“Disease” refers to the abnormalities of the structure and function of organs and systems that clinicians diagnose. To diagnose and treat the disease alone is to reduce the patient to a very complex machine, or to a biological “puzzle” to be figured out. Disease is experienced as “illness” because it interweaves with meaning systems, social networks, hopes, emotions, spirituality, and values. Illness refers to the overall subjective response of the patient to being sick. As a technical term in medical anthropology, “illness” refers to the psychological, social and cultural reaction to the disease process. How did I become ill? Why me? Why now? What does this mean? What will people think? How will it affect my hopes and plans for the future? Am I being punished? What can I hope for now? Where is “spirituality” in all this? What decisions will I need to make? Can I cope with this? What about my family? Am I ready to die? Why am I suffering?

The care of the patient is both a science and an art. It is on the one hand the competent application of science and the mastery of technical skill sets; on the other hand it is the art of being attentively present to the patient in all the complexity and meaning of his or her illness experience. In general, being present to the patient in their illness facilitates patient well-being, security, treatment adherence, and healing itself. Empathic and compassionate care is part of this art. What is empathic care? What does “compassion” add to empathy? Can these assets be taught? How do role modeling and narrative medicine fit in? Where does the idea of the “wounded healer” fit in? What does it mean to be an attentive listener? How does the clinician demonstrate respect for patient hope? What do we know about how empathy and hope influence physiology and adherence to treatment?

READINGS

The books below should all be ordered via Amazon. They are written by experienced clinicians (Carel is the exception) who have articulated in powerful ways the art of clinical care with attention to the subjective dimensions of illness.

All articles will be provided in a weekly email from Dr. Post as attachments.

Required Books


**2016 COURSE OUTLINE (Mondays)**

**August 29, 2016**

**Topic: What is “Illness”**

One way to get this distinction clear is to read some classic illness narratives written by patients who have felt that they were treated impersonally, in purely biological and objective terms. They may have felt more like diagnostic puzzles than “persons” grappling with all the ways in which a disease can affect their lives with respect to meaning, relationship, coping, anxiety, mortality, hope, suffering, spirituality, and the like.

In this session we will also touch on the model for the Center for Medical Humanities, Compassionate Care, and Bioethics, and why it is unique.

**Required Readings:**


Havi Carel’s *Illness,* Introduction


Post, et al., The Stony Brook Model (this is posted on the first page of the Center website)
September 5 (Labor Day - no class)

While we have no class, over Labor Day weekend please read Carel’s Illness, chapter 1 & 2.

September 12

Topic: Routine Care, Empathic Care & Compassionate Care

Care as an external activity is grounded in the expectations of the clinical environment in a very task-oriented sense, and can be disconnected from the underpinnings of empathic concern. We propose a model in which compassion is not redundant with care, but a special modulation and intensification of it under conditions of suffering as follows: CARE ⇒ COGNITIVE EMPATHY ⇒ AFFECTIVE EMPATHY ⇒ COMPASSIONATE CARE.

Required Readings


William Osler, “Eaquanimitas”


Optional Readings

Beth A. Lown, Julie Rosen and John Marttila, “An Agenda For Improving Compassionate Care: A Survey Shows About Half of Patients Say Such Care is Missing.” Health Affairs, Vol. 30(9), 2011, pp. 1772-1778.

Topic: Who Benefits from Empathic and Compassionate Care?

Who benefits from compassionate care? Patients of course, but also clinicians and institutions.
Required Readings


September 19 (Dr. Roess)

**Topic: Listening & Assisted Suicide in Relation to Empathic Care**

“We do not believe in ourselves until someone reveals that something deep inside us is valuable, worth listening to, worthy of our trust, sacred to our touch.”
e.e. cummings

One of the most important expressions of compassionate care is attentive listening. We begin with an exercise in listening to a middle-aged man with MS in a video entitled *A Request for Assisted Suicide*. Is the “listening” involved an example of “detached concern”? What do you think of this request and of assisted suicide for patients with chronic neurodegenerative diseases?

Required Readings

Anton Checkhov, “Misery”


September 26

Readings

Finish up Havi Carel’s *Illness*, Chapters 2 – 5.

Due: 4-page essay reflection on the art of listening in the video *A Request for Assisted Suicide* (contributes 10% to final grade)

October 3

Topic: Illness and the Wounded Healer

Sometimes healthcare professionals only realize the importance of healing relationships when they become ill themselves, and are suddenly wearing the shoes of a patient. The psychoanalyst Carl Jung referred to the “wounded healer” who, through his or her own illness experience, is able to heal others through increased empathy. Few ideas are new. The ancient Roman philosopher Seneca wrote, “The wounded doctor heals best.” Falling ill and seeing the other side of the coin can be tremendously creative and transforming. Perhaps it is the “wounded healer” who can most be trusted to carve out a space in daily practice where connection and personal care receive their rightful place of honor even in environments that do not nurture these things. Yet the idea of being a “wounded healer” is somewhat controversial, especially in psychiatry.

Required Readings


Optional Readings


October 10

Topic: Illness and the Wounded Healer (2) – “The Doctor”

An excellent account of compassionate transformation comes from a book entitled *A Taste of My Own Medicine*, written by Ed Rosenbaum about Jack MacKee, MD. The author, a successful surgeon whose bedside manner is unkind and discourteous, is too busy to show personal concern toward his patients or his family. One night he coughs blood and is soon diagnosed with throat cancer. During protracted treatment, he befriends June Ellis, a fellow cancer patient who eventually dies. Jack’s cancer is cured, but the experience transforms his practice as he begins to teach medical interns the importance of
compassion and personal concern for patients in making them better doctors. We will view and discuss *The Doctor*, a movie based on MacKee’s book.

**Required Readings**

Robert Klitzman, *When Doctors Become Patients*, PARTS II & III

**October 17**

**Topic: Hope in Clinical Ethics**

Any caring professional must be a minister to hope. From the early 19\textsuperscript{th} century American Codes of Medical Ethics have emphasized the physician’s responsibility to sustain hope in patients. This is a perennial aspect of the “art of medicine.” Thomas Percival famously described the physician as “minister of hope and comfort to the sick.” How can professionals respect the dynamic of hope in patients? Harvard hematologist-oncologist Jerome Groopman, in his *The Anatomy of Hope* (2004), writes that hope is “the elevated feeling we experience when we see – in the mind’s eye – a path to a better future. Hope acknowledges the significant obstacles and pitfalls along the path. True hope has no room for delusion” (p. xivi). Without endorsing the exaggerated popular literature on hope and healing, Groopman notes that belief and expectation, two aspects of hope, are fundamental to the placebo effect, and activate brain circuits that release endorphins (natural opiates) and dopamine (a feel good chemical). A careful assessment of the existing research compels Groopman to conclude, “Hope, I have come to believe, is as vital to our lives as the very oxygen that we breathe” (p. 208). Current researchers focus on the neurobiology of optimism, psychological resilience, physical health and optimism, and the promotion of optimism and hope. Significant NIH-funded investigations link hope to longevity, enhanced wound healing, stress reduction, dopamine release, and endorphin release. Hope for patients is about the uncertain expectations around which they constitute their lives in time of serious diagnosis or illness. The skilled clinician must handle patient hope empathically, and be able to redirect hope from one goal to another – e.g., from cure of cancer to the comfort care of hospice, from an earlier vision of a flourishing life to a modified vision, etc.

Skilled healers, aware of how the emotion of hope can make or break a patient, must be builders of hope, even while facilitating a shift in patient goals.

*Why is hope important in patient care, and what does it mean to “manage” hope effectively?*

*Is there such a thing as false hope in patients?*

*What might be some biological mechanisms by which hope impacts physical health?*

*Where does patient hope come from? Individual experience, special relationships, communities, spiritualities, religion, the physician?*

*Is it justifiable to disclose diagnosis, but not a clear prognosis, in order to sustain hope?*

*What is the difference between optimism and hope? (Many people consider optimism a dispositional trait, while they consider hope a virtue achieved through hardships.)*
Required Readings

Jerome Groopman, MD, The Anatomy of Hope: How People Prevail in the Face of Illness (all chapters)

October 24

Topic: Hope in Two Contexts: The Deeply Forgetful and Persons with Quadriplegia

Hope in the context of individuals with dementia and their carers is defined in this paper in terms of an “openness to surprises” with regard to indicators of continuing self-identity in the individual with dementia, active agency with regard to carers and affected individuals to the extent possible, and the affirmation of a theory of personhood and related moral status that breaks through the limits and prejudices of “hypercognitive values.” We will discuss the moral perspective on the deeply forgetful, a theory of inclusive moral standing, and various ethical issues that arise at the practical level.

Videos

Music & Memory

Required Readings


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The Cases of Brooke Ellison and Christina Symanski touch on hope in the context of persons with Quadriplegia. Here hope has more to have more to do with achieving specific goals.

October 31

Topic: Narrative Medicine

The “narrative medicine” movement has been quite influential in healthcare over the past twenty years as a method of encouraging and promoting empathic skills in healthcare
providers. Our task in this session is to understand what “narrative medicine” is, and assess its usefulness.

Required Readings

Rita Charon, *Narrative Medicine: Honoring the Stories of Illness.* PARTS I & II

[November 1 (voluntary) 4-5:30 p.m.]

Grand Rounds on empathy and outcomes with Dr. Mohammadreza Hojat.

November 7

**Topic: Narrative Medicine (2)**

Here we take a deeper look at narrative medicine with Charon and Halpern.

Required Readings

Rita Charon, *Narrative Medicine: Honoring the Stories of Illness.* PARTS III & IV

Jodi Halpern, *From Detached Concern to Empathy* (finish up).

November 14 & 21

**Student Presentations of Rough Drafts for Their Papers with Peer Feedback (5-7 Powerpoint Slides)**

1. Big Question and Significance & Beneficiaries
2. Thesis and Approach
3. Outline with Clear Headings and Subheadings
4. Conclusions and New Questions Raised
5. Five References Beyond Assigned Readings and Selection Process

These should be based on a developed draft, with 5 to 7 PowerPoint slides. Present for about 15 minutes and take feedback from peers and faculty for about 15 minutes. Peer feedback is vital. This contributes **10% to your final grade.**
November 28

Empathy in Decline?

Readings


GRADING AND ATTENDANCE

Active participation in class, including attendance, contributes 10% to the final grade (about 1% per class).

4-page essay reflation in response to A Request for Assisted Suicide contributes 10% to final grade.

Big Questions (10%)

Students come to class each session with a hard copy of a Big Question they have about the readings for the day. This should be handed into the instructor at the beginning of class. It should simply state:
1. A Big Question, usually something that may not have been clearly or thoroughly or rightly considered in readings that were assigned for the session, or perhaps entirely ignored. This should be in the form of a very clearly stated single sentence not more than several lines long.
2. Why your Big Question is significant.
3. What you think the answer to your Big Question is, and why you might be wrong.
4. What additional Big Question your answer raises.

Your Big Questions need to be carefully formulated, but never longer than a half page double-spaced with a single sentence only for each of items 1, 2, 3 & 4. (Four sentences total). Each of you will be called on sporadically at least twice to facilitate a conversation around your Big Question. Your Big Questions will contribute 10% to the final grade.

Student PowerPoint presentations of rough drafts for their papers will contribute 10% to the final grade.

Students will also write a 12- to 14- page final research paper (including a page of references in alphabetical order per APA reference style) due December 11. (60% of grade). It is fine to use articles and books assigned in the course, but students should also use at least 6 carefully self-selected outside articles from journal sources (these can be on-line journals or hard-copy journals). Of course if you wish, also draw on full books of relevance from outside the course readings, although this is not necessary. The paper will
contribute 60% to the final grade. Students will present their work in class in the month of November.

Use APA format in all papers.

**Structure of Final Paper**

**Writing Your Final Paper**

1. **Introduction**

A successful thesis-driven piece of scholarship will always begin with a very clear big question replete with careful definition of terms. Then state your answer to the question in a clear thesis statement. This is best placed in the first paragraph of the paper. You will need to work on this and revise as needed, but do not ever lose sight of your thesis statement. You do not want to veer off course, because the rest of the paper is an argument supporting your thesis. Every sentence in your paper ought to be connected to your thesis in some way. It might help introduce your audience to the nuances of the topic you are discussing so that they will understand how your thesis differs from claims made by others.

A good paper usually includes a second paragraph that discusses in brief why the question and thesis are important. Is the thesis important for solving a major problem? Is it innovative? Who might be impacted by your paper? What is your audience?

A third paragraph usually describes how you are planning to structure the paper, and some mention of key sources. It is a good idea to ask about every topic or point in your paper, “how will adding this information help my reader understand my thesis?” If you cannot answer this question, then the information is probably better left out. For example, “Although pre-emptive assisted suicide for the individuals with dementia is not possible in Oregon or Washington, it should be, as it currently is in the Netherlands. I will describe the differences in these approaches, and make a normative ethical argument in favor of the practice as it has evolved in the Netherlands.”

Or/

“I shall contend that under certain urgent conditions, the forced C-section can be justified. I will cover the history of debate over this issue, the philosophical and ethical positions of relevance, and some of the case law involved.”

Or/

“Selective abortion for reasons of gender alone is morally unacceptable. I will examine the history of this practice, and arguments for and against this practice drawing on gender studies, ethics, and policy. In addition to providing a balanced exposition of these arguments, I will contend that the practice is unacceptable for reasons x, y, and z.”

The outline and headings (i.e., the organization of the paper) should be designed to move your thesis forward in a constructive way. Outline your thoughts before you begin to write.
2. Main Body

Be certain to use headings well. Headings are a roadmap for the reader. They are like signposts on the highway. They should not be complex or long, so choose a few effective words. Subheadings can sometimes also be quite helpful. **Headings** should be in bold, and **subheadings** should be in italics.

Develop your ideas and use transitions to link the major strands of your exposition. Remember, though your interlocutors may be able to follow certain moves you make because they are familiar with the literature the public will not. Make sure that an intelligent person who is not an expert in your topic could easily follow your argument. If you jump around without an indication of why, it will be extremely difficult for your reader to follow you.

When agreeing or disagreeing with an author don’t merely state that you agree or disagree but make a case for why you do. Clearly identify the views of the author whom you will be discussing. Highlight important distinctions and concepts of which the author makes use. It is essential to use citations when doing this. This will indicate to your interlocutors precisely the point at which you disagree, while introducing the public to an important aspect of the conversation you are engaging in and of which they may not be aware.

If you plan to disagree with an author’s position then raise at least one objection that you would advance against the view as you understand it. While the public may be interested in simply learning alternative views on the matter, your interlocutors will want to know why your position differs from those already accepted. If you plan to agree with the author’s position, then be sure to explain why it is important that you agree. Others may have raised objections to the position with which you agree. Explain these objections and then explain how it is that the position you endorse overcomes them. Once again, proper citation is essential to this aspect of your paper.

When in doubt, break up long sentences and split up long paragraphs. Semi-colons are hard to use well, so avoid them unless you are sure of your grammar, and avoid page-long paragraphs that beg to be broken up into two or three.

Be care to select quoted phrases, sentences, or segments of several lines with scholarly precision. Only quote the material that makes your point best, and always reference it. There is no need to quote excessively, and you should help the reader understand what you want them to get from a block quote, rather than leave it dangling at the end of a paragraph. We will talk about quotes and style in class. Block quotes are okay if used wisely, but they should rarely, if ever, exceed five to ten lines.

So often, a student really gets clear on their thesis in the final and concluding paragraph of the paper. Therefore, it can be very useful to try placing that final paragraph up at the front of the paper as you go through drafts, and incorporate it into the thesis section. Then write a second conclusion in a later draft.
Conclusions
Conclude with a summary of your paper. Also, be sure to point to another Big Question (or two) that your paper has not answered, but that seems now to be the next one you would want to see answer in your topic area (and why).

From Official Stony Brook University Policy:
Statements required to appear in all syllabi on the Stony Brook campus:

Americans with Disabilities Act:
If you have a physical, psychological, medical or learning disability that may impact your course work, please contact Disability Support Services, ECC (Educational Communications Center) Building, room128, (631) 632-6748. They will determine with you what accommodations, if any, are necessary and appropriate. All information and documentation

Academic Integrity:
Each student must pursue his or her academic goals honestly and be personally accountable for all submitted work. Representing another person's work as your own is always wrong. Faculty are required to report and suspected instances of academic dishonesty to the Academic Judiciary. Faculty in the Health Sciences Center (Schools of Health Technology & Management, Nursing, Social Welfare, Dental Medicine) and School of Medicine are required to follow their school-specific procedures. For more comprehensive information on academic integrity, including categories of academic dishonesty, please refer to the academic judiciary website at http://www.stonybrook.edu/uaa/academicjudiciary/

Critical Incident Management:
Stony Brook University expects students to respect the rights, privileges, and property of other people. Faculty are required to report to the Office of Judicial Affairs any disruptive behavior that interrupts their ability to teach, compromises the safety of the learning environment, or inhibits students' ability to learn. Faculty in the HSC Schools and School of Medicine are required to follow their school-specific procedures.