

HUMANITIES 220 & SOCIOLOGY 220

“Health, Biomedicine, Culture, and Society”

Fall 2011

Tuesdays and Thursdays, 3:30-4:50 pm in Annenberg G15

**Professor Steven Epstein
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Drop-in office hours this quarter:

**Mondays, 2:30-3:30 pm, and Thursdays, 11:00 am – 12:00 pm
in University Hall, Rm 020 (garden level)**

A copy of this syllabus can be found on the Blackboard site for the course.

TA contact info:

Kellie Owens

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Office hours: Tuesdays, 1:15-3:15 pm in the Library Cafe

Margarita Rayzberg

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Office hours: Tuesdays, 1:15-3:15 pm in the Library Cafe

Section info:

Tuesdays, 5:00-5:50 in Kresge 4-310

TA: Kellie Owens

Wednesdays, 9:00-9:50 in Parkes Hall 223

TA: Kellie Owens

Wednesdays, 1:00-1:50 in Annenberg 101

TA: Margarita Rayzberg

Wednesdays, 5:00-5:50 in Kresge 4-310

TA: Margarita Rayzberg

Summary:

Of all the products of modern science, medical care and treatment are among the most familiar and the most desirable. We all would like to see cures for diseases, affordable and accessible health care, ethical treatment of patients, and rapid dissemination of effective new drugs. Yet present-day medicine and health care are flashpoints for a bewildering array of controversies. These controversies concern:

- whose interests the health care system should serve and how it should be organized;
- the trustworthiness of the medical knowledge we rely on when we are confronted with the threat of illness;
- the politics and ethics of biomedical research;
- the social management of medical risk in an uncertain world;
- whether health care can be made affordable;
- how the benefits of good health can be shared equitably across lines of social class, race, and gender; and
- the proper roles of health professionals, scientists, patients, activists, corporations, and the state in establishing medical, political, economic, and ethical priorities.

By providing a broad introduction to the domain of health and biomedicine, this course will take up such controversies as matters of concern to all. We will analyze the cultural meanings associated with health and illness; the political debates surrounding health care, medical knowledge production, and medical decision-making; and the structure of the social institutions that comprise the health care industry. We will examine many problems with the current state of health and health care in the United States, and we will also consider potential solutions.

The course is designed to address a broad range of questions: How does the experience of illness change people's lives and identities? How should the risks and benefits of new medical technologies be evaluated? Why do doctors and patients have trouble communicating? Is better cooperation possible between doctors and nurses? Should health care be considered a "right" or a "commodity"? Is a just system of health insurance a practical goal? Who should decide ethical disputes concerning the use of medical treatments, technologies, and procedures? What roles can activists play in reforming medical care and biomedical research?

The course is divided into three parts:

- We begin (Part One) with a **survey of the social meanings of health and illness**, emphasizing the social distribution of disease and the problem of health disparities, the social processes of framing or constructing illness, the medicalization of life, and the cultural manifestations of biomedical risk and uncertainty.
- Next, in Part Two, we turn to the **social structuring of biomedical encounters**. We analyze the social processes of becoming a patient and becoming a health care worker, the dynamics of the doctor-patient relationship, the authority of health professionals, and the ethics and politics of medical research. We also consider how those domains have been changing, especially as a consequence of patient activism.

- Finally, in Part Three, we study the **structure of the health-care industry**, including the dynamics of profit-seeking within health care, the twin crises of access to care and cost of care, the rise of managed care, and the recent history of health care reform. We examine alternative approaches to the organization of health care and consider both barriers to change and potential new directions.

Course Mechanics:

Please read the following bulleted items carefully. Along with providing basic information, this section also serves as fair warning of my classroom policies and expectations:

- ◆ Hum 220 / Soc 220 is one single course, listed in two different ways. There are absolutely no differences in terms of requirements, assignments, possibilities to fulfill distribution requirements, or anything else.

In Fall 2009 and Fall 2010, the same course was offered under temporary names and numbers, including Hum 260, Soc 205, and Soc 276. The course should not be taken by anyone who already took it under a different rubric.

- ◆ This course will make use of the “**Blackboard**” course management system (<https://courses.northwestern.edu/webapps/login/>). Students are responsible for logging in, checking regularly for posted announcements, and obtaining readings and assignments from the site.
- ◆ Important course **announcements** may also be sent to students’ registered campus email addresses. You are responsible for monitoring those email accounts.
- ◆ This syllabus and schedule are **subject to change** in the event of circumstances beyond my control. Announcements of changes will be posted on Blackboard and emailed to students.
- ◆ There is one required book for this course:

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

Note: This book is the selection for “One Book, One Northwestern, 2011-12” (<http://www.northwestern.edu/onebook/>).

The book is available at the university bookstore. **All other course readings** are available for download from the Blackboard site in the form of PDFs. I recommend that you print readings so that they can be read carefully and brought with you to class.

Note that some PDFs appear sideways when viewed in Adobe Acrobat. They will print fine as is, but to read them on screen, select “Rotate View” from the “View” menu.

- ◆ Your **grade** for the quarter will be calculated on the basis of the following four **course requirements**:

1. A **take-home short essay (4-5 pages)** that will focus on the material in Part One of the course (**25%** of the grade). The assignment will be distributed on Tuesday, October 4, and it is due at the beginning of class on Thursday, October 13. You must submit a hardcopy, and you must also submit it electronically to “Safe Assignment” (see below).

2. A closed-book, **in-class midterm** on Thursday, November 3, covering all material up through that point (**25%**). The midterm will consist of one essay, focusing on the book *The Immortal Life of Henrietta Lacks*, as well as a list of concepts to be defined.

3. A **take-home final** covering the entire course but emphasizing Parts Two and Three (**40%**). The final will consist of two essays, each 4-5 pages in length. The essay questions will be posted Monday, November 28, and the final will be due no later than 10:00 am on Monday, December 5. (You are welcome to submit the final earlier.) You must submit a hardcopy, and you must also submit it electronically to “Safe Assignment” (see below).

4. **Section attendance and participation (10%)**. Your TA will explain how the section grade is determined, but attendance in section is a basic component.

Over the course of the quarter, your grades will be made available to you on Blackboard under “**My Grades.**” Please let me know immediately if there are any recording errors.

- ◆ Students are responsible for all material presented in the readings, films, lectures, and sections. **Class attendance** is required for both lectures and sections, and attendance will be taken formally at sections. While I will post my PowerPoints on Blackboard after class, these are not intended to be comprehensive, and often they will not make complete sense by themselves. Students are expected to attend class in order to learn the course material.
- ◆ I also fully expect that students will be not just physically present in the classroom but also mentally present (that is, conscious and not otherwise occupied with email, texting, Facebook, computer games, or other online activities). Laptops are permitted in class and should be used for note-taking or other class-related purposes only.
- ◆ Come to class having *already read* the readings for that day, and be prepared to **participate!** Please do ask questions and offer opinions! Discussion in lecture is heartily encouraged—and of course, in sections as well. Disagreement with the instructor, the TA, or fellow students is fine, as long as you are polite and patient in how you go about it.
- ◆ **Late take-home essays** will be marked down unless you have a medical excuse or comparably serious justification. **Make-up midterms** will be offered only to students who have a medical excuse or comparably serious justification. Late **take-home finals** will not be accepted at all, unless you contact me before the final is due *and* you have a medical excuse or comparably serious justification.

Please note that there is no excuse for failing to keep **electronic backups** of your data (for example, on flash drives, external hard drives, “cloud” storage sites, or other computers) in case your primary computer fails or your hard drive crashes.

- ◆ Any student with a documented **disability** who needs accommodations should contact the Office of Services for Students with Disabilities (SSD; 847-467-5530) and should speak with me as early as possible in the quarter, ideally within the first week of class. All discussions will remain confidential.
- ◆ A course on health issues almost inevitably will include material that will upset some students, particularly if they or people close to them have confronted health challenges. This may be especially true of films, which can have a strong and immediate emotional impact. Please keep this possibility in mind and be forewarned.
- ◆ I am committed to strict enforcement of university regulations concerning **academic integrity**, which means that **I report ALL suspected violations** of the policy (including suspicion of cheating, plagiarism, fabrication, obtaining an unfair advantage, and aiding and abetting dishonesty) to the Assistant Dean for Advising and Academic Integrity, who then carries out a formal investigation. Please be certain to familiarize yourself with the university's policy on academic integrity (see <http://www.northwestern.edu/uacc/>). You should understand that examples of **plagiarism** include obtaining text from any source (including the internet), and passing off such text as your own work, rather than citing the source of the material. In addition, while I encourage students to collaborate when studying or learning course material or when working on any group projects that TAs may assign, it should be clear that **no collaboration** is permitted on written work or exams, and any collaboration in those cases constitutes academic dishonesty.

If you have any questions about what constitutes plagiarism or academic dishonesty, I strongly encourage you to speak to me or your TA about it. **Confirmed violations of academic integrity will result in both an administrative penalty and an academic penalty.** The administrative penalty, assigned by university officials, typically is **suspension** for one quarter; any such suspension becomes part of your record, which is made available on request to potential employers and graduate school admissions committees. The academic penalty is assigned by the instructor, and my own policy in almost every case is to assign a **failing grade FOR THE ENTIRE COURSE.**

- ◆ This course makes use of **Safe Assignment**, a software program that compares your work against other texts in its database in order to safeguard academic integrity. Therefore you will be required to submit your written essays electronically on Blackboard in addition to submitting them in print form. All student work may be analyzed electronically for violations of the university's academic integrity policy and may also be included in a database for the purpose of testing for plagiarized content. Please contact me if you have any questions about Safe Assignment.
- ◆ Please be respectful of those around you. At the beginning of class, make sure your **cell phone** is turned off or set to vibrate. And please don't chat with other students during class. In addition, arriving late, leaving early, and walking in and out of class are distracting to those around you. Obviously they are sometimes unavoidable. But I'd appreciate your keeping them to a minimum.

- ◆ This syllabus and all lectures for this course are copyright 2011 by Steven Epstein. Students are prohibited from selling (or being paid for taking) notes during this course to or by any person or commercial firm without the express written permission of Professor Epstein. No **audio or video recordings** of class are permitted without the instructor's permission.

Schedule of Readings and Assignments:

WEEK 1

TUE, SEP 20: INTRODUCTION

****Sections begin meeting today and tomorrow****

PART ONE: Social Meanings of Health and Illness

THU, SEP 22: SOCIAL DETERMINANTS OF HEALTH: HEALTH DISPARITIES AND HOW TO ADDRESS THEM

Farmer, Paul. 2003. *Pathologies of Power: Health, Human Rights, and The New War on the Poor*. Berkeley: University of California Press. Pp. 29-41 **only**.

Klinenberg, Eric. 2009. "Dying Alone: The Social Production of Urban Isolation." Pp. 87-101 in *The Sociology of Health and Illness: Critical Perspectives*, 8th ed., edited by P. Conrad. New York: Worth.

Steinberg, Jonny. 2008. *Sizwe's Test: A Young Man's Journey through Africa's AIDS Epidemic*. New York: Simon & Schuster. Pp. 82-85 **only**.

Klug, Heinz. 2010. "Risking Health: HIV/AIDS and the Problem of Access to Essential Medicines." Pp. 100-104 and 115-124 **only** in *Disaster and the Politics of Intervention*, ed. Andrew Lakoff. New York: Columbia University Press.

WEEK 2

TUE, SEP 27: SOCIAL DETERMINANTS OF HEALTH: HEALTH DISPARITIES AND HOW TO ADDRESS THEM (CONT.)

Film: "Unnatural Causes: Is Inequality Making Us Sick?" (Episode 1: "In Sickness and in Wealth") (California Newsreel, 2008, 55 min.)

Lorber, Judith., and Lisa Jean Moore. 2008. "Women Get Sicker but Men Die Quicker: Gender and Health." Pp. 41-61 in *Perspectives in Medical Sociology*, 4th ed., edited by P. Brown. Prospect Heights, IL: Waveland Press.

Williams, David R., and Pamela Braboy Jackson. 2005. "Social Sources of Racial Disparities in Health." *Health Affairs* 24 (2): 325-334.

THU, SEP 29: FRAMING ILLNESS, CONSTRUCTING KNOWLEDGE

Brown, Phil. 2008. "Naming and Framing: The Social Construction of Diagnosis and Illness." Pp. 82 and 86-103 **only** in *Perspectives in Medical Sociology*, 4th ed.,

edited by P. Brown. Prospect Heights, IL: Waveland Press.

Epstein, Steven. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press. Pp. 47-78 **only**.

Aronowitz, Robert. 1991. "Lyme Disease: The Social Construction of a New Disease and Its Social Consequences." *Milbank Quarterly* 69 (1): 79-112.

WEEK 3

TUE, OCT 4: MEDICALIZATION

****Take-home essay assignment distributed****

Conrad, Peter. 2005. "The Shifting Engines of Medicalization." *Journal of Health and Social Behavior* 46 (1): 3-14.

Kessler, Suzanne J. 1998. *Lessons from the Intersexed*. New Brunswick, NJ: Rutgers University Press. Pp. 12-32 **only**.

Loe, Meika. 2004. *The Rise of Viagra: How the Little Blue Pill Changed Sex in America*. New York: New York University Press. Pp. 29-61 **only**.

THU, OCT 6: CULTURES OF RISK AND UNCERTAINTY

Fosket, Jennifer Ruth. 2010. "Breast Cancer Risk as Disease: Biomedicalizing Risk." Pp. 331-352 in *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, edited by A. E. Clark, L. Mamo, J. R. Fosket, J. R. Fishman and J. K. Shim. Durham, NC: Duke University Press.

Mamo, Laura, Amber Nelson, and Aleia Clark. 2010. "Producing and Protecting Risky Girlhoods." Pp. 121-145 in *Three Shots at Prevention: The HPV Vaccine and the Politics of Medicine's Simple Solutions*, edited by K. Wailoo, J. Livingston, S. Epstein and R. Aronowitz. Baltimore, MD: Johns Hopkins University Press.

Collier, Stephen J., and Andrew Lakoff. "Health, Security, and New Biological Threats: Reconfigurations of Expertise." Pp. 363-379 in *Handbooks of Medical Sociology, Sixth Edition*, edited by C. E. Bird, P. Conrad, A. M. Fremont and S. Timmermans. Nashville: Vanderbilt University Press

PART TWO: Patients and Professionals: Identities, Encounters, and the Politics of Authority

WEEK 4

TUE OCT 11: BECOMING A PATIENT

Film: “Wit” (Mike Nichols, 2001)

Kleinman, Arthur, and Don Seeman. 2000. “Personal Experience of Illness.” Pp. 237-238 **only** in *Social Studies in Health and Medicine*, ed. Gary L. Albrecht, Ray Fitzpatrick, and Susan C. Scrimshaw. London: Sage.

THU, OCT 13: BECOMING A PATIENT (CONT.); BECOMING A DOCTOR

****Take-home essays due at the beginning of class (hardcopy and Blackboard)****

Lella, Joseph W., and Dorothy Pawluch. 1988. “Medical Students and the Cadaver in Social and Cultural Context.” Pp. 125-135 in *Biomedicine Examined*, edited by M. Lock and D. R. Gordon. Dordrecht: Kluwer.

Fox, Renée C. 2000. “Medical Uncertainty Revisited.” Pp. 409-425 in *Handbook of Social Studies of Health and Medicine*, edited by G. L. Albrecht, R. Fitzpatrick and S. C. Scrimshaw. London: Sage.

WEEK 5

TUE, OCT 18: THE DOCTOR-PATIENT RELATIONSHIP

Taylor, Kathryn M. 1988. “Physicians and the Disclosure of Undesirable Information.” Pp. 441-463 in *Biomedicine Examined*, edited by M. Lock and D. R. Gordon. Dordrecht: Kluwer.

Conrad, Peter. 1994. “The Meaning of Medications: Another Look at Compliance.” Pp. 149-161 in *The Sociology of Health and Illness: Critical Perspectives*, 4th ed., edited by P. Conrad and R. Kern. New York: St. Martin’s.

THU, OCT 20: THE ETHICS AND POLITICS OF MEDICAL RESEARCH

Film: “Deadly Deception” (PBS, 1993).

Brandt, Allan M. 1978. “Racism and Research: The Case of the Tuskegee Syphilis Study.” *Hastings Center Report* 8 (6): 21-29.

Begin reading Skloot, *The Immortal Life of Henrietta Lacks*.

WEEK 6

TUE, OCT 25 : THE ETHICS AND POLITICS OF MEDICAL RESEARCH (CONT.)

Elliott, Carl. 2008. “Guinea-pigging.” *The New Yorker*, 7 January.

Finish reading Skloot, *The Immortal Life of Henrietta Lacks*.

THU, OCT 27: THE TRAJECTORY OF PROFESSIONAL AUTHORITY

Starr, Paul. 1982. *The Social Transformation of American Medicine*. Pp. 3-29 **only**.

Goldstein, Michael S. 2000. "The Growing Acceptance of Complementary and Alternative Medicine." Pp. 284-297 in *Handbook of Medical Sociology*, 5th ed., edited by C. E. Bird, P. Conrad and A. M. Fremont. Upper Saddle River, NJ: Prentice Hall.

WEEK 7

TUE, NOV 1: RESPONSES TO PROFESSIONAL AUTHORITY

Film clip: "Lorenzo's Oil" (George Miller, 1993)

Lerner, Barron H. 2006. *When Illness Goes Public: Celebrity Patients and How We Look at Medicine*. Baltimore: Johns Hopkins University Press. Pp. 246-267 **only**.

THU, NOV 3: ****IN-CLASS MIDTERM****

(No books, notes, or electronic devices.)

WEEK 8

TUE, NOV 8: PATIENT GROUPS AND HEALTH MOVEMENTS

Film clip: "Voices from the Front" (Testing the Limits Collective, 1991)

Epstein, Steven. 2000. "Democracy, Expertise, and AIDS Treatment Activism." Pp. 15-32 in *Science, Technology, and Democracy*, edited by D. Kleinman. Albany: State University of New York Press.

Klawiter, Maren. 2001. "Racing for the Cure, Walking Women, and Toxic Touring: Mapping Cultures of Action." Pp. 433-446 in *The Sociology of Health and Illness: Critical Perspectives*, 6th ed., edited by P. Conrad. New York: Worth.

Note: At 6:30 pm this evening, please attend the Sociology department special event focusing on *The Immortal Life of Henrietta Lacks* (location to be announced).

PART THREE: The Structure of the Health Care Industry and the Crises of Health Care

THU, NOV 10: THE "MEDICAL-INDUSTRIAL COMPLEX" AND THE POLITICS OF "BIG PHARMA"

Holmer, Alan F. 1999. "Direct-to-Consumer Prescription Drug Advertising Builds Bridges between Patients and Physicians." *Journal of the American Medical Association* 281 (4): 380-382.

Hollon, Matthew F. 1999. "Direct-to-Consumer Marketing of Prescription Drugs: Creating Consumer Demand." *Journal of the American Medical Association* 281 (4): 382-384.

Angell, Marcia. 2008. "Industry-Sponsored Clinical Research: A Broken System." *Journal of the American Medical Association* 300(9): 1069-1071.

Relman, Arnold S. 2008. "Industry Support of Medical Education." *Journal of the American Medical Association* 300(9): 1071-1073.

WEEK 9

TUE, NOV 15: THE CRISES OF ACCESS AND COST, AND THE RISE OF MANAGED CARE

Weitz, Rose. 2010. *The Sociology of Health, Illness, and Health Care: A Critical Approach*, 5th ed. Boston: Wadsworth. Pp. 192-221 (Chapter 8: "Health Care in the United States").

Light, Donald W. 2008. "Managed Care: Its Origins and Prospects." Pp. 382-399 in *Perspectives in Medical Sociology*, 4th ed., edited by P. Brown. Prospect Heights, IL: Waveland Press.

THU, NOV 17: ALTERNATIVE SYSTEMS

Film: "Sick Around the World" (Frontline, 2008; 51 min.)

Weitz, Rose. 2010. *The Sociology of Health, Illness, and Health Care: A Critical Approach*, 5th ed. Boston: Wadsworth. Pp. 222-245 (Chapter 9: "Health Care in Other Countries").

WEEK 10

****Sections do not meet this week ****

TUE, NOV 22: THE POLITICS OF HEALTH CARE REFORM

Connors, Elenora E., and Lawrence O. Gostin. 2010. "Health Care Reform—A Historic Moment in US Social Policy." *JAMA* 303, no. 24 (23 June): 2521-2522.

Feldman, Eric, and Eli Y. Adashi. 2010. "The Right to Health as the Unheralded Narrative of Health Care Reform." *Journal of the American Medical Association* 304(23): 2639-2640.

Quadagno, Jill. 2011. "Interest Group Influence on the Patient Protection and Affordability Act of 2010: Winners and Losers in the Health Care Reform Debate." *Journal of Health Politics, Policy and Law* 36(3): 449-453.

Marmor, Theodore, and Jonathan Oberlander. 2011. "The Patchwork: Health Reform, American Style." *Social Science & Medicine* 72: 125-128.

READING PERIOD

****Optional review sessions in section this week****

MON, NOV 28

****Take-home FINAL EXAM assignment posted on Blackboard ****

EXAM WEEK

MON, DEC 5

****Take-home FINAL EXAM due by 10:00 am – hardcopy and Blackboard****