Challenges for the Future of Genetic Medicine

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The future of genetic medicine will be marked by social, ethical, and legal challenges, especially for the disability community. Some of the most important challenges include the diagnosis/therapy gap, confidentiality, and prenatal screening--each of which is briefly addressed below.

The Diagnosis/Therapy Gap

While the ability to diagnose genetic conditions continues to grow almost exponentially, there remains a profound time gap between the capacity to diagnose and the capacity to treat. Sadly, to date there are very few effective therapies for genetically linked conditions. It is likely that for some time there will be many more genetic diseases diagnosed than can be treated.

This phenomenon has resulted in the emergence of a new class of patient: the presymptomatic ill. These are persons who have been diagnosed with a genetic disease for which there is no treatment. In many cases they may not show symptoms of the disease for a number of years, sometimes never. Yet they carry the knowledge that they have a genetic condition that may one day lead to their disability or death.

No one knows what the psychological and social implications of the diagnostic/therapy gap will be. What might it be like for a young girl to know at eight years of age that she has the gene for
Huntington's, a disease whose debilitating symptoms do not appear until about 40-50 years of age? How will that knowledge affect her life’s choices? More importantly, how will that knowledge affect the choices of her parents as they nurture her? Will they be over-protective and smothering? Will they discourage long-term life planning?

Genetic knowledge indeed carries the power to shape lives for good or ill. The challenge of genetic knowledge is knowing what to do with that information. For instance, women diagnosed with one of the breast cancer genes, BRCA-1 or BRCA-2, sometimes undergo prophylactic mastectomy because of their fear of getting cancer. In some cases, though, these patients were either misdiagnosed or they misunderstood the meaning of the tests. Tragically, this results in unnecessary physical and psychological trauma associated with mastectomy. On the other hand, many women have doubtless dodged breast cancer by having the procedure. How do we balance the benefits and harms of genetic knowledge? This is a question with which we are only beginning to grapple.

Confidentiality

Information about one's possible disease conditions is highly personal information. Individuals may or may not want to know that information. Clearly there are others who might wish to have your personal genetic information--namely, your employer and your insurance company. After all, they, too, stand to gain or lose if you become ill.

In 1982, only 1.6% of companies reported that they were using genetic tests for employment purposes. By 1997, the American Management Association found that the number had grown to about 10% of companies. Increasing numbers of persons are reporting genetic discrimination in the workplace. They may be denied employment or promotions based on their genetic information. At the same time, only about 21 states have enacted laws to prevent workplace genetic discrimination, and only 42 states have even minimal protections against insurance discrimination based on genetic conditions. Poll after poll shows that overwhelming numbers of Americans want genetic privacy protected. Yet, there is no national comprehensive genetic privacy/anti-discrimination legislation.

What will the future hold for those with genetic conditions? Will they be able to get jobs? Will they be able to secure insurance? We should all contact our elected officials to let them know our concerns about our national genetic future.

Prenatal Screening

Another example of the power of genetic knowledge is its link to prenatal (before birth) genetic
screening. Prenatal screening may be performed either before implantation or in utero. In pre-implantation screening, embryos who have been created in the laboratory are tested for certain genetic conditions and are either implanted or destroyed depending on the results and wishes of the prospective parents. In post-implantation screening, unborn children are tested in the womb to see if they are carrying deleterious genes, and then a decision is made either to carry them to term or abort them. Some parents who are morally opposed to embryo selection or abortion may refuse prenatal genetic testing, since they intend to bring a child to term regardless of genetic condition. Others may find the information important as they prepare for a child who may have disabilities.

**For a Truly Human Future**

Most people in the disability community already know that "disease" and "illness" are not value-free labels. Disabilities (like abilities) are largely social constructs rather than clear-cut categories. Unfortunately, many healthy persons and many in the scientific community seem unaware that this is the case. Discrimination against persons because of their race, gender, or disability is an ugly reality. Discrimination based on genetic identity is uglier still. If we are to attain a truly human future for ourselves and for our children, we must value individuals for who they are--not for what they can do. As imagers of God, every person should receive respect and be treated with dignity, regardless of their genetic condition.

To be sure, the genetic revolution will lead to great advances in the relief of human suffering and the treatment of human diseases. We may even witness the emergence of genetic cures. Our laudable goal of treating human disease and relieving human suffering must not be allowed to become a tool for eliminating the persons who are suffering. To do so would be to use the good gift of genetic knowledge for evil ends. Only vigilance on the part of us all can prevent a bleak genetic future from unfolding. Contrary to what many people may believe, the social, ethical, and legal implications of the new genetics are not merely the domain of the scientist, philosopher, theologian, or lawyer. We all have a stake in our genetic future.

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1 Adapted from the authors' new book, *Does God Need Our Help? Cloning, Assisted Suicide, & Other Challenges in Bioethics* (Tyndale 2003). Available from the publisher or online from CBHD.

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