Rights and Genomic Medicine: Risks to Individuals

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Nature and Significance of Rights

- Human rights are possessed by all persons.
- Human rights protect persons' most vital interests.
- The values underlying human rights are autonomy and individual welfare.

- Rights protect people's interests by imposing <u>obligations</u> on others.
- "Others" include other individuals, health care providers, and institutions (e.g., governments, corporations, hospitals, etc.).
- Any of these "others" might violate rights. Protection comes from <u>compliance</u> or <u>enforcement</u>.

- Rights have been historically ascribed to individual persons.
- But there is an emerging consensus that **groups** too may possess rights.
- Ethically significant features of groups include: size, whether membership is chosen, whether there is a history of discrimination.

Right of Access

- Access to health care is widely regarded as a human right.
- But in the United States access to health care is not guaranteed to all citizens.

- Access to health care gives persons the opportunity to sustain their well-being (by treating or preventing disease, and by promoting health).
- Access to health care both **promotes autonomy** and gives people a chance to **thrive**.

Privacy

- Though ‘privacy’ has multiple meanings, in the context of health care it refers to <u>protected information</u> (information that others may not have without our consent).
- It is important to us that some information be private (e.g., health information and financial records).

- Privacy interests can protect both welfare and autonomy.
- Welfare: Some information is such that if others have access to it they will be more likely to harm us.
- Autonomy: We believe that some things are not others’ business, regardless of the impact on welfare.

Risks

- How might genomic medicine put access to health care and privacy at risk?

- Here the rights of access to health care and privacy are interdependent.

- Genetic information can be gleaned from genetic testing or family history.
- In the U.S., for most of us access to health care comes from having health insurance (usually through our employer).
- Health insurance is provided by for-profit corporations.

- If genetic testing and family history are part of one’s medical record, individuals may face a dilemma.
- On the one hand, family history and/or genetic testing may promote health.
- On the other hand, this information may be used to deny health insurance or increase premiums.

Other ways that genetic information in the hands of others may threaten individual welfare:

- Loss of employment
- Inability to purchase disability insurance
- Inability to purchase life insurance

- Research in genetics may pose a risk to **groups**.
- If a group’s greater predisposition to certain diseases is shown to have (in part) a genetic basis, the group may suffer from stigmatization, stereotyping, and the like.

Right Not to Know

- A right not to know may seem strange since patients and research subjects have struggled to secure a right of informed consent.
- But to prevent anxiety and for fear of social losses, <u>some</u> prefer not to know that they will get or are at greater risk of getting a disease.

The right not to know is now widely recognized.

European Convention on Human Rights and Biomedicine: “Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.” [Article 10.2, 1997]

UNESCO Universal Declaration on the Human Genome and Human Rights: “The right of every individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected.” [Article 5c, 1997]

“Declaration on the Rights of the Patient” adopted by the World Medical Association: “... the patient has the right not to be informed on his/her explicit request, unless required for the protection of another person’s life.” [Article 7d, 1995]

If the right not to know is taken seriously, then minimally it requires providers:

- Not to perform genetic tests without the consent of the patient
- Not to pressure patients to give family history if they are opposed
- Not to foist information on patients against their explicit request

- Genomic medicine can do much good.
- Yet if genomic medicine exacerbates threats to access to health care, privacy, and the right not to know, patients will be ambivalent.
- Can these threats be overcome?