

# SOCIOLOGY OF HEALTH AND ILLNESS

SOC 531

Fall 2020

Taught Synchronously Online: Tuesdays 9:40-12:30

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Tarbutton Hall 209  
Online Office Hour Tuesdays 3:00-5:00 (by Zoom; link on Canvas)

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## **Course Description**

This course will provide graduate students with a survey of research on the social origins of the health, illness, and health care of individuals and populations. Students will be introduced to the process of formulating important social research questions in health and illness, including attention to major theoretical perspectives, measurement of concepts, the merits of various study designs, and both qualitative and quantitative approaches to data collection and analysis. The sociology of health and illness is a large and historically important subdiscipline within the field, distinctively sociological, but with important links to public health, social epidemiology, and health psychology. To quote from a newsletter of the Medical Sociology Section of the American Sociological Association:

"In its early decades medical sociology was often construed as an applied field. Now we are known for our many and wide-ranging contributions, including sophisticated applications. Medical sociologists explore every type of question found in the larger discipline and sometimes stretch its borders to include new frontiers. We bring the body back into sociological theorizing and empirical research. We reveal the rhythms of cultural rituals in ordinary routines. We chart the development of biomedicine and map its consequences. We challenge preconceptions as we study institutional and interactional practices. We develop ever more exacting instruments and analytic tools to conduct our demographic studies and survey research. Whether we examine large data bases or study micro interactions, we raise innovative questions that generate new understandings."

Kathy Charmaz, 2004 Section Chair

More than any other area of the discipline, the sociology of health and illness exemplifies C. Wright Mills' concept of the "sociological imagination" -- the interplay between personal troubles and public issues:

"It is the political task of the social scientist — as of any liberal educator — continually to translate personal troubles into public issues, and public issues into the terms of their human meaning for a variety of individuals. It is his task to display in his work — and, as an educator, in his life as well — this kind of sociological imagination. And it is his purpose to cultivate such habits of mind among the men and women who are publicly exposed to him. To secure these ends is to secure reason and individuality, and to make these the predominant values of a democratic society."

C. Wright Mills, *The Sociological Imagination*, 1959

Regular class sessions will be taught on Zoom and will include: an introductory lecture on background concepts, theory, and/or methods; discussion of assigned chapters or articles that have been read by the class and are critiqued by individual students; and a "Minute for Books" with a focus on nonfiction accounts of illness or descriptions of contemporary health care systems. Assigned articles are all posted on Canvas; books chosen for the "Minute for Books" may or may not be available in the Woodruff Library, but they are almost all inexpensive paperbacks available on Amazon. During the semester each student will collaborate with the instructor on a peer review of a journal article. The final two weeks of the semester will be devoted to the presentation of student research projects.

### Course Requirements and Grading

The final grade will be based on class participation (10%), completion of weekly article extracts (20%), presentation of “Minutes” for books (one each) (10%), completion of written peer review (10%), class presentation of project (20%), and a final paper (30%).

### Course Objectives

- To understand the **social determinants of health perspective** within an aging and life course framework
- To recognize indicators and **trends in population health** over time
- To identify patterns in the **intellectual history and development of the field**
- To become familiar with and compare **current social theories of health-related perceptions and behaviors** of individuals
- To become familiar with and be able to assess the requirements and advantages of **common study designs and types of analysis**
- To be able to “put words to numbers” in **interpreting study findings**
- To think critically about **social and institutional arrangements related to health and medicine**
- To develop applications of social scientific thinking from **analysis of nonfiction narrative literature**
- To develop **original research questions** based on unstudied or contested areas of work in the field

### Learning Outcomes

- Students will write a short paper on, and lead a class discussion of, a work of narrative nonfiction concerning the experience of health and illness, and propose research questions arising from the work.
- Students will complete a weekly written article extract on one empirical paper assigned for that week. The student will identify features of the study, describe the background studies, methods, and results, and analyze the strengths and weaknesses of the research.
- Students writing an article extract for a particular study will lead the discussion on that study during class.
- Students will complete a peer review (partnering with the instructor) of a paper submitted to an academic journal. The student will meet with the instructor to discuss and merge the two sets of comments, make a recommendation to the editor, and observe the process of submitting reviews.
- [Probably not going to happen, but check out the exhibit anyway] Students will develop an online learning activity to accompany the CDC’s digital exhibit on the 2014 Ebola outbreak in West Africa, “Ebola: People + Public Health + Political Will” <http://cdcmuseum.org/>
- Students will propose and write a final paper that either a) reports on original analysis of secondary data; 2) proposes new research in the form of a National Science Foundation (or other agency) grant proposal; or 3) reports on a systematic or scoping review of the research literature on a topic of interest, using PRISMA guidelines.

### Synchronous Seminar Considerations

- This course will be taught synchronously to maximize our interaction with each other. A 3-hour in-person class (usual graduate seminar format) was not possible in Fall 2020. On the schedule it appears as two 75 minutes classes with a 25 minute break.
- Class Zoom sessions will be recorded for later viewing.
- Powerpoint slides will be shared online and available on Canvas.
- There is a preference for students to keep their video on, especially when speaking, to promote engagement.

### Honor Code

We abide by the Honor Code of the Laney Graduate School.

<https://gs.emory.edu/handbook/honor-conduct-grievance/honor/index.html>

## SCHEDULE OF TOPICS AND READING ASSIGNMENTS

### Session 1 – August 25

#### Introductions

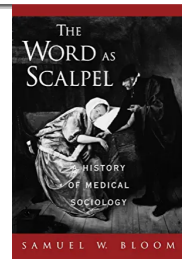
##### Course overview

A (somewhat but not entirely personal) history of the sociology of medicine, health, and illness

Social factors in health, illness, and health care are all around us

#### Required reading:

None



### Session 2 – September 1

The backdrop to the study of the sociology of health and illness:

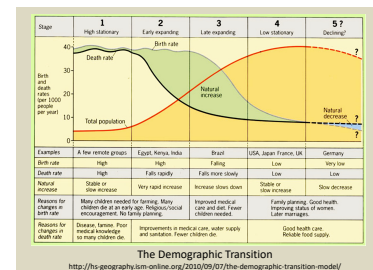
the (first) demographic transition

the epidemiologic transition

aging populations

trends in disability

the (second) demographic transition



What are the radical changes that have taken place in the health of populations in the past two centuries?

How have those changes shifted the age structure of populations?

What are the prospects for the improvement of the health of populations in the coming decades?

How have cultural shifts caused and also been affected by population changes?

#### Required reading:

\*Crimmins, Eileen, Yuan Zhang, Yasuhiko Saito. 2016. "Trends Over 4 Decades in Disability-Free Life Expectancy in the United States." *American Journal of Public Health* 106(7): 1287-1293.

\*Case, Anne, Angus Deaton. 2015. "Rising Morbidity and Mortality in Midlife among White Non-Hispanic Americans in the 21st Century." *Proceedings of the National Academy of Sciences* 112(49): 15078-83.

Lesthaeghe, Ron. 2014. "The second demographic transition: A concise overview of its development." *Proceedings of the National Academy of Sciences* 111(51): 18112-18115.

#### Recommended reading:

McFalls, Joseph A. 2003. "Population: A lively introduction." *Population Bulletin* 58(4): 1-44.

McKinlay, John, and Sonja McKinlay. 1977. "The Questionable Contribution of Medical Measures to the Decline of Mortality in the United States in the Twentieth Century." *Milbank Memorial Fund Quarterly* 55:405-428.

Meslé, France, and Jacques Vallin. 2011. "Historical Trends in Mortality." In Richard G. Rogers and Eileen Crimmins, Editors, *International Handbook of Adult Mortality*, pp.9-47. New York: Springer.

\* Readings marked with an asterisk are empirical -- data-based -- research articles. There are a varying number of these each week. On the Canvas site you will find a blank Article Extract form to be used for summarizing and critiquing these papers. Do one per week – you choose which article to do if there is more than one listed. The forms should be submitted online to the Canvas site. They are due before class begins.

### Session 3 – September 8

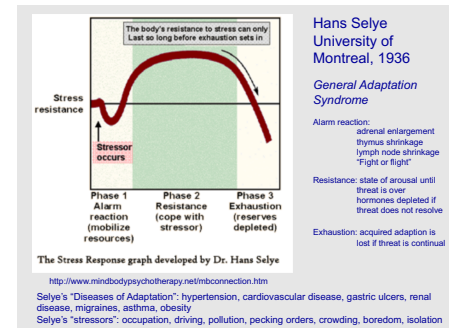
The history of social causation: the original lens of the stress process

How does the social environment “get under the skin”?

How did the story of the effect of the social environment on health begin, and then evolve?

What is the relationship between acute and chronic stress, and which is more important for research on health disparities?

Are the effects of the social environment primarily negative?



#### Required reading:

Brunner, Eric, and Michael Marmot. 2006. “Social Organization, Stress, and Health.” In Michael Marmot and Richard Wilkinson, Editors, *Social Determinants of Health*, 2nd Edition, pp. 6-30. Oxford: Oxford University Press.

Pearlin, Leonard I. 1989. “The Sociological Study of Stress.” *Journal of Health and Social Behavior* 30:241-56.

\*Sternthal, Michelle, Natalie Slopen and David Williams. 2011. “Racial Disparities in Health: How Much Does Stress Really Matter?” *Du Bois Review* 8(1): 95-113.

\*Boen, Courtney and Robert Hummer. 2019. “Longer – but Harder – Lives? The Hispanic Health paradox and the Social Determinants of Racial, Ethnic, and Immigrant-Native Health Disparities from Midlife through Late Life.” *Journal of Health and Social Behavior* 60(4): 434-452.

#### Recommended reading:

Marmot, Michael. 2004. *The Status Syndrome: How Social Standing Affects Our Health and Longevity*. New York: Henry Holt. Introduction and Chapter 1, pp.1-36.

### Session 4 – September 15

Adding the lens of structural inequality to the lens of the stress process

Is health determined by relative inequality, or absolute vulnerability?

Does social inequality research require the stress paradigm?

What is the relationship between SES inequality and race inequality?

#### Required reading:

Lahelma, Eero. 2010. “Health and Social Stratification.” In William Cockerham, Editor, *The New Blackwell Companion to Medical Sociology*, pp.71-96. West Sussex, UK: John Wiley.

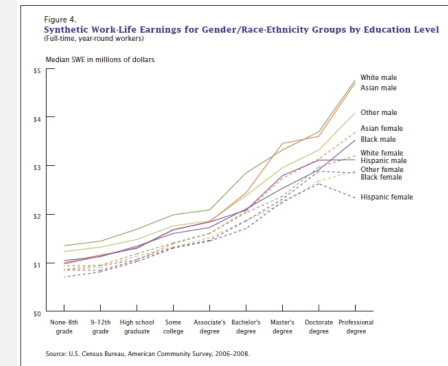
\*Phelan, Jo C., Bruce Link, Ana Diez-Roux, Ichiro Kawachi, Bruce Levin. 2004. “‘Fundamental Causes’ of Social Inequalities in Mortality: A Test of the Theory.” *Journal of Health and Social Behavior* 45:265-285.

\*Braveman, Paula, Catherine Cubbin, Susan Egerter, David Williams, Elsie Pamuk. 2010. “Socioeconomic Disparities in Health in the United States: What the Patterns Tell Us.” *American Journal of Public Health* 100 (Supplement 1): S186-S196.

Williams, David and Chiquita Collins. 2001. “Racial Residential Segregation: A Fundamental Cause of Racial Disparities in Health.” *Public Health Reports* 116: 404-116.

#### Recommended reading:

Case, Anne and Angus Deaton. 2020. *Deaths of Despair and the Future of Capitalism*. Princeton: Princeton University Press.





**Session 5 – September 22**

Health consequences of social networks and social capital: ties to family, friends, religious and community groups

Should we treat all components of social networks alike when it comes to health?  
Should network ties all have equal values?

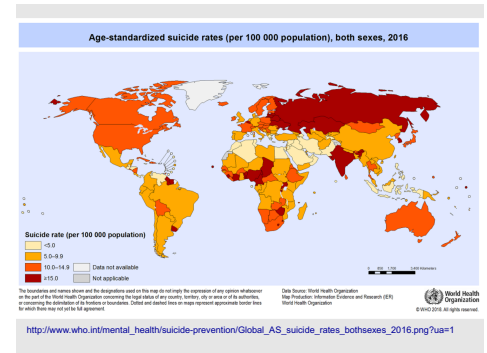
How does the influence of the social environment on health in the social network / social capital approach differ from the effects seen in the stress / social determinants approach?

**Required reading:**

- \*Pantell, Matthew, David Rehkopf, Douglas Jutte, S. Leonard Syme, John Balmes, Nancy Adler. 2013. "Social Isolation: A Predictor of Mortality Comparable to Traditional Clinical Risk Factors." *American Journal of Public Health* 103(11): 2056-62.
- \*Dupre, Matthew, Audrey N. Beck, and Sarah O. Meadows. 2009. "Marital Trajectories and Mortality among US Adults." *American Journal of Epidemiology* 170:546-555.
- Idler, Ellen, John Blevins, Mimi Kiser, Carol Hogue. 2017. "Religion, a Social Determinant of Mortality? A 10-year Follow-up of the Health and Retirement Study." *PLoS One* 12(12): e0189134
- Klinenberg, Eric. 2002. *Heat Wave: A Social Autopsy of Disaster in Chicago*, Chap. 2, pp.79-128. Chicago: University of Chicago Press.
- Umberson, Debra. 2017. "Black Deaths Matter: Race, Relationship Loss, and Effects on Survivors." *Journal of Health and Social Behavior* 58(4): 405-420.

**Recommended reading:**

- Durkheim, Emile. 1951. *Suicide: A Study in Sociology*. "The Social Element of Suicide." Book 3, Chapter 1 (pp.297-325). New York: Free Press.
- Song, Lijun, Joonmo Son, and Nan Lin. 2010. "Social Capital and Health." In William Cockerham, Editor, *The New Blackwell Companion to Medical Sociology*, pp.184-210. West Sussex, UK: John Wiley.



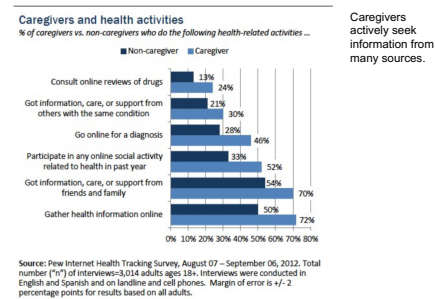
## Session 7 – October 6

Social support and caregiving as mediators of the association of social networks with health

Is it social integration or social regulation that provides the glue that keeps these arrangements together?

What are the differences between caring for a loved one who is a child and one who is an adult?

What do qualitative approaches to data collection have to add to the quantitative study of social support and caregiving?



### Required reading:

Christakis, Nicholas A. and James H. Fowler. 2009. *Connected: How Your Friends' Friends' Friends Affect Everything You Feel, Think, and Do*. Chapter 3, pp.61-94. New York: Little, Brown.

\*Idler, Ellen, David Boulifard and Richard Contrada. 2012. "Mending Broken Hearts: Marriage and Survival Following Cardiac Surgery". *Journal of Health and Social Behavior* 53(1):33-49.

\*Gengler, Amanda. 2014. "'I want you to save my kid!' Illness Management Strategies, Access, and Inequality at an Elite University Research Hospital." *Journal of Health and Social Behavior* 55(3): 342-359.

\*Nieuwenhuis, Anna V., Scott R. Beach, Richard Schulz. 2018. "Care Recipient Concerns About Being a Burden and Unmet Needs for Care." *Innovation in Aging* 2(3):1-10.

### Recommended reading:

Berkman, Lisa, and Thomas Glass. 2000. "Social Integration, Social Networks, Social Support, and Health." In Berkman, Lisa, and Ichiro Kawachi, Editors, *Social Epidemiology*, pp.137-173.

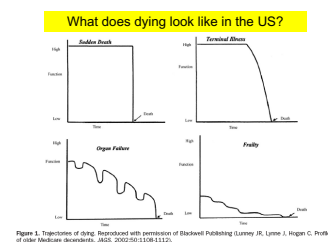
## Session 8 – October 13

Awareness of health, awareness of finitude

Which types of health status measures are most subject to framing, or being socially constructed?

Who is in the best position to make judgments about "healthiness" and what are those judgments based on?

Do end of life trajectories show awareness of finitude?



### Required reading:

Rosenberg, Charles E. 1992. "Introduction. Framing Disease: Illness, Society, and History." In Charles E. Rosenberg, and Janet Golden (Eds.), *Framing Disease: Studies in Cultural History*, pp. xiii-xxvi. New Brunswick, NY: Rutgers University Press.

\*Schnittker, Jason and Valerio Bacak. 2014. "The Increasing Predictive Validity of Self-Rated Health." *PLoS ONE* 9(1): e84933

\*Cohen-Mansfield, Jiska, Michal Skornick-Bouchfinder, Shai Brill. 2018. "Trajectories of End of Life: A Systematic Review." *Journals of Gerontology: Psychological Sciences* 73(4): 564-572.

\*Ohnsorge, Kathrin, Christoph Rehmann-Sutter, Nina Streeck, Heike Gudat. 2019. "Wishes to Die at the End of Life and Subjective Experience of Four Different Typical Dying Trajectories: A Qualitative Interview Study." *PLoS One* 14(1): e0210784

### Recommended reading:

Idler, Ellen, and Yael Benyamini. 1997. "Self-Rated Health and Mortality: A Review of 27 Community Studies." *Journal of Health and Social Behavior* 38:21-37.

Glaser, Barney and Anselm Strauss. 1965. *Awareness of Dying*. Chap. 1, pp. 3-15. New Brunswick, NJ: Aldine Publishers.

### Session 9 - October 20

Suffering, stigma, and deaths of despair

How have sociologists characterized the interpersonal dimensions of suffering?

#### Required reading:

Charmaz, Kathy. 1999. "Stories of Suffering: Subjective Tales and Research Narratives." *Qualitative Health Research* 9(3):362-82.

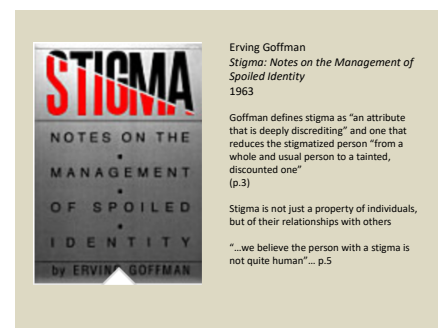
Link, Bruce, and Jo Phelan. 2001 "Conceptualizing Stigma." *Annual Review of Sociology* 27:363-85.

\*Pescosolido, Bernice. 2013. "The Public Stigma of Mental Illness: What Do We Think; What do we know; What can we prove?" *Journal of Health and Social Behavior* 54(1):1-21.

\*Siddiqi, Arjumand, Odmaa Sod-Erdene, Darrick Hamilton, Tressie McMillan Cottom, William Darity, Jr. 2019. "Growing Sense of Social Status Threat and Concomitant Deaths of Despair among Whites." *Social Science & Medicine – Population Health* 9: 100449

#### Recommended reading:

Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster.



### Session 10 – October 27

Physician – patient relationships: The sick role, medicalization, and healing

In what ways is Parsons' view of the physician-patient relationship dated, specific to the postwar period? In what ways is it still relevant?

How can we reconcile the "superior" knowledge of the physician about the patient's condition with the patient's own strong prognostic ability that is shown in the studies of self-rated health and mortality?

#### Required reading:

Parsons, Talcott. 1951. *The Social System*. Chapter X, pp.428-479. New York: The Free Press.

Timmermans, Stefan and Hyeyoung Oh. 2010. "The Continued Social Transformation of the Medical Profession." *Journal of Health and Social Behavior* 51(S): S94-S106.

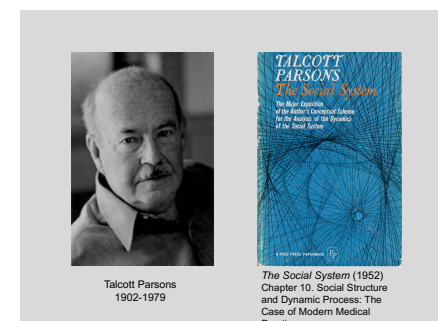
\*Levinson, Wendy, Audley Kao, Alma Kuby, Ronald Thisted. 2005. "Not All Patients Want to Participate in Decision Making." *Journal of General Internal Medicine* 20:531-535.

\*Bell, Robert, Xinyi Hu, Sharon Orrange, and Richard L. Kravitz. 2011. "Lingering Questions and Doubts: Online Information-Seeking of Support Forum Members Following their Medical Visits." *Patient Education and Counseling* 85:525-528.

Moerman, Daniel. 2002. *Meaning, Medicine and the 'Placebo Effect'*. Chapter 4, pp.32-46. Cambridge, UK: Cambridge University Press.

#### Recommended reading:

Davis, Joseph. 2010. "Medicalization, Social Control and the Relief of Suffering." In William Cockerham, Editor, *The New Blackwell Companion to Medical Sociology*, pp.211-241. West Sussex, UK: John Wiley.



Student paper presentations.

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**DETAILS FOR WRITTEN ASSIGNMENTS**

Date Due	Assignment	Instructions
Varies, one per week	Minute for Books – lead opening discussion and write short paper	<p>Students will take turns doing a brief book review of a nonfiction account of illness (first-person or third-person).</p> <p>There is a list of books to choose from at the end of this syllabus, but others may be used with approval.</p> <p>Write a one-page summary of the book; note the social factors that play a causal role in the illness experience and/or coping strategies that are used by the patient and family.</p> <p>Formulate a researchable question from your single “case”.</p> <p>Lead the opening discussion for the class that week by describing the work and its potential relevance for research.</p> <p>There will be a sign-up sheet on Canvas.</p> <p>Upload your completed paper to Canvas.</p>
Varies with availability of articles to review	Journal article peer review	<p>Each student (or a pair of students) will collaborate with me on a professional peer review.</p> <p>General instructions for peer reviewing will be covered in class.</p> <p>When an article becomes available for review, I will email the class and the first volunteer I hear from will get to do the review.</p> <p>You will have two weeks to draft your review, then we will meet and discuss our reviews, prepare a merged version, and submit it online to the journal – Accept, Revise and Resubmit, or Reject.</p>
Sessions 2-10	Article extracts	<p>Each week you will choose one empirical research paper from the readings (marked with *) and write an analytic summary.</p> <p>There is a Word document template for these article extracts on Canvas. that you can use.</p> <p>Upload your completed work to Canvas before class. If you will have a problem getting it in on time, let me know.</p> <p>Students who completed the article extract will lead discussion of that article in the class.</p> <p>I will provide feedback on the assignment prior to the next class.</p>
Session 5	Research paper proposal	<p>Prepare a 1-2 page proposal for research (see following types of research papers).</p> <p>Include a paragraph of background, a specific research question, and a list of annotated readings on the topic.</p> <p>Upload your proposal to Canvas. I will meet individually with everyone to discuss your proposal.</p> <p>Choose from the following types of papers:</p> <p>1. <i>Conduct a systematic review</i> of the research literature. Choose a disease, disorder, or health problem. Identify a social/behavioral risk factor known or suspected to play a role in its causation and review the existing literature on this association.</p> <p>A true systematic review would use multiple bibliographic data bases (e.g. JSTOR, PubMed, Medline, SocINDEX) to identify studies; for this paper assignment you may limit yourself to one or two data bases, and to papers published in the last 5-10 years, as long as you identify at least 6-8 studies on your topic.</p>

		<p>Evaluate the evidence for this risk factor's association with the disease, disorder, or health problem.          Use the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist on the Canvas site and here <a href="http://prismastatement.org/documents/PRISMA 2009 checklist.pdf">http://prismastatement.org/documents/PRISMA 2009 checklist.pdf</a>          Present your findings in a table.          Conclude with an agenda for future research.</p> <p>2. <i>Conduct a scoping review</i> of the research literature. Scoping reviews are used for broader, or less well-defined areas of research where mapping a range of different types of studies would be appropriate. Your topic may involve health policy or practice or emerging areas in social scientific health research.          A true systematic review would use multiple bibliographic data bases (e.g. JSTOR, PubMed, Medline, SocINDEX) to identify studies; for this paper assignment you may limit yourself to one or two data bases, and to papers published in the last 5-10 years, as long as you identify at least 6-8 studies on your topic.          Use the framework for scoping studies given by Tricco et al. 2018, in the Resources section on Canvas.          Present your findings in a table.          Conclude with an agenda for future research.</p> <p>3. <i>Propose an original study</i> using primary or secondary data, as if for a National Science Foundation or other grant.  <u>Background:</u>          Review the key research and relevant theoretical framework(s), and the gap in the research your study will address. Identify the important concepts you will use in your study.  <u>Research Question:</u>          State a research question that will provide new knowledge to address those gaps.  <u>Methods:</u>  <i>Study Population.</i> If you will be using existing data, identify the data set and characteristics of the sample and how they were selected. If you will collect your own data, describe your sample selection and recruitment procedures.  <i>Measures.</i> Describe the concepts you want to measure, and how you will measure these constructs. Identify the important independent (exposure) and dependent (outcome) variables, and any mediating, moderating, and/or confounding variables that will be included.  <i>Analysis.</i> Describe the steps you will use to analyze your data. Prepare a blank table or chart to show how you would display your results.  <i>Significance of Study.</i> Why is it important to fund your proposal? How would your findings add to existing knowledge? Would your findings have potential practical or public health implications?          Good overview of the elements of a proposal:  <a href="http://libguides.usc.edu/writingguide/researchproposal">http://libguides.usc.edu/writingguide/researchproposal</a></p> <p>4. <i>Begin the study proposed in 3</i>, most likely a secondary data analysis. Identify and obtain an appropriate data set; identify sample characteristics; run frequencies for important dependent and independent variables; run bivariate cross-tabs or correlations for important associations; determine appropriate multivariate techniques and run preliminary models. Display your results in tables or charts.</p>
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Sessions 13-14	Paper presentations	Prepare and deliver a 12-15 minute presentation of your paper as you might for ASA or other professional conference. Speak from notes or slides; do not read your paper. Use visual aids to organize the material and present findings. Be prepared for questions. Upload your slides to Canvas.
December 8	Final papers due	Papers should be approximately 20 pages double-spaced, 11 point font, including tables and references. Citations and references should use ASA style. Attach appendices for data sets, scales, measures of key variables, as appropriate. Upload to Canvas.

## BOOKS

### Texts with Assigned Reading

Many of the following are inexpensive paperbacks or ebooks that you could add to your library. All of the following are available on Course Reserves at the Woodruff Library.

Christakis, Nicholas. 2009. *Connected: How Your Friends' Friends' Friends Affect Everything You Feel, Think and Do*. New York: Little, Brown.

Cockerham, William, Editor. 2010. *The New Blackwell Companion to Medical Sociology*. West Sussex, UK: John Wiley.

Emanuel, Ezekiel. 2014. *Reinventing American Health Care*. New York: Public Affairs.

Kellehear, Allan. 2007. *A Social History of Dying*. Cambridge, UK: Cambridge University Press.

Klinenberg, Eric. 2002. *Heat Wave: A Social Autopsy of Disaster in Chicago*. Chicago: University of Chicago Press.

Marmot, Michael. 2004. *The Status Syndrome: How Social Standing Affects Our Health and Longevity*. New York: Henry Holt.

Moerman, Daniel. 2002. *Meaning, Medicine, and the 'Placebo Effect'*. Cambridge, UK: Cambridge University Press.

Reid, T. R. 2010. *The Healing of America: A Global Quest for Better, Cheaper, and Fairer Health Care*. New York: Penguin.

Starr, Paul. 2011. *Remedy and Reaction: The Peculiar American Debate over Health Care*. Pp. 161-266. New Haven: Yale University Press.

### Recommended Nonfiction Illness Narratives

I own most of the following and would have been happy to lend to you, if not for the pandemic. Most are also available as paperbacks for purchase. These books are not on reserve, although the library may have copies, and if you are unable to obtain the book, let me know and I will have it put on reserve for you.

Bauby, Jean-Dominique. 1997. *The Diving Bell and the Butterfly: A Memoir of Life in Death*. New York: Alfred A. Knopf. Written by a man completely paralyzed except for his eyelids; he chose the words one letter at a time.

Bennett, Amanda. 2012. *The Cost of Hope: A Memoir*. New York: Random House. Written by the first woman to be editor of *The Philadelphia Inquirer*; account of the illness and death of her husband from a rare form of kidney cancer. Was first published in Bloomberg News as several articles on the cost of health care and the complexity of the US health care system.



- Cohen, Richard M. 2004. *Blindsided: Lifting a Life Above Illness*. New York: Harper Collins.  
First-person account of a former television news producer stricken with multiple sclerosis in his 20s; he also has colon cancer.
- Coutts, Marion. 2016. *The Iceberg*. Black Cat.  
A wife's account of her writer-husband's two-year illness and eventual death from a brain tumor. From the NYT review: "Coutts's prose blinds and burns you, but it is also purifying."
- Didion, Joan. 2006. *The Year of Magical Thinking*. New York: Vintage Books.  
A famous-writer-wife's account of her writer-husband's sudden death, followed closely by the untimely death of her adult daughter. A National Book Award winner.
- Egan, Kerry. *On Living*. New York: Riverhead Books, 2017.  
A hospice chaplain's account of the end-of-life period of patients in a long-term care facility. Memorable interactions.
- Fadiman, Anne. 1997. *The Spirit Catches You and You Fall Down*. New York: Farrar, Straus, and Giroux.  
Story of a Hmong refugee family in California; cultural differences in the treatment of their seriously ill child.
- Hsi, Stephen, with Jim Belshaw and Beth Corbin-Hsi. 2004. *Closing the Chart: A Dying Physician Examines Family, Faith, and Medicine*. Albuquerque, NM: University of New Mexico Press.  
A young physician's first person account of his three heart surgeries, necessitated by a rare disease of the blood vessels; strongly critical of his mostly technically competent, but psychosocially insensitive care.
- Kalanithi, Paul. 2016. *When Breath Becomes Air*. New York: Random House.  
A first-person account by a neurosurgeon who is diagnosed with lung cancer; he writes about the reversal of roles when a physician becomes a patient.
- Neuhaus, Richard John. 2002. *As I Lay Dying: Meditations Upon Returning*. New York: Basic Books.  
First person account of a Roman Catholic priest's near-death experience during treatment for colon cancer.
- Price, Reynolds. 1994. *A Whole New Life: An Illness and a Healing*. New York: Penguin.  
First person account of a Duke literature professor/novelist's diagnosis and treatment for spinal cancer.
- Roiphe, Katie. 2016. *The Violet Hour: Great Writers at the End*. Dial Press.  
Following her own illness with pneumonia, the author does a "forensic investigation" into the writings and documented experiences of six famous authors at the end of their lives: Sigmund Freud, Dylan Thomas, Susan Sontag, Maurice Sendak, John Updike, and James Salter.
- Sheehan, Susan. 1984. *Kate Quinton's Days*. New York: Houghton Mifflin.  
Originally published in The New Yorker, a journalist's account of an elderly woman's multiple chronic, disabling, but not life-threatening illnesses. Highlights issues of family and professional caregiving for community-living elderly.
- Skloot, Rebecca. 2011. *The Immortal Life of Henrietta Lacks*. New York: Random House.  
Story of an African-American woman's death from cervical cancer in 1951 and the history of her family, interwoven with the history of the scientific and medical discoveries that came from tissue samples taken from her without her knowledge.
- Woolf, Virginia. 2012 (1930). *On Being Ill*. Ashfield, Massachusetts: Paris Press.  
This has two parts, one written by Virginia Woolf, and one written by her mother, her nurse.
- Yip-Williams, Julie. 2019. *The Unwinding of the Miracle: A Memoir of Life, Death, and Everything that Comes After*. New York: Random House.  
A first-person story of a blind Vietnamese woman who emigrated to the US as a child, had some partial vision

restored in surgery at UCLA, went to Harvard Law School, and then was diagnosed with colon cancer at age 37.

### **Recommended Accounts of the US Health Care System**

As with the illness narratives, I own these but cannot lend to you this semester, so you can purchase as paperback or ebook, or borrow from the library.

Bradley, Elizabeth H. and Lauren Taylor. 2013. *The American Health Care Paradox: Why Spending More is Getting Us Less*. New York: Public Affairs.

Emanuel, Ezekiel J. 2014. *Reinventing American Health Care: How the Affordable Care Act Will Improve Our Terribly Complex, Blatantly Unjust, Outrageously Expensive, Grossly Inefficient, Error Prone System*. New York: Public Affairs.

Emanuel, Ezekiel J. 2020. *Which Country Has the World's Best Health Care?* New York: Public Affairs.

Macy, Beth. 2018. *Dopesick: Dealers, Doctors, and the Drug Company That Addicted America*. Boston: Little Brown

Quinones, Sam. 2015. *Dreamland: The True Tale of America's Opiate Epidemic*. New York: Bloomsbury Press.

Rosenthal, Elisabeth. 2017. *An American Sickness: How Healthcare Became Big Business and How You Can Take It Back*. New York: Penguin Press.

### **Recommended Reference Texts**

Berkman, Lisa F. and Ichiro Kawachi, Editors. 2000. *Social Epidemiology*. New York: Oxford University Press.  
The first textbook in the field of social epidemiology, or the systematic study of the social determinants of health.

Bloom, Samuel W. 2002. *The Word as Scalpel: A History of Medical Sociology*. New York: Oxford University Press.  
A history of the field by a first hand observer.

Freund, Peter E. S. and Meredith B. McGuire. 1995. *Health, Illness, and the Social Body: A Critical Sociology*. 2<sup>nd</sup> Edition. Englewood Cliffs: Prentice-Hall.  
A textbook emphasizing power relationships in health.

Gabe, Jonathan, Mike Bury, and Mary Ann Elston. 2004. *Key Concepts in Medical Sociology*. London: Sage.  
Handbook-style review of important concepts and research areas. Offers a definition and summary of current controversies.

Last, John M., Ed. 2001. *A Dictionary of Epidemiology*. 4<sup>th</sup> Edition. London: Oxford University Press.  
The new edition of a classic "look-up" book for brief definitions of methods, statistics, measurements, techniques, study designs, data presentations, biases, data sources, data collection

Oakes, J. Michael and Jay S. Kaufman, Editors. 2006. *Methods in Social Epidemiology*. San Francisco: Jossey-Bass.  
Extensive text on methods, measures, design, and analysis of social factors in disease causation.

Palmore, James A. and Robert W. Gardner. 1983. *Measuring Mortality, Fertility, and Natural Increase: A Self-Teaching Guide to Elementary Measures*. Honolulu: East-West Population Institute.  
Rates, ratios, and life tables.

Selvin, Steve. 2001. *Epidemiologic Analysis: A Case-oriented Approach*. New York: Oxford University Press.  
Uses examples of specific health problems (e.g. maternal weight gain in multiple pregnancies, risk of Alzheimer's disease, trends in Hodgkins' Disease among African-Americans, etc.) and identifies appropriate study designs and

statistical tests.

Susser, Mervyn. 1973. *Causal Thinking in the Health Sciences*. New York: Oxford University Press.

A classic exposition of the logic of health research, particularly strong on the conditions of observations, screening for extraneous variables, and establishing causal associations.

Valente, Thomas. 2010. *Social Networks in Health: Models, Methods, and Applications*. New York: Oxford University Press.

A readable new text on network methods for health, with excellent examples.

Young, T. Kue. 1998. *Population Health: Concepts and Methods*. New York: Oxford University Press.

Integrates the concepts of epidemiology with the relevant social sciences: sociology, anthropology, demography.