

Bioethics and Genomics: Exploring the Representation of Race and Gender in Popular Culture

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Gender, Race, and the Complexities of Science and Technology
Revised April 13, 2009

Voices of the Academy:

In 2003 a multidisciplinary group of faculty from Stanford University organized a two-day workshop designed to engage dialog focused on the debates about the connection between genetic traits and racial difference. The workshop developed into an ongoing research seminar with a goal of creating a set of principles to guide the research of race and ethnicity categories in genetic variation.

In July 2008, the collective published an open letter in *Genome Biology* outlining ten statements endorsed by all participants. While the ten statements published by members of this aggregate are specifically designed to explore race and ethnicity dynamics in genetic research, sex and gender can easily be substituted in the majority of the ten statements.

<http://genomebiology.com/2008/9/7/404>

EXERCISE 1.

Read the 10 statements published by Sandra Soo-Jin Lee et. al. (2008). What is the importance of creating a set of ethical guidelines for the future research of human genetics and racial/ethnic variations? Can sex/gender be substituted for race/ethnicity in these tenets? Does this substitution not work in any of the statements? Why? Is there a need to alter the framework of statements where sex/gender cannot be substituted for race/ethnicity? How can this be done?

Voices of Science Fiction:

Science fiction is often a creative outlet for individuals to express their hopes, fears and concerns about current developments in science and technology. Literature, art, television and film are all venues that used science fiction to both represent the achievements and challenges of current scientific development and technology and comment on the social conditions of a society.

EXERCISE 2.

Watch the following two-minute clip from the 1997 movie *Gattaca*. Keep in mind the ten statements published by the Stanford collective concerning the ethical guidelines for human genetic research and the alternative list you created in Exercise 1. After you have viewed the clip answer the following questions.

[Gattaca Clip](#)

<http://www.youtube.com/watch?v=9xY1ke6KNcY>

- Does this clip represent an ethical approach to practical use of genetic technology? Cite specific example from the film and use the ethical tools from exercise 1 to create a concrete argument. There is no right or wrong answer to this question but you must support your findings to avoid simply proposing your “gut reaction.”
- Go through each of the statements and alternative gender specific guidelines from exercise 1. Are any of these issues seen in the clip? Remember both race and gender are discussed in the segment. While it might not be the focal point of the film, the inclusion of these topics suggest they are social issues wrapped up in genetic dialog.
- Film often uses elements such as lighting, music, line delivery, the physical look of an actor to give the audience a deeper understanding of the filmmaker’s intent and even opinion of certain social and

political issues. How are bioethics and human genetics represented in the scene from *Gattaca*? What hopes and fears of genetic development are explored in this segment? Would this scene be different if the screenwriter created a world where genetic scientists all followed the guidelines presented in the Stanford project? Explain how.

- Using the statements published by Sandra Soo-Jin Lee et. al. (2008) and the scene from the film *Gattaca* discuss the difference between genetic engineering and genetic enhancement. Is there a difference? What variation would be more ethical based on the statements of Lee et. al. and the alternative gender statements produced in exercise 1. Be prepared to defend your answer by citing specific points in the Lee text.

Fueling the Abortion Debate:

Prenatal genetic testing has become a common procedure within the United States and the consequences of these tests have become a hot bed of debate on moral, ethical, health and social development grounds. Disagreements about the impact of genetic testing and abortion politics are seen in pop culture, the mass media, academia and the medical sphere with no one voice able to outline a standard ethical framework.

EXERCISE 3.

Below are three articles exploring the complex dimensions of prenatal genetic testing, genetic disabilities and abortion. Read the three articles and take a position on this issue. Use the journal articles to build upon the human interest story published in the New York Times. Try to explore as many dimensions of the debate as possible. [For example a woman's right to choose, the quality of life for a genetically disabled person, social-economic status, accuracy of information, legal implications, health care provider biases, etc.] Remember by exploring more paradigms of the debate you will be able to create a stronger argument. .

Genetic Testing + Abortion= ???

<http://www.nytimes.com/2007/05/13/weekinreview/13harm.html>

Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy

<http://www.ajph.org/cgi/content/abstract/89/11/1649>

Human Embryos and Genetic Testing: A Private Policy Model

<http://www.jstor.org/resources.library.brandeis.edu/stable/4235833?&Search=yes&term=Model&term=Policy&term=Human&term=Embryos&term=Testing&term=Private&term=Genetic&list=hide&searchUri=%2Faction%2FdoBasicSearch%3FQuery%3DHuman%2BEmbryos%2BAnd%2BGenetic%2BTesting%253A%2BA%2BPrivate%2BPolicy%2BModel%26x%3D10%26y%3D10%26wc%3Don&item=1&ttl=444&returnArticleService=showArticle>

[Note: You will have to login to JSTOR to view this article.]

Asch, A. (1999). Prenatal diagnosis and selective abortion: A challenge to practice and policy. *American Journal of Public Health, 89*(11), 1649-1657

Bolnick, D. A. et al. (2007). The science and business of genetic ancestry testing. *Science 318*(5849), 399-400.

Bonnicksen, A. (1992). Human embryos and genetic testing: A private policy model. *Politics and the Life Sciences, 11*(1), 53-62.

DeVito, D. (Producer), & Niccol, A. (Director). (1997). *Gattaca* [Motion Picture]. United States: Columbia Pictures.

Harmon, A. (2007, May 13). Genetic testing + abortion = ??? New York Times (New York, NY). Retrieved March 18, 2009 from <http://www.nytimes.com/2007/05/13/weekinreview/13harm.html>

Lee, S. S. et. al. (2008). The ethics of characterizing difference: Guiding principles on using racial categories in human genetics. *Genome Biology, 9*(7). Retrieved March 18, 2009 from <http://genomebiology.com/2008/9/7/404>

Lee, S. S. & Mudaliar, A. (2009). Racing forward: The genomics and personalized medicine act. *Science 323*(5912), 342.