

Genetics, Ethics and Human Rights

Prof. Victor B. Penchaszadeh
Genetics and Public Health
Mailman School of Public Health
Columbia University
April 15, 2003

Genetics Applied to Human Rights Issues

Genetic Identification of Victims of Human Rights Violations

- Identifications of human remains
- Enables to establish the truth
- Facilitates family mourning and funeral rituals
- Provides information for prosecution of perpetrators

Identification of abducted children in Argentina

- The military dictatorship (1976-1983) disappeared 30 thousand people
- Three hundred of the disappeared were pregnant women
- Births occurred in clandestine detention centers, mothers were killed and babies appropriated by childless couples linked to the military
- Mothers and Grandmothers of Plaza de Mayo

Identification of abducted children in Argentina

- Democracy restored in 1983
- Genetic Database established, with banked DNA of putative grandparents
- Court-ordered genetic tests on children suspected of being offspring of the disappeared
- Sixty-three children identified
- Ethical and psychological issues

Ethical Principles in Medicine

SOCIAL JUSTICE

- Fair distribution of benefits and burdens to all members of society
- Equitable access to health care independent of ability to pay, ethnic origin, cultural background, genetic characteristics, presence of disability, etc
- Any differential treatment should be based on fairness, justice and accepted medical criteria

Ethical Principles in Medicine

RESPECT FOR PERSONS

- Respect the self-determination and choices of autonomous persons
- Protect persons with diminished autonomy
- Respect for human dignity and the basic intelligence of persons as the basis of relationship between health professional and user of health service

Ethical Principles in Medicine

BENEFICENCE

- Secure the well-being of persons by acting positively in their behalf
- Maximize the benefits that can be attained by health actions

Ethical Principles in Medicine

NON-MALEFICENCE

- “Do not cause harm”
- Conduct health actions in such ways to minimize possible harms to persons
- Wherever possible, remove causes of harm altogether

Ethical Principles in Medicine

PROPORTIONALITY

- Duty, when taking actions involving risks of harm, to so balance risks and benefits that actions have the greatest chance to result in the least harm and the most benefit

Ethical Issues in Genetics

- Privacy of genetic information
- Confidentiality
- Voluntariness and Informed Consent
- Stigmatization
- Discrimination
- Acceptance of diversity

Ethical Principles Applied to Genetic Services I

- Genetic information on individuals is private and should not be divulged without explicit written consent
- Genetic information should not be used to discriminate individuals in access to health care or in the workplace

Ethical Principles Applied to Genetic Services II

- Fair allocation of public resources for the management and prevention of genetic disorders and birth defects on the basis of need.
- Needs defined according to magnitude and severity of problems to be addressed, benefits anticipated from proposed actions, and possible competing priorities.

Ethical Principles Applied to Genetic Services III

- Equitable access and timely provision of medically indicated services.
- Refraining from offering tests or procedures whose validity and safety are not proven.
- Adequate information, genetic counseling and informed consent preceding any genetic testing.

Ethical Principles Applied to Genetic Services IV

- Voluntary approach to genetic testing, prevention and treatment.
- Avoidance of coercion by government, commercial interests, health professions, religious leaders and other social agents.
- Freedom of choice in all matters relevant to genetics, particularly in reproduction options and predictive testing.

Ethical Principles Applied to Genetic Services V

- Special caution when testing asymptomatic individuals for predisposition to late onset conditions when no proven medical beneficial interventions are available.
- Presymptomatic and predisposition testing of healthy children for adult-onset conditions should only be offered if there are clear medical or psychological benefits.

Ethical Principles Applied to Genetic Services VI

- Prenatal diagnosis should always be voluntary, preceded by genetic counseling and equitably accessible, according to medical indications established by genetic services policies.
- Its goal is to provide relevant information on the health of the fetus to expand the reproductive options of prospective parents.
- The performance of prenatal diagnosis for non-medical uses (paternity testing, gender selection, enhancement) is unethical.

Ethical Principles Applied to Genetic Services VII

- The decision of whether to continue or terminate a pregnancy of an affected fetus should be made by the prospective parents without interference or coercion.
- The imposition of prenatal diagnosis through direct or subtle means to enforce public health goals or social policies of any kind is unethical.

Ethical Principles Applied to Genetic Services VIII

- Stimulation of public debate and active participation of the community in the setting of goals and implementation of genetic services.
- Role of patient/parents organizations.
- Respect for human genetic and cultural diversity, and tolerance for differences.

Problems For the Ethical Applications of Genetics

- Gap between diagnostic capacity and therapeutic interventions
- Lack of societal consensus on goals and strategies of genetic services
- Fear and intolerance of human differences
- Notion that individuals with disabilities are less worthy than “normal” people
- Excessive emphasis on genetic determinants of disease at the expense of environmental factors

Genetic Reductionism

“Genes provide the ultimate explanation for many aspects of human health and behavior, social arrangements and life activities”

“Genes are the fundamental element to which human phenomena can be reduced”

Genetic Determinism

- “Any human trait influenced by genes is a relatively fixed trait, such that it is little affected by changes in the physical and social environment”
- “Traits ascribed to genes are unchangeable”
- *Actually, depending on the nature of a gene or a mutation in a gene, interactions with the environment or other genes in the individual may either yield wide or limited variations in the degree to which a trait is expressed*

Determinism in the Words of its Advocates

- “We now know that in large measure our fate is in our genes (Watson, 1989)
- “From the genome sequence we can have the ultimate explanation of a human being”(Gilbert, 1987)
- “Knowledge from the HGP could solve problems of the homelessness and crime and aid the poor, the infirm and the underprivileged” (Koshland, 1991)

Ethical Pitfalls of Genetic Determinism

- Shift blame from environments and socioeconomic structures, to individuals and biology
- Distract attention from social determinants of disease and behavior
- Privilege research on biological determinants of health and behavior
- Support for “individualized” genetic approaches to health promotion and disease prevention
- Genetic discrimination
- Racial prejudice
- Stigmatization of people with disabilities

Consequences of determinism

- Racial prejudice
- Marginalization of disenfranchised groups and the poor
- Stigmatization of people with disabilities
- Violation of reproductive rights
- Forced sterilization in the name of “eugenics”
- Genetic discrimination

Influence of for-profit interests

- Marketing genetic tests without sufficient proof of validity and safety
- Genetic discrimination by insurance companies and the workplace
- Commercial appropriation of genetic knowledge through gene patenting and restrictive licensing increase inequalities

DNA patenting

- Invention *versus* discovery
- Natural substance *versus* composition of matter
- **Product patents:** covers all uses of that product
- **Process Patents:** patent on a method or technique
- **Use patents:** only a specified use is patented

Criteria for Patenting

- **Novelty**: an invention must not have been previously disclosed to the public
- **Inventiveness**: the claimed invention would not be obvious to the 'skilled' person
- **Usefulness**: 'capable of industrial application' (EU) or with 'specific, substantial and credible utility' (USA)

Patent Licensing

- Restricted licensing

- Compulsory extensive licensing

Effects of DNA patenting

- Hampers research
- Creates monopolies
- Raises costs of genetic tests and therapies
- Increases inequities
- Invites expensive and lengthy litigations

UNESCO, 1997

The Universal Declaration on
the Human Genome and
Human Rights

UNESCO DECLARATION
HIGHLIGHTS. 1.

- Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics
- It is imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity

UNESCO DECLARATION
HIGHLIGHTS. 2.

- The human genome contains potentialities that are expressed differently according to each individual's natural and social environment.
- No one shall be subjected to discrimination based on genetic characteristics.
- All genetic information must remain private and confidential

UNESCO DECLARATION
HIGHLIGHTS. 3.

- Research, treatment or diagnosis affecting an individual's genome requires prior:
 - consideration of risks and benefits
 - informed consent
 - right to decide whether or not to be informed about the results
 - prior independent scientific and ethical review

UNESCO DECLARATION
HIGHLIGHTS. 4.

- No research should prevail over respect for the human rights, freedoms and dignity of individuals or groups of people
- Benefits from scientific advances shall be made available to all
- Freedom of research should be upheld.

UNESCO DECLARATION
HIGHLIGHTS. 5.

- Research on the human genome shall seek to offer relief from suffering and improve the health of individuals and humankind.
- States should ensure that research results are not used for non-peaceful purposes

UNESCO DECLARATION
HIGHLIGHTS. 6.

- States should foster free exercise of research and international dissemination of scientific knowledge on human genome, safeguarding respect for human rights, fundamental freedoms and human dignity, and to protect public health
- States should promote scientific co-operation between industrialized and developing countries

UNESCO DECLARATION
HIGHLIGHTS. 7.

- Respect and promote solidarity towards individuals, families and population groups affected by genetic disabilities
- Strengthen capacity of developing countries to carry out genetic research and enabling them to benefit from scientific and technological achievements
- Promote free exchange of scientific knowledge and information

UNESCO DECLARATION
HIGHLIGHTS. 8.

- In a *symbolic* sense, the human genome is the heritage of humanity
- The human genome in its *natural state* shall not give rise to financial gains

Main Ethical and Human Rights Challenges in Human Genetics

- Insure equitable and appropriate application of technologies for the benefit of all in need, independent of the ability to pay
- Resist genetic determinism and reductionism (genomania)
- Resist eugenic tendencies and uphold the right to autonomous reproductive decisions
- Avoid and combat genetic discrimination and stigmatization

Main Ethical and Human Rights Challenges in Human Genetics

- Achieve genetic literacy for health professionals, the public, the media, and political and social leaders.
- Limit the use of genetic technologies for health purposes and not for “enhancement”
- Achieve a more balanced bio-psycho-social view of human nature where social and cultural context is given full recognition.
