HCB501
Compassionate Care, Medical Humanities, and the Illness Experience
Instructors:
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Semester: Fall 2018
Schedule: Mondays, 6-8:20 pm
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COMPASSIONATE CARE, MEDICAL HUMANITIES & THE ILLNESS EXPERIENCE

“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. 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?

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? How does a compassionate practice contribute to clinician meaning, well-being, and professional gratification?

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 Books (Purchase)


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

2018 COURSE OUTLINE (Mondays)

**August 27, 2018**

**Facilitator:** SG Post

**Topic:** “Disease,” “Syndrome,” “Illness”? Where Does Culture Come In?

A “disease” causes a “syndrome,” or cluster of related symptoms. So we think of Alzheimer’s disease, for example, as causing dementia. Dementia can be caused by lots of other diseases (like syphilis, CTE, alcoholism, etc.). But then again, is Alzheimer’s really a disease, or a natural part of growing old to which we would all succumb given enough years (as Dr. Alzheimer himself believed)? But wait, maybe aging is a disease (Arthur Caplan)? At least is feels like a syndrome. Confused?

The experience of a disease is culturally and individually varied 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 relationships? Is this a punishment?

In general, patients want to be treated as persons who experience an illness rather than as biological slabs and diagnostic puzzles to be figured out. They do not wish to be over-objectified. Illness narratives are useful for getting at subjective experience.
In Class Video:
https://www.youtube.com/watch?v=cDDWvj_q-o8
(Empathy: The Human Connection to Patient Care)

Readings:


September 3 (Labor Day - no class in session but a meaningful reading assignment)
Topic: 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.

Readings:
While we do not have a class this evening due to Labor Day, read all of Paul Kalanith, *When Breath Becomes Air*, “Foreword” by Abraham Verghese. New York: Random House (2016).

And of course, read materials for September 10.

September 10
Facilitator: SG Post
Topic: Routine Care, 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.

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

“The Sparrow”

Readings:

William Osler, “Eaquanimitas”


Listening 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

Readings


September 17
Facilitator: SG Post
Topic: Who Benefits from Empathic and Compassionate Care?

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

Readings


September 24  
Facilitator: SG Post  
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.

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

Before Class Video:
“The Doctor” with William Hurt

Readings:

October 1  
Facilitator: SG Post  
Topic: 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 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.  
*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.)*

In Class Video:  
We begin with an exercise in listening to a middle-aged man with MS in a video entitled *A Request for Assisted Suicide.* Where is “hope” found in this amazing interview with a man who requests PAS?

Readings  
Jerome Groopman, MD, *The Anatomy of Hope: How People Prevail in the*
*Face of Illness* (all chapters). Also, review *When Breath Becomes Air* with the theme of hope in mind.

**October 8**  
**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**


JS Trilling, Handouts from as yet unpublished text, *The Circle of Change: Problem-solving the Doctor-Patient Impasse in Primary Care*.
October 15  
Facilitators: SG Post, Jeffrey Trilling  
All Student In-Class Power Point Presentations (5 slides) of Preliminary Ideas for Papers (big question, thesis, approach, headings, at least 3 references) and feedback. (5 % of final grade)

October 22  
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 Halper. From Detached concern to Empathy. (complete all).
October 29  
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:


November 5
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 12
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:

November 19
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 26**
Student Presentations of Rough Drafts of their Papers for Peer Feedback

**December 3**
Topic: Film

**Research Papers due December 10 (50% of final grade)**

**GRADING AND ATTENDANCE**

**Active participation in class, including attendance (10%)**

**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:
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 paragraph, double-spaced with a **single sentence only** for each of items 1, 2, 3 & 4. (Four sentences total).

**Grading:**

October 8: Reflection Essay Due (15%) **5-page essay reflection** in response to *A Request for Assisted Suicide*

October 22: Reflection Essay Due (15%) **5-page essay reflection** on *The Doctor* and the wounded healer theme

October 15: 5-slide PP (5%)
November 19 & 26:  Student Presentations of Rough Drafts of their Papers for Peer Feedback (10%)

Final Research Paper (50%)

General Class Participation (5%)

**Research Paper**

Students will also write a 12-page final research paper (including a page of references in alphabetical order per APA reference style) **due December 10. (50% 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?”

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 documentatio

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.