

NARRATIVES OF ILLNESS

Winter 2023

Instructor: Chris Sinding

Classes: Wednesdays, January 11 to April
12, 2:30pm – 5:20pm, KTH B104

Office: KTH 239

Office Hours: 3 – 4:30pm Thursdays or by
appointment

Email: Contact me through Avenue Mail

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Course Description

Many claims are made for stories and storytelling in the contexts of illness and care. Stories and storytelling are said to ease suffering, increase empathy, and improve healthcare practice.

In this course, we will explore these and other claims about what stories are and do. We will do this by engaging with:

- Classic sociological analyses of illness stories and the concepts they have generated (biographical disruption; narrative reconstruction; restitution, quest, and chaos narratives, etc.)
- Stories by people living with illness
- Social science literature about how people who are living with illness understand and use stories
- Critical scholarship about stories and storytelling, including the limitations and harms of (the call to tell) stories

The course is designed to deepen your understanding of the multiple purposes and effects of stories and storytelling, including as they unfold for particular communities and in particular interactions. The overall goal of the course is to support you to become more knowledgeable and thoughtful/ critical about illness stories, storytelling and story listening.

Course Objectives

By the end of the course students should be able to:

1. Articulate key social science theories, concepts and arguments about stories and storytelling in the contexts of illness and care
2. Demonstrate personal reflection, and a capacity to apply social science concepts about stories and storytelling, in responding to an illness story
3. Make a persuasive case for (or against) certain kinds of illness stories or storytelling in a specific context

Required Materials and Texts

Required readings are listed in the weekly course schedule below, and available on Avenue to Learn.

Class Format

The course will be presented through lectures, guest speakers, and workshops. We will have opportunities to learn from one another through class discussion, and small group activities and discussion.

Course Evaluation – Overview

Assignment 1: Reading summary. Prepare a written summary from 2 course readings over the term and contribute to in-class discussion based on your summary. Written summaries are worth 10% each and are due by 9am on the day before the class at which they are discussed (for example, if you have signed up for the reading by Riessman that we'll discuss in class on Wednesday January 25, your written summary is due by 9am on Tuesday January 24). The in-class component is not graded.

Assignment 2: Response and analysis paper. Respond to and analyze an illness story with reference to one course reading, 20%, due February 15

Assignment 3: Proposal presentation, and evaluation of your own and peers' presentations

- a) Working in groups, present a proposal for the use of stories in a specific illness or care context. Presentations on March 15 or 22 – 25%
- b) Evaluate your own and one other group's proposal presentations – 5%, due March 29

Assignment 4: Final paper: respond to and analyze an illness story in a way that demonstrates personal reflection and learning, and analysis grounded in course readings – 30%, due on April 17

Course Evaluation – Details

Assignment 1: Reading summary (2 x 10%), Various Deadlines. Prepare a written summary from 2 course readings over the term, 2.5 - 3 double-spaced pages each. Sign up for readings on Avenue to Learn – one reading from Reading List A and one from Reading List B. Your summary should offer:

- An explanation of one or two of the author's key concepts, insights or arguments
- A discussion of relevance or importance of these concepts/ insights/ arguments to your own knowledge about health and illness, to your paid or volunteer work (or work you hope to do), or to your life experiences

In class, participate with others who are presenting this reading on a panel, sharing your summary and facilitating discussion about the reading. You can read from your summary or add in your reflections more informally. You do not need to co-ordinate with other students ahead of time. *This assignment links with course objective 1.*

Assignment 2: Response and analysis paper (20%), Due February 15. Choose among the illness stories available on Avenue to Learn. Respond to and analyze the story with reference to one course reading (a different reading than you used for Assignment 1, from week 2 or 3); no other sources should be used. *This assignment is linked with course objective 2.*

Length: 5 – 6 double-spaced pages. Your paper should include:

- Your initial response to the story (based on learning in other courses, (volunteer) work, life experience or knowledge of others' experiences, etc.) (about 1 page)
- A summary of key arguments, insights or concepts from the course reading (about 1 page)
- A consideration of the key concepts, insights and arguments from the reading, in relation to this specific illness story. *How is the reading relevant to this story? When you consider the story in light of the reading, what aspects of the story become important? What do you learn about the story from thinking about it with the reading?*
- A discussion about how the course reading changed your own initial response to the story (.5 to 1 page).

Assignment 3: Proposal presentation, and evaluation.

Many of the readings in this course 'make the case' for the use of stories. Some of the readings also raise cautions about stories and storytelling. In this assignment you'll have the chance to be creative and persuasive: to convince an audience about the value of using illness stories or storytelling in a specific context. If you wish, you could also make the case *against* the use of stories in a specific context. *This assignment is linked to course objective 3.*

a) Proposal presentation (25%), Due March 15 OR 22:

You will work in groups of three or four, assigned by me based on a list of topics that interest you. The form of your presentation is up to you: a PowerPoint, a debate, a skit... Use at least 4 course readings to develop your proposal presentation. You will have class time to meet as a group and prepare your presentation.

Groups will present for about 25 minutes, including time for questions from your audience. On the day of your presentation, submit a 1 - 1.5-page (double-spaced) point-form overview of the presentation that shows me where and how you will use the course readings.

Your proposal presentation should:

- Identify the specific care context in which you propose to use stories or storytelling, and the people involved (a mental health peer support group for university students? A teaching and learning forum for oncologists? A community consultation with newcomers to Canada? An advocacy initiative for LGBTQ healthcare?)
- Identify who the proposal is directed to (a funder? A community health agency? Potential participants in the storytelling group?) The proposal should be presented with that audience in mind
- Explain how you plan to use the stories or involve the storytellers, and why you chose this approach

- Discuss the benefits you expect, and any potential harms you anticipate; explain how you plan to ensure benefits and avoid or address potential harms
- Offer a summary 'pitch' about the value of using stories in this setting

b) Evaluation of your own and peers' presentations (5%), Due March 29

Using a template, evaluate your own group's presentation and your role in it, and provide constructive feedback on one of your peer group's presentations.

Assignment 4: Final paper (30%), Due April 17: Respond to an illness story in a way that demonstrates personal reflection and learning, and analysis grounded in course readings. Length: 10 - 12 double-spaced pages.

In this final paper you will have a chance to show how your own learning about stories and storytelling has developed since the beginning of the course, and to demonstrate your grasp of social science literature about the multiple purposes and effects of illness stories and storytelling. *This assignment is linked with course objectives 1 and 2.*

You may identify the story yourself or you can choose among the stories provided for Assignment 2 (not the same story!). It must be a personal story of illness written in the first person (not an interview or an article with short personal components), approximately 1000 – 3000 words (if in doubt, check with me). If you identify your own story, include the story as an appendix to your assignment.

Use at least 6 course readings in this assignment (you can include the readings you did for Assignment 1 and Assignment 2). You can also draw on conversations we have had in class.

Your paper should include:

- An overview of the story and your initial response to the story (about 1.5 pages)
- An overview of the key arguments, insights or concepts from the selected readings that you plan to apply to this illness story (about 1.5 pages)
- An application of the readings, to the story. *What do you learn about the story by thinking about it with the concepts/ insights/ arguments from these readings?* (most of your paper should focus here. Use specific examples from the story to support your analysis)
- A discussion about how the course readings changed your own initial response to the story (about 1 page)

Weekly Course Schedule and Required Readings

All classes in person unless otherwise noted

Week 1: January 11 – Introductions, objectives & design of the course

Week 2: January 18 – Key concepts in the social science analysis of illness narratives

Guest: Susan Cape, MSW, PhD candidate, School of Social Work

Readings:

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167-182.

Williams. (1984). The genesis of chronic illness: narrative re-construction. *Sociology of Health & Illness*, 6(2), 175–200.

Frank, A. W. (1998). Just listening: Narrative and deep illness. *Families, Systems, & Health*, 16(3), 197.

Week 3: January 25 – Key concepts continued

Readings:

Pound, P., Gompertz, P. and Ebrahim, S. (1998). Illness in the context of older age: The case of stroke. *Sociology of Health & Illness*, 20(4), 489–506.

Riessman, C. K. (2015). Ruptures and sutures: time, audience and identity in an illness narrative. *Sociology of Health & Illness*, 37(7), 1055-1071.

Week 4: February 1 – What do stories do? Stories & empathy, stories & community

Readings:

Gerdes, Karen E, et al. "Teaching Empathy: A Framework Rooted in Social Cognitive Neuroscience and Social Justice." *Journal of Social Work Education* 47.1 (2011): 109-31.

Rushforth, A., Ladds, E., Wieringa, S., Taylor, S., Husain, L., & Greenhalgh, T. (2021). Long covid – the illness narratives. *Social Science & Medicine*, 286, 114326.

Week 5: February 8 – What do stories do (differently)?

Readings:

Gray, R., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000). Managing the impact of illness: The experiences of men with prostate cancer and their spouses. *Journal of Health Psychology*, 5, 525-542. [read this in comparison with *I was just a number*]

Gray, R. (2003). I was just a number. In *Prostate Tales: Men's experiences with prostate cancer* (pp. 103-109). Harriman, Tennessee: Men's Studies Press.

Week 6: February 15 – Stories & public engagement

Readings:

Cox, S. M., Kazubowski-Houston, M., & Nisker, J. (2009). Genetics on stage: Public engagement in health policy development on preimplantation genetic diagnosis. *Social Science & Medicine*, 68(8), 1472-1480.

Response and Analysis paper due

Week 7: February 22 – Reading Week; no class

Week 8: March 1 – Ethics and politics of personal storytelling

Readings:

Jones, Alison, and Kuni Jenkins. Rethinking Collaboration: Working the Indigene-Colonizer Hyphen, in *Handbook of Critical and Indigenous Methodologies*. Eds. N. K. Denzin, Y. S. Lincoln & L. T. Smith, Thousand Oaks: Sage, 2008. 471-86.

de Bie, A. (2022). Teaching with madness/'mental illness' autobiographies in postsecondary education: Ethical and epistemological implications. *Medical Humanities*, 48(1), 37-50.

Week 9: March 8 – Meet with presentation groups & consult with me if needed (ON ZOOM)

Week 10: March 15 – Presentations

Week 11: March 22 – Presentations

Week 12: March 29 – Stories as constraint and co-optation

Readings:

Costa, L., Voronka, J., Landry, D., Reid, J., Mcfarlane, B., Reville, D., & Church, K. (2012). "Recovering our stories": A small act of resistance. *Studies in social justice*, 6(1), 85-101.

Woods, A., Hart, A., & Spandler, H. (2022). The recovery narrative: Politics and possibilities of a genre. *Culture, Medicine, and Psychiatry*, 46(2), 221-247.

Evaluation of your own and peers' presentations due

Week 13: April 5 – Stories as advocacy

Readings:

Curry-Stevens, Ann. "Persuasion: Infusing Advocacy Practice with Insights from Anti-Oppression Practice." *Journal of Social Work* 12.4 (2012): 345-63.

Final paper due April 17

Course Policies

Submission of Assignments

- Written assignments must be submitted in Microsoft Word (PDFs will not be accepted)
 - Front page should contain the title, student's name, student number, and the date.
 - Number all pages (except title page).
 - Font size: 12 point; spacing: double spaced; and margins: minimum of 1 inch at the top, bottom, left and right of each page.
- Submit assignments in the Assessments section of Avenue to Learn. Feedback and grades will also be made available via Avenue to Learn.
 - The document file name should include your first and last name, course code, and the assignment number.
 - Keep a copy of your assignments.
- Students are expected to make use of relevant professional and social science literature and other bodies of knowledge in their term assignments.
 - References must be in accordance with the current edition of American Psychological Association (APA) publication manual.
- Unless a different deadline has been negotiated prior to the original deadline, late assignments will be docked 2% per day, weekends included.

Grades

Grades will be based on the McMaster University grading scale:

MARK	GRADE
90-100	A+
85-90	A
80-84	A-
77-79	B+
73-76	B
70-72	B-
67-69	C+
63-66	C
60-62	C-
57-59	D+
53-56	D

MARK	GRADE
50-52	D-
0-49	F

Late Assignments

If you need more time to complete an assignment, email me to discuss – *in advance of the assignment deadline!* Once we have agreed on a new due date, it is your responsibility to submit your assignment on time. Unless a different deadline has been negotiated prior to the original deadline, late assignments will be docked 2% per day, weekends included. Note that there are no extensions on the assignments that require in-class contributions.

Course Modification

The instructor reserves the right to modify elements of the course during the term. If any modification becomes necessary, reasonable notice and communication with the students will be given with explanation and the opportunity to comment on changes. It is the responsibility of the student to check his/her McMaster email and course websites weekly during the term and to note any changes.

University Policies

Academic Integrity

You are expected to exhibit honesty and use ethical behaviour in all aspects of the learning process. Academic credentials you earn are rooted in principles of honesty and academic integrity. **It is your responsibility to understand what constitutes academic dishonesty.**

Academic dishonesty is to knowingly act or fail to act in a way that results or could result in unearned academic credit or advantage. This behaviour can result in serious consequences, e.g. the grade of zero on an assignment, loss of credit with a notation on the transcript (notation reads: “Grade of F assigned for academic dishonesty”), and/or suspension or expulsion from the university. For information on the various types of academic dishonesty please refer to the [Academic Integrity Policy](https://secretariat.mcmaster.ca/university-policies-procedures-guidelines/), located at <https://secretariat.mcmaster.ca/university-policies-procedures-guidelines/>

The following illustrates only three forms of academic dishonesty:

- plagiarism, e.g. the submission of work that is not one’s own or for which other credit has been obtained.
- improper collaboration in group work.
- copying or using unauthorized aids in tests and examinations.

Authenticity / Plagiarism Detection

Some courses may use a web-based service (Turnitin.com) to reveal authenticity and ownership of student submitted work. For courses using such software, students will be expected to submit their work electronically either directly to Turnitin.com or via an online learning

platform (e.g. A2L, etc.) using plagiarism detection (a service supported by Turnitin.com) so it can be checked for academic dishonesty.

Students who do not wish their work to be submitted through the plagiarism detection software must inform the Instructor before the assignment is due. No penalty will be assigned to a student who does not submit work to the plagiarism detection software. **All submitted work is subject to normal verification that standards of academic integrity have been upheld** (e.g., on-line search, other software, etc.). For more details about McMaster's use of Turnitin.com please go to www.mcmaster.ca/academicintegrity.

Courses with an On-line Element

Some courses may use on-line elements (e.g. e-mail, Avenue to Learn (A2L), LearnLink, web pages, capa, Moodle, ThinkingCap, etc.). Students should be aware that, when they access the electronic components of a course using these elements, private information such as first and last names, user names for the McMaster e-mail accounts, and program affiliation may become apparent to all other students in the same course. The available information is dependent on the technology used. Continuation in a course that uses on-line elements will be deemed consent to this disclosure. If you have any questions or concerns about such disclosure please discuss this with the course instructor.

Conduct Expectations

As a McMaster student, you have the right to experience, and the responsibility to demonstrate, respectful and dignified interactions within all of our living, learning and working communities. These expectations are described in the [Code of Student Rights & Responsibilities](#) (the "Code"). All students share the responsibility of maintaining a positive environment for the academic and personal growth of all McMaster community members, **whether in person or online**.

It is essential that students be mindful of their interactions online, as the Code remains in effect in virtual learning environments. The Code applies to any interactions that adversely affect, disrupt, or interfere with reasonable participation in University activities. Student disruptions or behaviours that interfere with university functions on online platforms (e.g. use of Avenue 2 Learn, WebEx or Zoom for delivery), will be taken very seriously and will be investigated. Outcomes may include restriction or removal of the involved students' access to these platforms.

Academic Accommodation of Students With Disabilities

Students with disabilities who require academic accommodation must contact [Student Accessibility Services](#) (SAS) at 905-525-9140 ext. 28652 or sas@mcmaster.ca to make arrangements with a Program Coordinator. For further information, consult McMaster University's [Academic Accommodation of Students with Disabilities](#) policy.

Requests For Relief For Missed Academic Term Work

In the event of an absence for medical or other reasons, students should review and follow the [Policy on Requests for Relief for Missed Academic Term Work](#).

Academic Accommodation For Religious, Indigenous or Spiritual Observances (RISO)

Students requiring academic accommodation based on religious, indigenous or spiritual observances should follow the procedures set out in the [RISO](#) policy. Students should submit their request to their Faculty Office **normally within 10 working days** of the beginning of term in which they anticipate a need for accommodation or to the Registrar's Office prior to their examinations. Students should also contact their instructors as soon as possible to make alternative arrangements for classes, assignments, and tests.

Copyright And Recording

Students are advised that lectures, demonstrations, performances, and any other course material provided by an instructor include copyright protected works. The Copyright Act and copyright law protect every original literary, dramatic, musical and artistic work, **including lectures** by University instructors.

The recording of lectures, tutorials, or other methods of instruction may occur during a course. Recording may be done by either the instructor for the purpose of authorized distribution, or by a student for the purpose of personal study. Students should be aware that their voice and/or image may be recorded by others during the class. Please speak with the instructor if this is a concern for you.

Extreme Circumstances

The University reserves the right to change the dates and deadlines for any or all courses in extreme circumstances (e.g., severe weather, labour disruptions, etc.). Changes will be communicated through regular McMaster communication channels, such as McMaster Daily News, A2L and/or McMaster email.

Faculty of Social Sciences E-mail Communication Policy

Effective September 1, 2010, it is the policy of the Faculty of Social Sciences that all e-mail communication sent from students to instructors (including TAs), and from students to staff, must originate from the student's own McMaster University e-mail account. This policy protects confidentiality and confirms the identity of the student. It is the student's responsibility to ensure that communication is sent to the university from a McMaster account. If an instructor becomes aware that a communication has come from an alternate address, the instructor may not reply at his or her discretion.