REPRESENTATIONS OF HEALTH AND ILLNESS ACROSS THE LIFE COURSE Winter 2023

Instructor: Chris Sinding **Office:** KTH 239

Classes: Thursdays, January 12 to April 6, Office Hours: 3 – 4:30pm Thursdays or by

11:30am – 2:20pm, LR Wilson Hall Room appointment

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Course Description

Everywhere there are 'representations' – portrayals, images – of health and illness and related themes: in social media, ads, artworks, academic articles, daily news, policy papers.

Representations of health and illness call on us to see the issues in a particular way – they show us their version, their truth, about their subject, whatever it is: cancer, migraine, depression, illness prognosis, frailty, caregiving, health information, etc.

Most representations wash over us. But they matter – they shape how we understand and relate to ourselves and others with illness; they shape policy decisions, programs and practice.

In this course, we will explore how illness and related issues are represented. We will do this by engaging with *poetry and artworks* about illness themes, and by engaging with *social science* analyses of illness representations.

The course is designed to enhance your capacity for reading/ analyzing representations – to allow you to develop a broader, deeper repertoire of 'ways of reading' representations. Its overall goal is to support you to become more aware of, thoughtful/ critical about, and skillful in analyzing, representations of health and illness, including your own.

In the capstone assignment, you will analyze a podcast episode about serious illness and articulate your interpretation of it, drawing on learning from the course. Working with your peers you will create a presentation to share a collective analysis and interpretation of the representation.

Course Objectives

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

- 1. Explain the significance of metaphors and images in representations of health and illness, and demonstrate a capacity to analyze metaphors;
- 2. Demonstrate a capacity to engage with poetry and visual artworks on illness and aging themes;
- 3. Summarize and synthesize a range of critical social science research about illness representations;
- 4. Apply social science analyses (concepts, theories, insights, arguments from the course literature) to representations of illness and related issues; and
- 5. Present a persuasive analysis and evaluation of a public representation of illness.

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. You will engage with academic articles as well as poems, artworks and podcasts. We will have opportunities to learn from one another through discussion and group activities.

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 <u>due by 9am on the day before the class at which they are discussed</u> (for example, if you have signed up for a reading by Radley that we'll discuss in class on Thursday January 26, your written summary is due by 9am on Wednesday January 25). The in-class component is not graded.

Assignment 2: Response paper. Respond to and analyze a poem/ artwork with reference to one course reading, 20%, due February 16.

Assignment 3: Capstone assignment: Analysis of an episode of <u>The Waiting Room Revolution</u> podcast; presentation of key themes from your analysis; and evaluation of your own and peers' presentations.

- a) Analytic paper 35%, due on March 23
- b) Presentation 20%, due on March 30 or April 6
- c) Evaluation of your own and peers' presentations 5%, due on April 13

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 <u>one or two</u> of the author's key concepts, insights or arguments
- A discussion of the 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 3.

Assignment 2: Response paper (20%), Due February 16. Respond to and analyze a poem/ artwork with reference to one course reading. Length: 5 to 6 double-spaced pages.

Choose among the poems and artworks available on Avenue. Analyze the poem/ artwork with reference to one course reading (a different reading than you used for Assignment 1, selected from week 2, 3 or 4); no other sources should be used. This assignment links with course objectives 1 and 2.

Your paper should include:

- Your initial responses to the artwork/ poem. What did you notice, what struck you about it?
 (about 1 page)
- A summary of key concepts, insights or arguments from the course reading (about 1 page)
- A consideration of these concepts/ insights/ arguments from the reading, in relation to this artwork or poem. How is the reading relevant to this artwork/ poem? What can you learn about the art/ poem from thinking about it with the reading?
- A discussion about how the course reading changed your own initial response to the artwork / poem, or how the artwork/ poem changed your analysis of the reading (about 1 page)

Assignment 3: Capstone assignment: This assignment has three components: a) A paper analyzing an episode of <u>The Waiting Room Revolution</u> podcast; b) a group presentation about the podcast episode and c) an evaluation of your own and peers' presentations. *Sign up on Avenue to Learn for the episode you'll focus on.*

a) Analytic paper (35%), Due March 23

<u>The Waiting Room Revolution</u> podcast deals with many of the themes we have discussed in this course: serious illness, disability, aging, informal care, healthcare, information, professional-patient relationships, self-advocacy, self-management, and more. In this analytic paper, you will demonstrate your capacity to identify and critically analyze illness-related representations. *This assignment links with course objectives 1, 3 and 4*.

Length: 8 to 9 double-spaced pages. Use at least 5 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:

- Your initial response to the podcast episode (about half a page)
- An outline of the key concepts, insights and arguments from your selected readings, that you plan to apply to this podcast episode (about 1.5 pages)
- Identify the representation(s) that you intend to analyze (no more than 3, to allow for depth)
- An analysis of the representation(s) using the insights/ concepts/ arguments from the readings. What insights do you have about the representation(s) in the podcast, by thinking about them with these readings? (Most of your paper should focus here. Use specific examples from the podcast to support your analysis)
- An assessment of the value of this podcast episode to its intended audience, in light of your initial response and the readings (about 1 page)

b) Presentation (20%), Due March 30 OR April 6: You will work in groups, based on the podcast episode you analyzed. The form of your presentation is up to you: a PowerPoint, a debate, a mock interview (live or pre-recorded), clips from the podcast... feel free to be creative. You will have class time to meet as a group and prepare your presentation. This assignment links with course objectives 1 and 5.

Groups will present for about a half hour total, including time for engagement with your audience.

- Describe the podcast episode
- Present your reflections on, and analysis of, the podcast episode. You can draw on:
 - the initial responses group members had to the episode (based on learning in other courses, (volunteer) work, life experience or observations, etc.)
 - o concepts / insights/ arguments from course readings
 - your insights about the representations in the podcast from having done the written assignment, and from having discussed your insights with your group
- Offer an endorsement or warning (or both) about the podcast to people living with serious illness, grounded in your analysis
- c) Evaluation of your own and peers' presentations (5%), Due April 13: 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.

Weekly Course Schedule and Required Readings

All classes in person unless otherwise noted

Week 1: January 12 – Introductions, objectives & design of the course

Week 2: January 19 – Re-presenting illness and disability

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

Bérubé, Michael. 2015. "Representation." In *Keywords for Disability Studies*, eds. D. Adams, R., Reiss, B., & Serlin, D. NYU Press, 151–55.

Fudge Schormans, A. (2010). Epilogues and prefaces: Research and social work and people with intellectual disabilities. *Australian Social Work,* 63(1), 51-66.

Kempner, J. (2006). Gendering the migraine market: do representations of illness matter? *Social Science & Medicine*, *63*(8), 1986-1997.

Week 3: January 26 – Responding to poetry workshop ON ZOOM

Guest workshop with Ronna Bloom

Readings:

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Radley, A. (2009). 'Making Present' for Others: the art of witness. Chapter 3 (pp. 79 – 110) in *Works of illness: Narrative, picturing and the social response to serious disease*. London, InkerMen Press.

Radley, A. (2009). Illness Activism: making visible, finding a voice. Chapter 2 (pp. 43 – 78) in *Works of illness: Narrative, picturing and the social response to serious disease*. London, InkerMen Press.

Week 4: February 2 – Illness, healthcare and metaphor

Readings:

Lakoff, G., & Johnson, M. (1980). Concepts We Live By (chapter 1) and The Systematicity of Metaphorical Concepts (chapter 2). In *Metaphors We Live By* (p. 3-6 and 7 - 9). Chicago: University of Chicago Press.

Gordon, E. J., & Daugherty, C. K. (2003). 'Hitting You Over the Head': Oncologists' Disclosure of Prognosis to Advanced Cancer Patients. *Bioethics*, 17, 142 - 168.

Carger, Elizabeth. 2010. "Thinking in Pictures: The Deep Metaphors That Drive How Politicians See Health Disparities" (p. 13 – 20). Appendix A in *A New Way to Talk about the Social Determinants of Health*, edited by the Robert Wood Johnson Foundation. Princeton, NJ: Robert Wood Johnson Foundation www.rwjf.org/files/research/vpmessageguide20101029.pdf

Westen, Drew. 2010. "Changing Our Frame of Mind: The Role of the Mind, Brain and Emotion in Developing Messages," (p. 21 – 35). Appendix B in *A New Way to Talk about the Social Determinants of Health*, edited by the Robert Wood Johnson Foundation. Princeton, NJ: Robert Wood Johnson Foundation www.rwjf.org/files/research/vpmessageguide20101029.pdf.

Week 5: February 9 – Representations of *health information*

Readings:

Nelson, J., & Macias, T. (2008). Living with a White Disease: Women of Colour & Their Engagement with Breast Cancer Information. *Women's Health and Urban Life*, 7(1), 20–39.

Barnes, M., & Henwood, F. (2015). Inform with care: Ethics and information in care for people with dementia. *Ethics and Social Welfare*, 9(2), 147–163.

Week 6: February 16 – Representations of *healthy aging*

Readings:

Harris, R., Wathen, C. N., MacGregor, J. C. D., Dennhardt, S., Naimi, A., & Ellis, K. S. (2016). "Blaming the Flowers for Wilting": Idealized Aging in a Health Charity Video. *Qualitative Health Research*, 26(3), 377–386.

Response Paper due

Week 7: February 23 – Reading Week; no class

Week 8: March 2 – Representations of autonomy & care, in/dependence and self-management

Readings:

Lewis, S., Kenny, K., Broom, A., Kirby, E., & Boyle, F. (2021). The social meanings of choice in living-with advanced breast cancer. *Social Science & Medicine*, 280, 114047, 1-8.

Struhkamp, R., Mol, A., & Swierstra, T. (2009). Dealing with in/dependence: doctoring in physical rehabilitation practice. *Science, technology, & human values*, 34(1), 55-76.

Kendall, E., & Rogers, A. (2007). Extinguishing the social?: state sponsored self-care policy and the Chronic Disease Self-management Programme. *Disability & Society*, 22(2), 129–143.

For a Canadian example of a program like the one described by Kendall and Rogers, see the <u>Online Self-Management Program of Ontario</u>

Week 9: March 9 – Representations in *health policy*

Readings:

Pholi, K., Black, D., & Richards, C. (2009). Is 'Close the Gap' a useful approach to improving the health and wellbeing of Indigenous Australians? *Australian Review of Public Affairs*, 9(2), 1–13.

Russell, J., Greenhalgh, T., Byrne, E., & McDonnell, J. (2008). Recognizing rhetoric in health care policy analysis. *Journal of Health Services Research and Policy*, 13(1), 40–46.

Week 10: March 16 – Review key course themes & discuss presentations ON ZOOM

This week you will have your initial meeting with me and your presentation working groups about your presentations.

Week 11: March 23 – Meetings with working groups to prepare presentation

Analytic paper due

Week 12: March 30 – Presentations

Waiting Room Revolution episodes 2, 3, 4, 5.

Week 13: April 6 – Presentations & course wrap up

Waiting Room Revolution episodes 6, 7, 8, 9.

Written evaluation of your own and peers' presentations due on April 13

Course Policies

Submission of Assignments

- Written assignments must be submitted in Microsoft Word (PDFs will not be accepted)
 - o 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:

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MARK	GRADE
90-100	A+
85-90	Α
80-84	A-
77-79	B+
73-76	В
70-72	B-
67-69	C+
63-66	С
60-62	C-
57-59	D+
53-56	D
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 <u>Academic Integrity Policy</u>, 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 <u>Code of Student Rights & Responsibilities</u> (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 <u>Student Accessibility Services</u> (SAS) at 905-525-9140 ext. 28652 or <u>sas@mcmaster.ca</u> to make arrangements with a Program Coordinator. For further information, consult McMaster University's <u>Academic Accommodation of Students with Disabilities</u> 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 <u>RISO</u> 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.