

HUMANITIES 220 & SOCIOLOGY 220
“Health, Biomedicine, Culture, and Society”
Fall 2014

Tuesdays and Thursdays, 11:00-12:20 in Annenberg G21

Professor Steven Epstein
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Northwestern University

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Drop-in office hours this quarter:

Mondays, 2:30-3:30 pm, and Thursdays, 2:00-3:00 pm
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A copy of this syllabus can be found on the Canvas site for the course.

TA contact info:

Megan Bonham

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Office hours: Tuesdays, 9:30-10:30 am, in Crowe Cafe

Ryan Mack

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Office hours: Wednesdays, 5:00-6:00 pm, in the Norris Starbucks

Jane Pryma

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Office hours: Thursdays, 2:00-4:00 pm, in 1 South at the University Library

Section info:

Section 60:	Wednesdays, 9:00-9:50 am in Frances Searle 2407	TA: Jane Pryma
Section 61:	Wednesdays, 3:00-3:50 pm in Frances Searle 2407	TA: Megan Bonham
Section 62:	Wednesdays, 5:00-5:50 pm in University Hall 102	TA: Megan Bonham
Section 63:	Thursdays, 9:00-9:50 am in Tech M152	TA: Ryan Mack
Section 64:	Wednesdays, 4:00-4:50 pm in Parkes 224	TA: Ryan Mack
Section 65:	Tuesdays, 5:00-5:50 pm in Harris L05	TA: Jane Pryma

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, gender, and nation; 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 exercised by

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 systems of managed care, and the recent history of health care reform (up to and including the implementation of “Obamacare”) We examine alternative approaches to the organization of health care and consider both barriers to change and potential new directions.

Course Mechanics and Policies:

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:

- ◆ Humanities 220 / Sociology 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.
- ◆ This course will make use of the “**Canvas**” course management system (<http://www.it.northwestern.edu/education/learning-management/login.html>). 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.
- ◆ Unless you are directed to do so by me or your TA, please do not use Canvas to send broadcast announcements to the rest of the class. If you have material that you think should be shared, please ask me or your TA to distribute it.
- ◆ This syllabus and schedule are **subject to change** in the event of circumstances beyond my control. Announcements of changes will be posted on Canvas and emailed to students.
- ◆ There are no required books for this course. **All course readings** are available for download from the Canvas site in the form of PDFs. I encourage you to bring readings with you to class, either as printouts or on your laptops or tablets.

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 7, and it is due by 10:00 am on Thursday, October 16. You must submit it electronically on Canvas via “TurnItIn” (see below). Your essay will be graded directly on Canvas, and a marked-up and graded version will be made available to you through Canvas.
 2. A closed-book, **in-class midterm** on Thursday, November 6, covering all material in Parts One and Two of the course (**25%**). The midterm will consist of a list of concepts to be defined and discussed. You will write your responses in a blue book. The graded midterm will be returned to you in class.

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, December 1, and the final will be due no later than 10:00 am on Monday, December 8. (You are welcome to submit the final earlier.) You must submit it electronically on Canvas via “TurnItIn” (see below). Your essay will be graded directly on Canvas, and a marked-up and graded version will be made available to you through Canvas.

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

Over the course of the quarter, your grades will be made available to you on Canvas. 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 Canvas 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). You are welcome to bring technology to the lecture hall as long as you can handle it responsibly and respectfully. Laptops and tablets 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.

Please note that my office is on the second floor of a building without an elevator. Any student who cannot attend my office hours as a result is welcome to make an appointment with me to meet elsewhere.

- ◆ 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/provost/policies/academic-integrity/index.html>). 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 **Turnitin**, a software product that compares your work against other texts in its database in order to safeguard academic integrity. Students agree that by taking this course all required papers may be subject to submission for textual similarity review to Turnitin.com for the detection of plagiarism. All submitted papers will be included as source documents in the Turnitin.com reference database solely for the purpose of detecting plagiarism of such papers. Use of the Turnitin.com service is subject to the Usage Policy posted on the Turnitin.com site. Please contact me if you have any questions about Turnitin.
- ◆ 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 and PowerPoint presentations for this course are copyright 2014 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. 23: INTRODUCTION

****Sections begin meeting this week****

PART ONE: Social Meanings of Health and Illness

THU., SEP. 25: SOCIAL DETERMINANTS OF HEALTH: HEALTH DISPARITIES AND HOW TO ADDRESS THEM

Committee on Population at the National Research Council. 2013. "U.S. Health in International Perspective: Shorter Lives, Poorer Health." Washington, D.C.: National Academies, January, 1-4.

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. 2005. "Campaigning for Life: Building a New Transnational Solidarity in the Face of HIV/AIDS and TRIPS." In *Law and Globalization from Below: Towards a Cosmopolitan Legality*, edited by B. d. S. Santos and C. A. Rodríguez-Garavito. Cambridge, England: Cambridge University Press. Pp. 118-21 **only**.

WEEK 2

TUE., SEP. 30: 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., OCT. 2: 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. 7: 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**.

THU., OCT. 9: CULTURES OF RISK AND RESPONSIBILITY

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.

Lupton, Deborah. 2012. "M-Health and Health Promotion: The Digital Cyborg and Surveillance Society." *Social Theory & Health* 10 (3):229–244.

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

WEEK 4

TUE., OCT. 14: BECOMING A PATIENT AND BECOMING A DOCTOR

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.

O'Rourke, Meghan. 2013. "What's Wrong with Me?" *New Yorker*, 26 August, 32-37.

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.

THU., OCT. 16: THE DOCTOR-PATIENT RELATIONSHIP

****Take-home essays due by 10:00 am on Canvas****

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.

WEEK 5

TUE., OCT. 21: THE ETHICS AND POLITICS OF MEDICAL RESEARCH

Film: “Deadly Deception” (PBS, 1993, 53 min.)

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

Rothman, David J. 1991. *Strangers at the Bedside*. New York: Basic Books. Pp. 15-29 **only**.

Frieden, Thomas R., and Francis S. Collins. 2010. “Intentional Infection of Vulnerable Populations in 1946-1948: Another Tragic History Lesson.” *JAMA* 304 (18):2063-2064.

THU., OCT. 23: THE ETHICS AND POLITICS OF MEDICAL RESEARCH (CONT.)

Gamble, Vanessa Northington. 1997. “Under the Shadow of Tuskegee: African Americans and Health Care.” *American Journal of Public Health* 87 (11): 1773-1778.

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

Chapkis, Wendy and Richard J. Webb. 2008. *Dying to Get High: Marijuana as Medicine*. New York: New York University Press. Pp. 64-68 **only**.

WEEK 6

TUE., OCT. 28 : THE TRAJECTORY OF PROFESSIONAL AUTHORITY

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

Fairman, Julie A. 2012. “The Right to Write: Prescription and Nurse Practitioners.” Pp. 117-133 in *Prescribed: Writing, Filling, Using, and Abusing the Prescription in Modern America*, edited by J. A. Greene and E. S. Watkins. Baltimore: Johns Hopkins University Press.

THU. OCT. 30: 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**.

Barker, Kristin. 2002. “Self-Help Literature and the Making of an Illness Identity: The Case of Fibromyalgia Syndrome (FMS).” *Social Problems* 49 (3):279-300.

WEEK 7

TUE., NOV. 4: 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.

Brown, Phil, Stephen Zavestoski, Sabrina McCormick, Brian Mayer, Rachel Morello-Frosch, and Rebecca Gasior Altman. 2004. “Embodied Health Movements: New Approaches to Social Movements in Health.” *Sociology of Health & Illness* 26 (1):50-80.

THU., NOV. 6: ****IN-CLASS MIDTERM****

(No books, notes, or electronic devices.)

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

WEEK 8

TUE., NOV. 11: THE “MEDICAL-INDUSTRIAL COMPLEX” AND THE POLITICS OF “BIG PHARMA”

Dumit, Joseph. 2012. *Drugs for Life: How Pharmaceutical Companies Define Our Health*. Durham, NC: Duke University Press. Pp. 55-85 **only**.

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.

THU., NOV. 13: THE CRISES OF ACCESS AND COST, AND THE RISE OF MANAGED CARE

Weitz, Rose. 2011. *The Sociology of Health, Illness, and Health Care: A Critical Approach*, 6th ed. Boston: Wadsworth. Pp. 176-204 (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.

WEEK 9

TUE., NOV. 18: ALTERNATIVE SYSTEMS

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

Weitz, Rose. 2011. *The Sociology of Health, Illness, and Health Care: A Critical Approach*, 6th ed. Boston: Wadsworth. Pp. 205-231 (Chapter 9: "Health Care Around the Globe").

THU., NOV. 20: HISTORIES AND POLITICS OF HEALTH CARE REFORM

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

WEEK 10

****No section meetings this week****

TUE., NOV. 25: "OBAMACARE"

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.

Quadagno, Jill. 2014. "Right-Wing Conspiracy? Socialist Plot? The Origins of the Patient Protection and Affordable Care Act." *Journal of Health Politics, Policy and Law* 39(1): 35-56.

READING PERIOD

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

MON., DEC. 1

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

TUE., DEC. 2: OPTIONAL SESSION W/PROFESSOR EPSTEIN TO REVIEW TAKE-HOME FINAL

EXAM WEEK

MON., DEC. 8

****Take-home FINAL EXAM due by 10:00 am on Canvas****