the issues.

Respect for Human Dignity Because each person is created in the image of God, each one is sacred and possesses inalienable worth. For this reason, individuals should be treated with profound respect and utmost regard (see the *Ethical and Religious Directives for Catholic Health Care Services*, Introduction, Part One, p. 8¹).

• **Equality** This value, grounded in human dignity, affirms the basic equality of all. A corollary is that equals should be treated equally. No one should be treated unequally on the basis of irrelevant differences. This would be a violation of both dignity and justice (see Directive 23).

• **Confidentiality** This value encourages respect for an individual's decision not to have information that he or she has disclosed to another shared with a third party without consent (see Directive 34). Maintaining confidentiality is not an absolute requirement, but the burden of proof in breaching it is on those who would do so. Confidentiality may sometimes be breached in order to prevent serious harm from occurring to another.

• **Privacy** This value gives the individual dignity-grounded protection against unwanted and unwarranted intrusions into zones that he or she has designated as his or her personal life (see Directive 34). Privacy is not an absolute requirement, though the burden of proof is on those who would breach it.

Solidarity Because we are made in the image of a triune God, we are social by nature. This fundamental relationality with others implies responsibilities to them. At minimum, we should not harm them. Optimally, we ought to seek their good.

Common Good Because of our social nature, we

ought to contribute to the creation of "conditions of social life by which individuals, families, and groups can achieve their own fulfillment in a relatively thorough and ready way" (*The Church in the Modern World*, section 74²; see also the *Ethical and Religious Directives*, Introduction, Part One, pp. 8-9).

Stewardship Health care resources should be used prudently and justly (see the *Ethical and Religious Directives*, Introduction, Part One, Directive 6, p. 10). □

RESOURCES

Committee on Science and Human Values, "Critical Decisions: Genetic Testing and Its Implications," U.S. Conference of Catholic Bishops, Washington, DC, 1996.

Rothstein, Mark, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, Yale University Press, New Haven, CT, 1997.

Tauer, Carol, "Personal Privacy and the Common Good," *Health Progress*, March-April 2001, pp. 36-42, 78.

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NOTES

1. *Ethical and Religious Directives for Catholic Health Care Services*, U.S. Conference of Catholic Bishops, Washington, DC, 2001.

2. Pope Paul VI, *Gaudium et Spes*, 1965, section 74.

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