8-19-2021 Final syllabus
HCB501
Compassionate Care, Medical Humanities, and the Illness Experience
Instructors:
Stephen G. Post, PhD & Jeffrey Trilling, MD
Semester: Fall 2021
Schedule: Mondays, 6-8:30 pm
Location: FPPM Conference room 067
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COMPASSIONATE CARE, MEDICAL HUMANITIES & THE ILLNESS EXPERIENCE

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 the subjective 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 even healing itself. Kindness is a relatively uncomplicated mode of acknowledging patients (as Dr. Trilling puts it, a “gentle curiosity”), whereas empathy requires focused listening and understanding, clarification, and some degree of affective resonance. Compassion is an action to alleviate suffering as shaped by empathy in the context of suffering. Can these assets be taught? How do role modeling and narrative medicine fit in? Where does the idea of the “wounded healer” enter 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 patient physiology and adherence to treatment? How does a compassionate practice contribute to clinician meaning, well-being, and professional gratification?

*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. *Illness* refers to how disease is subjectively experienced and interpreted by the patient who has 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. Big Questions arise: 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?
READINGS

The books below should all be ordered via Amazon. They are written by experienced clinicians 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 or Dr. Trilling as attachments.

4 Required Inexpensive Paperback Books (Purchase)
(These are all written by renowned experienced clinicians who have great wisdom.)


All assigned articles will be emailed to you as attachments weekly.

2021 COURSE OUTLINE (Mondays)
PART ONE

August 23, 2021
Facilitator: Post/Trilling
Topic 1: What Do We Mean By “Disease” and “Illness”? Where Does Culture Come In? What is Suffering? How Do We Diagnosis It?

What is a “disease”? What is a “syndrome” (hint- a cluster of related symptoms)? So we think of Alzheimer’s disease, for example, as causing the syndrome of dementia. Dementia can be caused by lots of other diseases (like syphilis/neurosylphilis, CTE, alcoholism, Parkinson’s disease, etc.). But then again, is Alzheimer’s really a disease at all, or “just” a natural part of growing old to which we would all succumb given enough years, as Dr. Alzheimer himself believed? This might explain why no one has found its
“cause” other than to associate it with aging itself. But wait, maybe aging is itself is a disease, as Arthur Caplan argues. At least is feels like one. Confused? By the way, the National Institute of Aging devotes half its budget to anti-aging research, suggesting that maybe aging is a disease? Diseases can be quite objective, but they also tend to be culturally and historically shaped. (You have just entered the area known as “philosophy of disease.”)

Can a normal psychological state come to be a psychiatric disorder, and at what point? Sadness is a normal human emotion is response to loss and disappointment, but this is not depression. Depression is “sadness for no reason.” But then again, sometimes sadness becomes so intense that is spills over into depression. Is autism a “flow state” in extreme? Is schizophrenia analogous thinking in extreme? We will have some things to say about “nosology” and evolutionary psychiatry.

Whatever the “disease,” it will be individually varied when experienced as an illness (with regard to interpretation and meaning). Eric Cassell writes that “disease is something an organ has; illness is something a man has.” Illness revolves around big questions: What has happened? Why has it happened? Why to me? Why now? What does it mean? What do I fear most? What are my hopes? How can I be resilient? What about my relationships? Is this a punishment? A blessing in disguise? In general, patients want to be treated as persons who experience an illness rather than as biological and diagnostic puzzles to be figured out (House).

*What is Suffering? How do we Diagnosis it*? Try to come up with your definition of suffering and how you might diagnosis is.

*Before Class Video:*  
https://www.youtube.com/watch?v=cDDWvj_q-o8  
(Empathy: The Human Connection to Patient Care)

*Readings:*  


August 30
Facilitators: Post/Trilling
Topic 2: Suffering and Hope in an Illness Narrative

An illness narrative elegantly written by a dying physician, *When Breath Becomes Air* was deservedly a best-seller in 2016. It seemed to touch everyone who reads it. Pay special attention to themes such as suffering, hope, love, creativity, meaning, perseverance, grit, and resilience.

*Readings:*

(September 6 Labor Day Vacation: But Start Reading for September 13th!)

September 13
Facilitator: Post/Trilling
Topic 3: HUMILITY, Routine Care, Kindness and Curiosity, Empathic Care & Compassionate Care; Listening

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. But it is the case, as Coulehan argues, that without humility there is no care.

*In Class Videos:*
https://www.youtube.com/watch?v=7s22HX18wDY&app=desktop

*Readings:*

John L. Coulehan, Frederic W. Platt, Barry Egener, Richard Frankel, Chen-Tan Lin, Beth Lown, William H. Salazar, “‘Let Me See If I Have This Right…’: Words That Help Build Empathy,” *Annals of Internal Medicine,* Vol. 135(3), 2001, pp. 221-227. (But is it about more than words?)

Reflection Essay One Due (10%) **4-page essay on When Breath Becomes Air** with an emphasis on the experience of illness in relation to suffering and hope

**September 20**

**Facilitator:** Post/Trilling

**Topic 4: Who Benefits from Empathic and Compassionate Care?**

Who benefits from compassionate care?

**Readings**


September 27  
Facilitator: Post/Trilling  
Topic 5: 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.

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 discuss segments of *The Doctor*, a movie based on MacKee’s book.

**Before Class Video:**  
Watch “The Doctor” starring William Hurt

**Readings:**  


**Reflection Essay Two Due (10%) 4-page essay on the nature of humility in relation to compassionate care**

October 4  
Facilitator: Post/Trilling  
Topic 6: Hope in Clinical Ethics
Any caring professional must be a minister to hope. From the early 19th 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 feelgood 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.

*Is there such a thing as false hope in patients?*
*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.)*
*Does a state of hopelessness have any bearing on respect for decisional capacity?*
*How does hope vary under differing illness conditions?*

*Pre-class Video (6 minutes: https://www.youtube.com/watch?v=5FWn4JB2YLU*

*Readings*


October 18
Facilitator: Jeffrey Trilling
Topic: Placing the Patient-Doctor Relationship in Context

The patient-doctor relationship is a conduit for information flow. When the relationship is strong and empathic, information is more readily ascertained and passed between the patient-doctor dyad. The biomedical and psychosocial problems at the root of suffering may become more easily recognized, delineated, and resolved. But, as in any relationship, conflict may arise, resulting in impasse, impeding the flow of information between patient and doctor; thwarting relationship’s purpose of compassion itself… the alleviation of suffering.

This session addresses the relevance of the patient-doctor relationship within a meaning-centered model of illness, one in which the experience and meanings of illness are at the center of clinical practice. In this session we will ponder the definition and purpose of the patient-doctor relationship, particularly, how it relates to primary care. We will discuss some of the attributes brought into this relationship by each member of the patient/doctor dyad. Some of the other “big questions” to be addressed are, “What is the purpose of the practice of medicine?”; “What is it that the patient is asking for when h/she enters this relationship?”; “What is the physician’s area of expertise?”; “What does the patient bring to this relationship?” We will introduce the importance of context, the circumstances in which a problem occurs… including the mistakes we make when context is ignored. We will be introducing and learning to apply such concepts as straight-linear logic, first-order and second-order change. Ultimately, this section invites the participant to appraise the need for a contextual, biopsychosocial approach to primary care problem-solving that addresses such reciprocity inherent within and between psychosocial and biomedical systems.

Readings


Reflection Essay Three Due (10%) 4-page essay on the wounded healer, pros and cons

October 25
Facilitator: Jeffrey Trilling
Topic: The Significance of the Patient’s Story

The interpretation of illness meanings and the managing of deeply felt emotions are clinically relevant, and should not be dismissed as peripheral tasks for physicians.

“…They constitute, rather, the point of medicine. These are the activities with which the practitioner should be engaged. The failure to address these issues is a fundamental flaw in the work of doctoring. It is in this very particular sense, then, that we can say of contemporary biomedicine: in spite of remarkable progress in the control of disease, it has turned its back on the purpose of medicine.” Arthur Kleinman

Contemporary biomedicine pays little attention to the interpretation of illness meanings and takes the stance that the management of deeply felt emotions are clinically irrelevant or at best peripheral tasks for physicians. In session, participants will examine their own biases/opinions on this subject asking themselves such “big questions” as, “Does a physician’s “heartfelt” understanding help him/her grasp the patient’s human nature as it really is?; “Does sympathy play an important therapeutic role in medicine?”; “Can emotions provide reliable knowledge about reality?”; “What is the difference between a natural science and an applied science?”; “What good does it do if the physician is astute about diagnosing a disease and expert on how to treat it, if the patient does not follow through?”; When, if ever, do you stop trying to effect change in another person?”

Additionally, this session will propose the relevance of and raise awareness about the role personality differences between physician style and patient expectations play in the etiology of impasse.

Readings

Jodi Halpern, From Detached concern to Empathy. (complete all).

November 1
Facilitator: Jeffrey Trilling
Topic: Formulation of the Doctor-Patient Impasse

**Explanatory Models** and the **Consequences of Change** are the two major elements of the patient’s story or illness experience that underlie the patient’s **Perceptual Frame**. When the patient’s perceptual frame and that of the physician’s differ, an impasse may occur. An impasse, once established, can have its own consequences: 1. Patient nonadherence, with resultant ineffectual treatment plans; 2. Overutilization of medical services because of doctor shopping, resulting in multiple physician fees, fragmented care and repetitive testing… all of which increase the financial burden of the patient and society in general; 3. Physician fear of litigation and/or patient harm by omission, leading to emphasis on expensive and invasive high technologic procedures that have their own morbidity and mortality; and 4. Primary care physician “burn-out”; from… having tried “to please and pleased not”. While these consequences are not all-inclusive, they do paint a picture of a medical system gone wrong, whose characteristics are strikingly comparable to the one in which we practice today.

In this section, we will attempt to delineate some of the most common ways in which the doctor-patient impasse is formulated, keeping in mind that delineating a problem’s formulation is often the first step towards affecting its resolution. Participants will examine and discuss the “luggage” that we all carry with us wherever we go, in particular when physician and patient enter the examining room. Some of the “big questions” to consider: “What is the definition of perception?”; “How can perceptions of symptoms contribute to the formulation of impasse?”; “What are the consequences of the doctor-patient impasse?” Additionally this session will introduce new terminology such as Explanatory Model of Illness and the Consequences of Change, and how these concepts are our key to understanding the formulation of impasse.

**Readings:**


**Reflection Essay Four Due (10%) 4-page essay reflection on the wounded healer**

November 8
Facilitator: Jeffrey Trilling
Topic: Problem-solving the Doctor-Patient Impasse utilizing the Circle of Change
In this session, we will introduce the components of the structured, six-step, problem-solving technique that we call The Circle of Change, and be examining this problem-solving model’s utility in assessing, organizing, and implementing second-order change solutions in situations of impasse and conflict which may hinder diagnosis and treatment plans, as well as, contribute to counter-productive behavior. It is not a panacea for the management of illness, nor is it intended to replace the standard biomedical approach to treating disease processes. It does provide balance to the latter by providing a framework to guide the exploration of the psychosocial components of illness contributing to suffering; to delineate problem’s cause, and ultimately to aid in its resolution. But let me emphasize… it is a guide.

Readings

November 15
Facilitator: Jeffrey Trilling
Topic: Refining Our Approach

This section acknowledges that some of the concepts and terminology may be new to the participant, and it is an attempt, through stories, to review and clarify some of these definitions and their implications. It focuses on refining our approach; how to elicit the patient’s explanatory models by a more in-depth illustration of patient and physician illness attributions, fears, and hidden meanings that lie within the illness narrative. It guides the participant how to ask the right questions through open-ended and circular questioning to broaden context and move to the next meta-level to cogenerate new and more inclusive perceptual frames, utilizing the art of reframing and systemic hypothesis, for the patient as well as the physician. Again, the above definitions and concepts are brought to life and clarified through the use of clinical and non-clinical stories, because learning from them can be both efficient and enjoyable.

Readings:

Reflection Essay Five Due (10%) 4-page essay reflection on the Doctor-Patient Impasse

November 22
Topic: Student Presentations of Rough Drafts of their Papers for Peer Feedback

Prepare 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. Seven References beyond Assigned Readings and Selection Process

These should be based on a developed draft. Present for about 15 minutes and take feedback from peers and faculty for about 10 minutes. Peer feedback is vital. This contributes 10% to your final grade.

November 29
Student Presentations continued: responses to critique

December 6 Writing Time
Research Papers due December 14 (40% of final grade)

GRADING AND ATTENDANCE

Active participation in class, including attendance

Big Questions

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, in a brief 3 sentences in bullet point style:
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. Lead brief discussion on what the answer to the Big Question is.

Your Big Questions need to be carefully formulated, double-spaced with a single sentence only for each of items 1, 2, & 3.

Grading:

- Reflection Essays (5 x 10 = 50%)
- Student Presentations of Rough Drafts of their Papers (10%)
- December 10: Final Research Paper Due (40%)
Research Paper
Students will also write a 10-page (max) final research paper (including a page of references in alphabetical order per APA reference style) due December 10. (40% of grade). It is fine to focus on articles and books assigned in the course, but students should also use at least 76 carefully self-selected outside articles from journal sources (these can be on-line journals or hard-copy journals).
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?”

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.

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.

Student Accessibility Support Center Statement
If you have a physical, psychological, medical, or learning disability that may impact your course work, please contact the Student Accessibility Support Center, 128 ECC Building, (631) 632-6748, or at sasc@stonybrook.edu. They will determine with you what accommodations are necessary and appropriate. All information and documentation is confidential. Students who require assistance during emergency evacuation are encouraged to discuss their needs with their professors and the Student Accessibility Support Center. For procedures and information go to the following website: https://ehs.stonybrook.edu/programs/fire-safety/emergency-evacuation/evacuation-guide-people-physical-disabilities and search Fire Safety and Evacuation and Disabilities.