First Person: Narratives of Illness & Disability

Consortium for Culture and Medicine
Fall 2012

CCM 405/505, ETS 405, CCFM 1427, CCFM 427, CCFM 6427

Tuesdays 4:15 to 7:15 p.m.
Conference Room, Bioethics & Humanities, 618 Irving Ave. (at Adams St.)
Upstate Medical University

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Bioethics and Humanities
618 Irving Ave.
Upstate Medical University
464-8451
Office hours by appointment

This course foregrounds first-person accounts of chronic illness, disability, and difference, considering how those accounts can inform medical and nondisabled discourses of health, illness, and disability. Reading critical essays as well as first-hand accounts of authors whose narratives are becoming increasingly powerful within discourses of medicine, bioethics, and embodiment, we will examine narrative representations of the socio-cultural context of illness, disability, and medicine and consider how such narratives can counter the medicalization of illness and disability and generate knowledge and empathy. We will also explore the limits of narrative, that is, the potential for narrative to reinforce understandings of illness and disability as individual rather than social and the potentially coercive nature of narrative conventions.

Course Objectives: At the end of the course students will have learned to—

• discuss the perspectives of authors, bloggers, and video artists who identify as disabled or as chronically ill;
• identify and discuss the social contexts of the course texts, using critical approaches as a guide;
• analyze the structure of each narrative and its relation to conventions;
• describe and compare the medical and social models of disability and discuss critical understandings of the promise and pitfalls of narrative.
Course Topics and Readings

8/27/12
note: this schedule and the readings are subject to change

course blog: http://firstpersonnarratives.wordpress.com/

week 1 (8/28): intro to course
Introductions
In-class reading (Gramaglia) and discussion
Amanda Baggs, In My Language

week 2 (9/4): madness, mental health & narrative
Susanna Kaysen, Girl, Interrupted [excerpts]
Wiener, "Antipsychiatric Activism"
Wiener, review of Girl, Interrupted (film)
SQ 1 due (post responses on course blog)
Screening: Girl, Interrupted
Guest speaker: Diane R. Wiener
[start reading Autobiography of a Face]

week 3 (9/11): embodiment, identity and writing
“Getting Comfortable,” Laura Hershey, Beauty Is a Verb
“Reshaping the Outline,” Laurie Clements Lambeth, Beauty Is a Verb
Lisa Roney, Sweet, Invisible Body [excerpts]
AXIS Dance [videos]
SQ 2 due
discuss midterm paper

week 4 (9/18): disability and medicine
Nancy Mairs, Waist-High in the World [excerpts]
Jim Ferris, The Hospital Poems (selected poems)
William Peace, “Comfort Care as Denial of Personhood”
SQ 3 due
Jasmine Bailey, Sickle Cell, Brave New Voices video
discuss paper proposals

week 5 (9/25): appearances and the self in print
Lucy Grealy, Autobiography of a Face [first half of book]
Couser, chapters from Recovering Bodies
Lynn Manning, Weights [video]
paper proposal due

10/2: NO CLASS, WORK ON MIDTERM PAPER
peer review of proposal due
week 6 (10/9): ethics, the self & the other in the book market
Garden, “Telling Stories”
Guest: Diane Wiener
**paper draft due**

week 7 (10/16): disability, activism & intersectionality
Eli Clare, *Exile and Pride: Disability, Queerness & Liberation*
**peer review of draft due**
Guest: Diane Wiener
discuss papers

week 8 (10/23): madness and post-psychiatry
Allie Light, *Dialogues with Madwomen* [film]
review Wiener, “Antipsychiatric” and Wiener review from week 2
Guest speaker Diane Wiener
discuss final paper
**midsemester course evaluation**
**midterm paper/project due**

week 9 (10/30): Deaf culture, language and identity
Emmanuelle Laborit, *The Cry of the Gull*
Raymond Luczak, *Assembly Required: Notes from a Deaf Gay Life*
Padden & Humphries, *Inside Deaf Culture*
**final paper proposal due**
Guest speaker Michael Schwartz?

week 10 (11/6): neurodiversity
essays from special issue of *Disability Studies Quarterly:* “Autism and the Concept of Neurodiversity”
**peer review of proposal due**

*Nobody Ever Said AIDS: Poems and Stories from Southern Africa*
Paul Monette, *Borrowed Time*
*From a Burning House: The AIDS Project Los Angeles Writers Workshop Project Corpus* (journal of AIDS Project Los Angeles)
**final paper draft due**

11/20 NO CLASS: THANKSGIVING BREAK
**peer review of draft due**

week 12 (11/27): environmental memoir
Susanne Antonetta [Suzanne Paola], *Body Toxic*
Terry Tempest Williams, *Refuge*

week 13 (12/4): graphic illness & disability narratives
Pekar and Brabner, *Our Cancer Years*
Susan Squier, “Beyond Nescience: The Intersectional Insights of the Health Humanities”
**Final project due, wrap-up, and course evaluation**
Course Texts


AXIS Dance videos


*Corpus* (journal of AIDS Project Los Angeles)

Couser, Thomas G. *Recovering Bodies: Illness, Disability, and Life Writing*. [chapters]


Light, Allie. *Dialogues with Madwomen*. [film]


Savarese Thornton, Emily and Ralph J. Savarese, Disability Studies Quarterly special issue: “Autism and the Concept of Neurodiversity”


Access and Inclusion: Disability, Health, and Life

This course strives to be as inclusive as possible of all types of students and to be flexible when students experience significant life events. Students with disabilities or impairments (e.g., learning disabilities, ADHD, depression), health events (e.g., illness or injury), or significant life events (e.g., a loss, a caregiving emergency) who require accommodation with instruction, assignments, or attendance requirements should notify the professor as soon as possible (gardenr@upstate.edu or by phone 464-8451). Students who need further information about access should contact the disability services office in their home institution. Please contact the professor for assistance in identifying that office, if necessary.
Course Requirements

Attendance:
This class meets only once a week; therefore you will be allowed one unexcused absence. If you have any problems making it to class, please contact the professor (gardenr@upstate.edu, 464-8451).

Class Participation:
The class will be run as a seminar, not a lecture, and therefore depends on your ideas and input. You are expected to participate in class discussion. If you are really uncomfortable with speaking in class, you must compensate for that with your participation in the written conversation we have on our course blog, in response to study questions. However, keep in mind that the seminar is only as lively as its participants, and your participation adds an important dimension.

Study Questions
Each week I’ll give you a list questions and/or prompts for writing which you will respond to on the course blog. These study questions will address the next week’s readings. These will help you to know what I’m focusing on, and they’ll help you to formulate your ideas and opinions about the readings. Think of these writings as a basis for class discussion. I may ask you to read one or more of your responses out loud to the group. Write a couple of paragraphs in response to each, totaling one to two pages. Think of this writing as preparation for your papers.

Peer Review:
Students will review other students’ paper proposals and at least one other student’s paper draft. You will be given guidance on the sort of feedback that is needed and helpful to the student to develop that proposal or draft into an excellent paper.

Paper Proposals (2 total = 10% of grade):
Write one full page, single-spaced OR a detailed “mind map” or other visual-textual representation that gives readers a clear idea of what you will be covering in your paper. Remember to include a proposed title. Your proposal should cover most if not all of the following: what your argument/thesis might be; which texts you’ll be discussing and which passages you might be focusing on through “close readings”; what research you will include; which concepts from class you’ll be making use of in your analysis; problems you might encounter in writing; and a discussion of why you’re writing the paper. We will devote time during class to discussing these proposals and you will review each other’s proposals.

Paper Drafts (2 total = 10% of grade):
Submit rough drafts of at least 4 double-spaced pages but ideally 6 pages. The more finished the draft, the more opportunity you have to receive useful feedback from
another student and the professor, which you can use to revise and complete a really good paper.

Midterm Paper (8-10 for undergrads, 13-15 for grad students; 30% of grade)

Final Paper (8-10 pages for undergrads, 13-15 for grad students; term paper is 30% of grade.)

Papers
(See also Paper Proposals and Drafts above):

Students must write at least one traditional academic paper, as described below.

Students may choose one of the following options for the second paper:

1) Interview a person who has a chronic illness or disabled and write a paper that analyzes that interview and relates it to course readings, as well as reflects on the interview process itself. Ethical questions about reducing a person who is disabled or ill to a “research subject” must be considered in advance of the interview and when writing about the experience. One important question for the interviewee will be something like: “How do you feel about being interviewed by me?” The professor will provide guidance, resources, and potentially contacts for the interview.

or

2) Write a narrative of one’s own experience of chronic illness or disability, analyzing it in relation to the course readings and through critical perspectives. This approach could be understood as an “autoethnography,” and readings from the course, such as Nancy Mairs, provide excellent examples. You could also write the narrative of a family member or close friend who has lived with or is very close to a disabled or chronically ill person. This analysis should include discussion of the role of “caregiver” and/or ally and the ethics of speaking for and about a disabled or ill person. The professor will provide guidance and resources.

Traditional academic paper:

Both midterm and term paper topic (each student’s choice and approved by me) will relate to concepts covered in readings and class discussions and may focus on course text(s). These papers comprise a large part of the course grade, so students should think carefully about their topics. During the course, I will discuss with students how to select a topic for their papers and how to refine that topic into a question or argument that will lead into a fruitful paper project.

I will provide a grading rubric that can serve as a guide, an overview of and many resources for reviewing essay form so that students feel clear and confident about writing the paper. I will prepare the students for the paper writing process and leave a portion of several class periods open for discussion of papers. Peer review by other students will provide further feedback for revision and improvement.
Papers will be graded on the clarity of writing, the logic of the argument(s), demonstration of comprehension of concepts discussed in class, the coherence, and the persuasiveness of the essay. Form and content are two sides of the same coin; clear, logical, and carefully considered analysis will best reflect comprehension of the ideas set forth in the narratives we read and in our class discussions. (If you are expert, of course, you can be complex and experimental and still write with clarity.) Students will be guided to choose topics that will allow them to focus their energies on clear and straightforward engagements with their topics. **Papers must be proofread and edited for grammatical clarity (another component of one's argument).**

**Undergraduate students** may focus primarily on the readings assigned and recommended for the course or similar texts (approved in discussion with the professor). They should focus carefully on the texts at hand, engaging with their topic by plotting out an outline or map for the exploration of the question or argument and finding examples from the readings that support or further the question/argument. The paper is a way to think through a specific idea by poring over one or more readings and writing through one’s ideas about it/them. Putting your thoughts into writing that can be understood by others and persuades them of your argument demands that you set down and logically organize your ideas and test your hypotheses in a way that oral discussion does not require. Thus students who may not have a background in writing are nonetheless capable of well-argued writing as students with more experience writing. Additional research is welcome, but the paper should remain fairly focused on a small number of texts, both narratives and critical perspectives.

**Graduate students** will be expected to research their paper topics beyond the assigned course texts and to include a broader range of critical perspectives. Their papers will be graded in part on the aptness of the cited critical texts and the way that the students integrate them into their line of questioning or argument. The emphasis is on the usefulness of the material cited, rather than on the number of citations. Papers must include close readings of the text(s), where either a selected passage or passages are discussed in detail or images, tone, sequence of events, or other details of the structure of the narrative are explored in terms of language and the ideas expressed.

**CITATION STYLE AND ACCURACY:**
**Students are expected to know the rules of proper citation, both ethically and in terms of citation format, and to demonstrate that knowledge in their papers. I will supply students with resources for reviewing documentation and avoiding ambiguous citation that might appear as plagiarism.**