

Gender, Race, and Genetic Testing

SOCY 311/SOCY 547/WGSS 301

Fall 2012

Wednesday, 2:30-4:20

Professor Rene Almeling

Office: 493 College St., Room 309

Office hours: Mon 9:30-10:20, and by appt

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Course Overview

In this class, we will take a sociological approach to the field of medical genetics, focusing on how the development and use of genetic testing is shaped by the social categories of gender and race. Using a wide range of materials, from historical studies and memoir to social scientific analyses, the goal of this course is to compare and contrast the use of genetic information for different conditions and in different settings. Following introductory readings on the sociology of gender, race, and genetics, we will examine the process of genetic testing for specific conditions, such as pregnancy, Huntington's Disease, and breast cancer. We conclude with an overview of new developments in the field, from pharmacogenomics and biobanks to companies offering tests directly to consumers.

**No previous knowledge of genetics or sociology is required.*

Requirements

Attendance and Active Participation in Class - 20%

Weekly Response Memos - 25%

In 200-250 words, summarize the main point of the week's reading before offering your own reflections. Memos are due in the Assignments section of the Classes Server by 12:30pm on the day of class.

Paper Proposal - 10%

Briefly describe your topic and how you intend to approach it in 1-2 double-spaced pages. Include a preliminary bibliography of 5-8 articles or books not assigned in class. The proposal should be attached as a Word document in the Assignments section of the Classes Server, and it is due by 2:30pm on Nov 28th. You must discuss your ideas for the paper with me prior to submitting the proposal.

Research Presentation - 10%

5 minute presentation on the topic of your research paper, in class on Dec 5th

Research Paper - 35%

Undergraduates: 10-12 pages. Graduate students: 15-18 pages. Papers should be double-spaced with 1" margins written in Times New Roman, 12 point font. Papers are due by 4pm on Dec 14th in the Assignments section of the Classes Server. Late papers (after 4:05pm) will be marked down one letter grade per day.

Readings

Required readings are available via hyperlinks in the syllabus posted on the Classes Server, with the exception of *Mapping Fate* (Oct 3rd). Copies of *Mapping Fate* and *The DNA Mystique* (Sept 12) are on reserve at Bass Library or can be purchased in the campus bookstore.

Cheating and Plagiarism

Students who cheat on any of the assignments will receive an F for the class, and the matter will be referred to Yale's Executive Committee (see Yale's Academic Honesty Policy). A full discussion of using sources and avoiding plagiarism is on the Yale Writing Center Website.

Recommended Readings

"Exploring Genetics and Social Structure," a special issue of the *American Journal of Sociology*, 2008, edited by Bearman

"Genetics and Social Inquiry," *Annual Review of Sociology*, 2009, Freese and Shostak

Genetic Nature/Culture, 2003, edited by Goodman, Heath, and Lindee

The Handbook of Genetics and Society, 2009, edited by Atkinson, Glasner, and Lock

Schedule

Week 1 Aug 29 Introduction

Week 2 Sept 5 Sociological Approaches to Gender and Race

Fausto-Sterling, Anne. 2000. [*Sexing the Body: Gender Politics and the Construction of the Body*](#). New York: Basic Books. Pages 1-29, 233-255.

Glenn, Evelyn Nakano. 1999. ["The Social Construction and Institutionalization of Gender and Race: An Integrative Framework"](#) in *Revisioning Gender*, edited by Ferree, Lorber, and Hess. Thousand Oaks, CA: Sage. Pages 3-43.

Epstein, Steven. 2007. [*Inclusion: The Politics of Difference in Medical Research*](#). Chicago: University of Chicago Press. Pages 1-16, 203-257.

Week 3 Sept 12 Biological and Sociological Approaches to Genetics

2006. ["Coping with Complexity."](#) *Nature* 441: 383-384.

Collins, Francis S., Eric D. Green, Alan E. Guttmacher and Mark S. Guyer. 2003. ["A Vision for the Future of Genomics Research."](#) *Nature* 422: 835-847.

Nelkin, Dorothy and Susan Lindee. 2004. [*The DNA Mystique: Gene as Cultural Icon.*](#) University of Michigan Press. Pages 1-37, 102-148, 201-205.

Duster, Troy. 2003. [*Backdoor to Eugenics.*](#) New York: Routledge. Pages xi-xiv, 3-20.

Week 4 Sept 19 Gene/Environment Interactions & The Social Production of Genetic Data

McCabe, Linda and Edward McCabe. 2008. [*DNA: Promise and Peril.*](#) Berkeley: University of California Press. Pages 1-8.

Pescosolido, Bernice et al. 2008. ["Under the Influence of Genetics: How Transdisciplinarity Leads Us to Rethink Social Pathways to Illness."](#) *American Journal of Sociology* 114: S171-201.

Lindee, M. Susan. 2003. ["Provenance and the Pedigree: Victor McKusick's Fieldwork with the Old Order Amish"](#) in *Genetic Nature/Culture*, edited by Goodman, Heath, and Lindee. Berkeley: University of California Press. Pages 41-57.

Bolnick, Deborah. 2008. ["Individual Ancestry Inference and the Reification of Race as a Biological Phenomenon"](#) in *Revisiting Race in a Genomic Age*, edited by Koenig, Lee, and Richardson. New Brunswick: Rutgers University Press. Pages 70-85.

Reardon, Jenny. 2001. ["The Human Genome Diversity Project: A Case Study in Co-Production."](#) *Social Studies of Science* 31: 357-388.

Week 5 Sept 26 Race, Ethnicity, and the Development of Genetic Medicine

Wailoo, Keith and Stephen Pemberton. 2006. [*The Troubled Dream of Genetic Medicine: Ethnicity and Innovation in Tay-Sachs, Cystic Fibrosis, and Sickle Cell Disease.*](#) Baltimore: Johns Hopkins University Press. Pages 1-160.

Week 6 Oct 3 A Historian's Memoir of Living at Risk for Huntington's Disease

Wexler, Alice. 1995. *Mapping Fate: A Memoir of Family, Risk, and Genetic Research.* Berkeley: University of California Press. Pages xi-xxv, 3-81, 125-151, 182-209, 219-239, 265-276.

Week 7 Oct 10 An Ethnography of Genetic Testing in Pregnancy

Rapp, Rayna. 1999. [Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America](#). New York: Routledge. Pages 1-128.

Week 8 Oct 17 Following Cancer Genetic Knowledge from Provider to Patient

Parthasarathy, Shobita. 2007. [Building Genetic Medicine: Breast Cancer, Technology, and the Comparative Politics of Health Care](#). Cambridge: The MIT Press. Pages 1-25, 115-174.

Roter, Diane et al. 2006. ["The Genetic Counseling Video Project \(GCVP\): Models of Practice."](#) *American Journal of Medical Genetics Part C: Seminars in Medical Genetics* 142C: 209-220.

Hallowell, Nina. 2006. ["Varieties of Suffering: Living with the Risk of Ovarian Cancer."](#) *Health, Risk and Society* 8: 9-26.

Prouser, Nancy. 2000. ["Case Report: Genetic Susceptibility Testing for Breast and Ovarian Cancer: A Patient's Perspective."](#) *Journal of Genetic Counseling* 9: 153-159.

Week 9 Oct 31 Hearts and Minds: Emerging Areas of Genetic Risk Assessment

Weiner, Kate and Paul Martin. 2008. ["A Genetic Future for Coronary Heart Disease?"](#) *Sociology of Health and Illness* 30: 380-395.

Rabeharisoa, Vololona and Pascale Bourret. 2009. ["Staging and Weighting Evidence in Biomedicine: Comparing Clinical Practices in Cancer Genetics and Psychiatric Genetics."](#) *Social Studies of Science* 39: 691-715.

Lock, Margaret, Julia Freeman, Gillian Chilibeck, Briony Beveridge, and Miriam Padolsky. 2007. ["Susceptibility genes and the question of embodied identity."](#) *Medical Anthropology Quarterly* 21:256-276.

Almeling, Rene and Shana Gadarian. 2012. "Genetic Responsibility: A Nationally Representative Survey of American Adults' Responses to Genetic Risk Information." *Draft manuscript*.

Week 10 Nov 7 Pharmacogenomics & Biobanks

Fullwiley, Duana. 2007. "[The Molecularization of Race: Institutionalizing Racial Difference in Pharmacogenetics Practice.](#)" *Science as Culture* 16: 1-30.

Kahn, Jonathan. 2008. "[Exploiting Race in Drug Development: BiDiI's Interim Model of Pharmacogenomics.](#)" *Social Studies of Science* 38: 737-758.

Skloot, Rebecca. 2010. *The Immortal Life of Henrietta Lacks*. New York: Crown Press. 5 page excerpt.

Waldby, Catherine. 2009. "[Biobanking in Singapore: Post-Developmental State, Experimental Population.](#)" *New Genetics and Society* 28: 253-265

Hayden, Cori. 2007. "[Taking as Giving.](#)" *Social Studies of Science* 37: 729-758.

Week 11 Nov 14 Direct-to-Consumer Genetic Testing

Read through the websites for [23andMe](#) and [Navigenics](#).

Hamilton, Anita. Oct 28, 2008. "[Time's Best Inventions of 2008: The Retail DNA Test.](#)" *Time Magazine*.

Salkin, Allen. Sept 12, 2008. "[When in Doubt, Spit it Out.](#)" *The New York Times*.

United States General Accountability Office. 2010. [Direct-To-Consumer Genetic Tests: Misleading Test Results Are Further Complicated by Deceptive Marketing and Other Questionable Practices](#). Pages 1-33.

McBride, Colleen, et al. 2010. "[The Behavioral Response to Personalized Genetic Information: Will Genetic Risk Profiles Motivate Individuals and Families to Choose More Healthful Behaviors?](#)" *Annual Review of Public Health* 31: 89-103.

McGowan, Michelle L., Jennifer R. Fishman and Marcie A. Lambrix. 2010. "[Personal Genomics and Individual Identities: Motivations and Moral Imperatives of Early Users.](#)" *New Genetics and Society* 29: 261-290.

O'Daniel, Julianne M., Susanne B. Haga, and Huntington F. Willard. 2010. "[Considerations for the Impact of Personal Genome Information: A Study of Genomic Profiling among Genetics and Genomics Professionals.](#)" *Journal of Genetic Counseling* 19: 387-401.

Week 12 Nov 28 Commercial Ancestry Testing

**Paper proposals are due before class to the Assignments section of the Classes Server.*

Read through a few sites that appear in an internet search for ancestry and genetic testing.

Bolnick et al. 2007. "[The Science and Business of Ancestry Testing](#)," *Science* 318: 399-400.

Nelson, Alondra. 2008. "[Bio Science: Genetic Genealogy Testing and the Pursuit of African Ancestry.](#)" *Social Studies of Science*, 38: 759-78.

Tallbear, Kimberly. 2008. "[Native American DNA](#)" in *Revisiting Race in a Genomic Age*, edited by Koenig, Lee, and Richardson. New Brunswick: Rutgers University Press. Pages 235-252.

Week 13 Dec 5 Conclusion

Student presentations. No reading.

*Final papers are due Dec 14th by 4pm in the Assignments section of the classes server.