Application of Ethical Theories to Human Genome Sequencing

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Application of Ethical Theories to Human Genome Sequencing

Outlines

- Genome Sequencing
- Falling Cost of Sequencing
- Scientific Facts of Human Genome Sequencing
- Ethical Concerns and Issues
- Global Features of Ethical Theories
- Addressing Ethical Issues
- Conclusion
Genome Sequencing and Cost

**Human Genome Sequencing** = Sequencing of 23 pairs of chromosomes molecules → 23 pairs of DNA molecules → 3 billion DNA base pairs

- **Sequencing** → Readout, *letter-by-letter* (base by base)

**Why?**
- Application: Cure for diseases, Forensics, GMO food, Evolution…
- Further genetic research → Applications

**Cost** → **Affordable** → **Common Use**

→ Ethical concerns increase

**Falling fast**

In the first few years after the end of the Human Genome Project, the cost of genome sequencing roughly followed Moore’s law, which predicts exponential declines in computing costs. After 2007, sequencing costs dropped precipitously.

- **2003:** 3 billion U.S. dollars
- **Today:** ≤ 10,000 dollars
- **Goal:** 1,000 dollars

What are the ethical concerns in this case?
Scientific Fact and Ethical Concerns

- Genome is *blueprint of life* ➔ Unique biological identity ➔ Information: *ID, ethnicity, susceptibility to diseases, family background (tree)*…

  Sequencing ➔ Reveal this information

Ethical concerns regarding this information:
Ownership, Privacy, Abuse / misuse, benefit/profit…

- **Sequencing** ➔ Structure of DNA molecules ➔ Understand life at *molecular* and individual levels ➔ *Control (engineer) life* at that levels.

- Ability to *alter* life forms or *create* new life forms ➔ Dual research, can be used for both good and **bad end**.

So, main ethical issues are…?
Ethical Concerns

- Playing God
- Frankenstein (dual) science
  - Genome information:
    - Ownership
    - Privacy
    - Abuse / misuse
    - Benefit / profit
- Genome databases

How do we know what ethically right?
Ethical Theory

Ought to do, ought not to do

Issue

Input

Different theories may issue different judgment on the same issue.

Output

Ethical Theory → Moral Judgment

Based on

◆ Defensible Moral Value
◆ Fact
◆ Logic

Clear
Consistent
Universal

Common Grounds

What is the Playing God ethical issue?
Playing God

Argument in Strong Form

God created universe and life.

Only God can (has the right to) change it, or create a new life forms.

DNA sequencing leads to interfering with God’s creation process: Changing genes and potential of creating new forms

“Create monsters”…

Playing God ➔ Violation of divine commands

DNA sequencing is morally wrong.

Is that final?
Playing God

Counterargument: From Within the Divine Command Theory

God gave us a brain to use

Use it or lose it (scientific fact)

We better use it (Being rational)

Research to figure out how nature works ➔ GOOD thing.

Is sequencing really playing God?

What are divine commendments?

Criteria too vague

Multiple interpretations

Changing over time

Examples: Galileo, Darwin…

What about Galileo and Darwin?
Looking Back at History

Were They Playing God?

Earth moves

Obvious Scientific Fact?

Galileo spoke this fact…

Violated Divine Commands

Literally put him on trial and convicted!

Today

Even Divine Command believers believe in what Galileo said.

“Evolution Is Not Inconsistent With The Notion Of Creation”

Pope Francis, Oct. 27, 2014.

Proposed Theory of Evolution

Violated Divine Commands

Still on ‘trial’

Now, Listen:

“Genome Sequencing ≠ Playing God

OK, but how about the possibility of Frankenstein Science?”
Frankenstein Science

◆ Possibility harmful use of research (DNA sequencing) → STOP?

❖ Kant’s *categorical imperative*: Act as if the *rule* of your *action* were to become a *universal* law of nature.

◆ Discovery of atom → Atomic research → Atomic Bomb → No Atomic Research?

*Imagine* time reversal was possible, roll back:

No discovery of atom → No atomic research → No electronic age

Morally Wrong ← happiness/utility lost ← No Internet ← No computer

Can You Even Imagine That?

◆ Don’t stop research, but take steps to prevent its harmful use.

What are the issues with *genome information*?
Genome Information: Abuse or Misuse

Genome Sequencing 

Reveals

Genome Information

Unique ID

Ethnicity

Diseases Susceptibility

Great Value

- Steal
- Abuse
- Misuse
- Profit

By

- Insurance Companies
- Employers
- Politician
- Governments

Is this good or bad?
Information Misuse OK?

Genome Information: Steal, Abuse, Misuse, Profit

Ethical Egoism
- Pursue your own interest exclusively
  - OK

Social Contract
- Mutual Benefit
  - Social Contract
- Not OK
  - 1. Never treat others as mere means.
  - 2. Act as if rule of action will become universal law of nature.

Utilitarian
- Maximize aggregated Happiness

Kantian

Is that means no genome information databases?
No Genomics Databases?

Genome databases ➔ Some research STOP, some SLOW down ➔ ultimate target: humanity (no research benefits)

✧ Reduced total happiness (Utilitarian)
✧ Irrational (Kantian)

Morally wrong

Instead:
Right thing is in the middle of two extremes (vices):
Aristotelian Ethics:

❖ Decide whose and what information enter a given database (Consent)
❖ Implement better security (Privacy)
❖ Enforce proper use: Make it hard to misuse, regulations if needed,…
❖ Fair distributions of profit or benefits

OK, but how about ownership issue?
Who Owns Genome Information?

- You are a person ➔ Moral right of ownership on your genome; Your genome information.

- What happens to your ownership right?

- Why this issue is important? ➔ Abuse, Misuse, Profit, Consent

- A factor must be considered:

  Real (or most) scientific and medical value comes from collection of (rather than single) human genomes

  Profit ➔ Utilitarian, Kantian
  Social contract ➔ Should be distributed fairly

  Utilitarian ➔ Part of profit
  Common Good ➔ Education, Scientific Research, Environment...
Tool for Discrimination

**DNA Sequencing**: can be used as a tool against **women** and various **minorities**:

- Ethnic/Racial **minorities** in a given society
- People with **disabilities**
- People with specific **cultures** or **lifestyles**
- People with specific **genes**

**Justification?**

It all may be done in name of (under the cover of):

- Science
- Humanity

**It is not just imagination**

**We have been there before, big time!**
**Don’t Forget Eugenics**

**Eugenics**: field of study and practice of selective breeding as applied to humans with the goal of improving the human species.

**Started**: toward the end of the nineteenth century

**Eugenics Movement**

Several countries all over the world including **U.S.**

**Ended with**: Adolf Hitler (Nazi Germany)

**Victims**: Ethnic/racial minorities, people with disabilities…

**Justification?**

It all were done **in name of (under the cover of)**:

- Science (good genes VS bad genes) to Improve Humanity

http://www.eugenicsarchive.org

I highly recommend this Ref
Application of Ethical Theory to Genome Sequencing

Conclusions

- **Playing God.** While steps should be taken to prevent its possible harmful use, genomics research must continue.
- **Databases.** Genome databases are necessary for research. But steps must be taken to ensure privacy and only proper use of information.
- **Ownership.** Ethically, an Individual is the owner of information in his/her own genome.
- **Privacy and Consent.** Use of anyone’s genome information by others should require proper consent.
- **Profit.** Profit from genome information should be fairly distributed among all parties. Part of profit should go to common good.
- **Tool for Discrimination.** Learning from history of the eugenics movement, we should be on guard to make sure that genome sequencing is not used as a tool to commit injustice against any individual or group.
References


5. J. Rachels, "The Elements of Moral Philosophy," vol. 6th or 7th Ed.

