"Cultural competence is most often invoked in relation to the increasingly diverse, multicultural composition of U.S. society and the challenges of caring for patients of black, Hispanic, or to a lesser extent, Asian origin. The term is applied particularly to settings in which there are conspicuous ethnic, racial and economic disparities in the quality of and access to health care. Strikingly, the concept does not usually encompass the distinctive cultural attributes of U.S. society that shape the attitudes and values of the country’s inhabitants—health care professionals and patients alike. There is, for example, a detectable "Americanness" in the optimistic belief in medical science and technology, in their limitless progress and promise, their vigorous application, and their power to "overcome" disease, that pervades our society and is pronounced in medical training. "...if you can’t see that your own culture has its own set of interests, emotions and biases, how can you expect to deal successfully with someone else’s culture?” [Fox, R. (September 29, 2005). Cultural competence and the culture of medicine. NEJM, 353(13), 1316]
INTRODUCTION

Welcome to *Ethical and Cultural Competence in the Health Professions (ECC)*! *ECC* is a new course, developed in the process of Georgetown’s ongoing initiative to reform its undergraduate medical curriculum. *ECC*’s content is an amalgam of “old” and “new” material and themes, synthesized here with the aims of:

- Introducing you to the rich complexities of the central relationship in your professional life: the patient-physician relationship (clinical encounter).

- Illuminating the ways in which culture, ethnicity, race, faith and spirituality, socioeconomic status, and other dimensions of individual and collective identity shape the moral beliefs and commitments of patients, as well as of physicians.

- Promoting cura personalis or care of the whole person. This Jesuit ideal commits us to deep and real appreciation for and respect for each individual person and affirms the goodness and dignity of each person. No small challenge in today’s world.

- Asking and exploring the question: are there any universal ethical imperatives that transcend differences of time (i.e., they are not relative to a particular period of human history), differences of place (i.e., they are not relative to a particular geographic area), and differences in belief systems (i.e., they are not relative to a particular faith or culture or political perspective)? In other words, is there anything that physicians must always do (or not do) or be (or not be), no matter what the circumstances?

With these aims in mind, after introducing you to the concepts of ethical and cultural competence, we will first seek to bring some of the critical dimensions of the clinical encounter into focus. The session on September 18th will address the experience of illness and propose vulnerability as the grounding for the physician’s moral obligations. The next two classes (September 25 and October 2) will explore the promises physicians “profess” as a result of personal and professional codes of ethics and examine whether or not there are nonnegotiable moral obligations for all physicians. Classes on October 9 and 16 will explore the ideal of shared decisionmaking and models of the physician-patient relationship. Classes on October 23 and 30 will introduce respectively culture and ethical decisionmaking and religion, ethical decisionmaking and spiritual care. The last two classes will provide opportunities to synthesize and use class content.

Designing and implementing a new course (or curriculum) is necessarily a process of trial-and-error: although our responsibilities as faculty are to foster your learning, we know, too, that we will learn a great deal as well about what does and does not work—what is and is not effective in achieving the objectives of ECC. Thus, at the outset, please know that we welcome your constructive criticisms and suggestions for improvement.
The Faculty for Ethical and Cultural Competence in the Health Professions

- Barnet, Robert
- Blazek, William, S.J.
- DeScisciolo, Constance
- Duffy, James, S.J.
- Errico, Monica
- Gallagher, Michael
- Gillon, John
- Giordano, James
- Goglia, Bette
- Gomez, Carlos
- Grant, Edward
- Hudson, Korin
- Lane, Mary
- Lynch, John
- Moore, Eileen
- Neill, Edwin
- Pellegrino, Edmund
- Prograis, Lawrence
- Sharpe, Ashby
- Siberski, John, S.J.
- Taylor, Carol
- Wessell, Mary Louise

LEARNING OBJECTIVES

With the completion of ECC, the student should be able to

1. Define ethical and cultural competence in health care professionals.
2. Analyze the three sources of the physician’s moral obligations as articulated by Dr. Edmund Pellegrino
3. Explain how the fact of illness and resultant patient vulnerability result in obligations for health care professionals.
4. Describe the principal features of medicine as profession and the role codes of ethics play in articulating moral obligations.
5. Identify facilitating and constraining influences (personal, professional, and societal) on medical professionalism.
6. Critique the ethical ideal of shared decision making and its role in healing.
7. Describe the science, art, and ethics of the clinical encounter and models of the physician patient relationship.
8. Describe the relationship between culture, religion, ethical decisionmaking and good medical care.
PERENNIAL CHALLENGES

1. Communicating importance and relevance of this content at this point in your education...
   a. We plan to set two paths before you...
   b. What’s at stake for the public you serve, for yourselves and for medicine as a profession—especially in the present context
2. Clearly articulating where we [GU] “stand” on the professionalism debate...
3. Teaching the “right” stuff (addressing everyday, REAL concerns and issues vs. “hot topics”) Ethics is more central to everyday practice than only the BIG issues.
4. Addressing “ethics is a matter of opinion” and therefore relative and therefore “ungradable”

DATES, TIMES, TOPICS, LECTURERS, AND FORMATS

ECC consists of 10 weekly sessions, beginning Tuesday, September 11 and ending Tuesday, November 13: every session is scheduled for a Tuesday and will begin at 3:00 p.m. and end at 5:00 p.m. Plenary sessions with the full class are held in LA6 Preclinical Sciences Building.

DATES, TIMES, TOPICS, LECTURERS, AND FORMATS
2007

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>Lecturer</th>
<th>Format</th>
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<tbody>
<tr>
<td>9/11</td>
<td>What is ethical &amp; cultural competence in the health professions?</td>
<td>Taylor</td>
<td>General Session followed by small group</td>
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<tr>
<td>9/18</td>
<td>Grounding for Moral Obligations: The Fact of Illness and Patient Vulnerability</td>
<td>Giordano</td>
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<td>9/25</td>
<td>Grounding for Moral Obligations: The Promises Professionals “Profess” Part One: Personal Codes and Positive and Negative Influences on Practice</td>
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<tr>
<td>10/2</td>
<td>Grounding for Moral Obligations: The Promises Professionals “Profess” Part Two: Medicine as a Moral Profession and Codes</td>
<td>Pellegrino</td>
<td>General session followed by small group</td>
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<td>Beneficence in Trust vs. Respect for Autonomy</td>
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<td>10/16</td>
<td>The Healing Act: Models of the Physician—Patient Relationship and the science, art, and ethics of medicine</td>
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<td>10/23</td>
<td>Culture and Ethical Decisionmaking</td>
<td>Taylor</td>
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<tr>
<td>10/30</td>
<td>Religion, Ethical Decisionmaking, and Spiritual Care</td>
<td>Taylor</td>
<td>General session followed by small group</td>
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<tr>
<td>11/6</td>
<td>Putting It All Together: One</td>
<td>Taylor</td>
<td>General session</td>
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<tr>
<td>11/13</td>
<td>Putting it all together: Two</td>
<td>Gallagher</td>
<td>General Session Master Clinician-Patient Demonstration followed by small group</td>
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# Preparatory Assignments and Small Group activities

<table>
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<tr>
<th>Date</th>
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<th>Prep Exercise</th>
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<tr>
<td>9/11</td>
<td>What is ethical &amp; cultural competence in the health professions?</td>
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<td>Meet and Greet: Cultural and Ethical Competence Assessments</td>
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<tr>
<td>9/18</td>
<td>Grounding for Moral Obligations: The Fact of Illness and Patient Vulnerability Being a patient: the multiple dimensions of the experience of illness</td>
<td>Typed Patient Interview</td>
<td>A. General Discussion of patienthood and vulnerability</td>
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<td>B. Gross Anatomy Reflections</td>
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<tr>
<td>9/25</td>
<td>Grounding for Moral Obligations: The Promises Professionals “Profess” Part One: Personal Codes and Positive and Negative Influences on Practice</td>
<td>Typed statement of personal code</td>
<td>Share personal code statements and identify commonalities</td>
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<td>Research assigned practice setting and identify positive and constraining variables</td>
<td>Report on assigned practice settings; <em>identify key determinants</em> of ethical competence and professionalism</td>
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<tr>
<td>10/2</td>
<td>Grounding for Moral Obligations: The Promises Professionals “Profess” Part Two: Medicine as a Moral Profession and Codes</td>
<td>Prepare for small group discussion: Type a one page answer to the question of whether or not there are nonnegotiable moral obligations for all physicians. If yes, what are they. Justify your response and cite readings as appropriate.</td>
<td>General Discussion regarding moral authority of codes and Dr. Pellegrino’s grounding of medicine’s moral obligations Exploration of nonnegotiables using case studies</td>
</tr>
<tr>
<td>10/9</td>
<td>Grounding for Moral Obligations: The Healing Act Patients, physicians, and the ideal of shared decision making</td>
<td>Prepare for small group discussion: Type a one page statement</td>
<td>Role Play Health Care Decision making and Contrast three models:</td>
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<td>Date</td>
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<td>describing the role you believe physicians should play in helping patients make “good” decisions. Cite the readings as appropriate.</td>
<td>Paternalism, Shared Decisionmaking and Patient Sovereignty; Identify Situations where each might be applicable</td>
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<tr>
<td>10/16</td>
<td>The Clinical Encounter: Models of the Physician—Patient Relationship and the science, art, and ethics of medicine</td>
<td>Prepare for small group discussion and role play. Assess personal strengths and limitations for practice.</td>
<td>General Discussion Role play clinical encounters</td>
</tr>
<tr>
<td>10/23</td>
<td>Culture and Ethical Decision Making</td>
<td>Research culture of assigned case family and prepare to lead Case Analysis based on readings</td>
<td>Case Analysis [assign different cultural backgrounds for case discussion]</td>
</tr>
<tr>
<td>10/30</td>
<td>Religion, Ethical Decision making, and spiritual care</td>
<td>Perform and type two Spiritual Histories</td>
<td>Case Analysis</td>
</tr>
<tr>
<td>11/6</td>
<td>Putting it all together: One</td>
<td>Review course content for exam</td>
<td>No small groups</td>
</tr>
<tr>
<td>11/13</td>
<td>Putting it all together: Two</td>
<td></td>
<td>General Session Master Clinician-Patient Demonstration Small group analysis</td>
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**ASSIGNMENTS, REQUIREMENTS, AND STUDENT ASSESSMENT**

Each week will have assigned readings and some weeks will have a preparatory assignment with reflection and a short written response. The preparatory assignments should be typed and submitted to your small group facilitator at the end of each session. There is a typed take home examination.

**Readings**
There is no separate textbook for ECC; Readings for each session will be distributed.
Take home final examination—due November 13

After watching the film W;t in class on November 6, prepare a thoughtful 5-6 page typed, double-spaced, paper which analyzes the personal, professional and institutional factors (N.B. use these headings in your paper) which influence the care received by Dr. Vivian Bearing. Grading criteria (see below) include 1) depth and breadth of analysis, 2) thorough and creative grasp of course content (ethical and cultural competence), and 3) use of cited, supporting literature.

- The honors take home examination critically analyzes the personal (Dr. Vivian Bearing, Drs. Harvey Kelekian and Jason Posner), professional (medicine and clinical research) and institutional (academic health center) factors which affect the care received by Dr. Vivian Bearing in the play, W;t. The comprehensive analysis in the honors essay demonstrates a thorough and creative grasp of course content (ethical and cultural competence) and cites course and additional literature to support judgments.

- The high pass take home examination analyzes the personal (Dr. Vivian Bearing, Drs. Harvey Kelekian and Jason Posner), professional (medicine and clinical research) and institutional (academic health center) factors which affect the care received by Dr. Vivian Bearing in the play, W;t. The comprehensive analysis in the high pass essay demonstrates a thorough grasp of course content (ethical and cultural competence) and cites course and at least some additional literature to support judgments.

- The pass take home examination describes the personal (Dr. Vivian Bearing, Drs. Harvey Kelekian and Jason Posner), professional (medicine and clinical research) and institutional (academic health center) factors which affect the care received by Dr. Vivian Bearing in the play, W;t. The analysis in the pass essay demonstrates a basic grasp of course content (ethical and cultural competence) and cites course literature to support judgments.

- The fail take home examination fails to analyze or describe in more than an erratic manner the personal (Dr. Vivian Bearing, Drs. Harvey Kelekian and Jason Posner), professional (medicine and clinical research) and institutional (academic health center) factors which affect the care received by Dr. Vivian Bearing in the play, W;t. This response does not demonstrate the assimilation and ability to use pertinent course content (ethical and cultural competence) and fails to cite course and additional literature to support judgments.
course requirements and criteria for student assessment

Student assessment in ECC permits recognition of meritorious performance in the course. Medical students receive the grade of honors, high pass, pass or fail according to the following performance.

**Honors**
- No unexcused absences
- Well prepared for sessions
- Preparatory assignments *consistently* of high, outstanding quality
- Participation in small group exercises demonstrates mastery of class content
- Advances the group’s learning through active and scholarly participation in small group exercises
- Effective and creative problem solving
- Class work demonstrates commitment to excellence
- Competently advances and defends a philosophical justification for positions taken in class
- Constructively criticizes positions of others
- Meets criteria for *honors* take home examination

**High Pass**
- No unexcused absences
- Well prepared for sessions
- Preparatory assignments of good to excellent quality
- Contributes to group’s progress
- Effective problem solving
- Readily able to advance and defend a philosophical justification for positions taken in class
- Meets criteria for *high pass* take home examination

**Pass**
- No unexcused absences
- Basic preparation for sessions evidences minimal degree of preparation
- Preparatory assignments of adequate quality
- Knows the difference between an opinion and a philosophically based argument and can make the latter
- Meets criteria for *pass* take home examination

**Fail**
- Unexplained absences
- Consistently unprepared for sessions
- Preparatory assignments of poor quality; and/or failure to submit preparatory assignments
- Misinformed, not seemingly committed to excellence
- Unable to advance and defend a philosophical justification for positions taken in class
- Meets criteria for fail take home examination

Your grade will be derived from your small group instructor’s assessment of your preparation for, and participation and performance in the small group-based activities and the final examination.

- Attendance at each of the ten small group based activities is required. If you must be absent (e.g., due to illness or emergency), you MUST give advance notice (i.e., prior to the session) to your small group instructor (either via phone or e-mail). Unexcused absences will have an adverse impact on your final grade that is based on your performance in the small group-based activities.

- Prior to five of the small group-based activities, you are required to complete preparatory assignments. The directions for these preparatory assignments can be found in the syllabus. Submit your typed, completed preparatory assignments to your small group instructor. Your small group instructor will review your submissions and utilize a simple system to provide you with feedback on the quality of your preparation: a “-” sign (i.e., a minus sign) indicates that your preparation is deficient (in which case you should probably have a brief chat with the small group instructor); an “=” sign indicates that your preparation is adequate; and, a “+” sign indicates that your preparation is more than adequate.

- Take home final examination.
LEARNING OBJECTIVES

With the completion of this session, the student should be able to

1. Identify the elements of ethical and cultural competence
2. Describe the learning objectives, topics, and requirements for the course

LECTURE OUTLINE

I. From **CHA Ethics Lab 3: Facing Disparities in Health Care**

II. The elements of ethical and cultural competence: a first approximation based on a group analysis of

   A) What types of knowledge and what sorts of skill would a competent physician need to possess in order to form and sustain an effective healing relationship with Mr. Ellison and his family.

   B) What values and virtues would he or she need to cultivate and exemplify in his/her behavior?

III. The relevant general objectives of a Georgetown education in medicine

   A-3: an understanding of the psychological, socioeconomic, cultural, and spiritual dimensions of human health and illness

   A-5: an understanding and knowledge of oneself, including the scope and limits of one’s knowledge, skills, and values

   B-1: the ability to take a comprehensive history and to perform a comprehensive physical examination

   B-5: the ability to implement and manage the plan of care in an appropriate and professional fashion with sensitivity to patient diversity and values

   B-6: the ability to communicate and collaborate effectively with patients and colleagues
C-1: an understanding of the ethical dimensions of the physician-patient relationship and of the ethical dilemmas encountered in health care, at the bedside as well as in the formulation of health care policy

C-2: an understanding of the obligations – to patients, the profession, and society -- inherent in the practice of medicine

C-3: the clinical virtues of fidelity to trust, respect for others, excellence, duty, honor and integrity, humility and accountability, and compassion

IV.  *Cura personalis*

V.  **The elements of ethical and cultural competence: a second approximation**

A) A conceptual analysis of

i. Ethics and Morality

Ethics or morality poses questions about how we ought to act and how we should live. It is an inquiry into the justification of particular actions (are these actions right or wrong?) as well as a search for traits of moral character that promote human flourishing.

1. Ethics: that branch of philosophy that deals formally and systematically with morals--what ought to be done
2. Morals: individual and/or societal beliefs about what is right and wrong

Ethics is about how an individual or an institution (profession) *acts out its identity*...

**Ethics is the study of who we ought to be and how we should make decisions and act in light of who we are and who we say we are...**

**Two approaches to morality:** 1) *morality is knowledge*, the core of which is essentially theoretical, explicitly stateable, highly general, and systematically unified; think action guiding theories, such as utilitarianism, deontological ethics, or social contract theory, 2) *morality is something we do together, social and collaborative*; it requires participation in and collaboration with a system of accountability and responsibility that is negotiated (sometimes contested) and whose outcome is meant to be a life that is decently habitable for

- Unlike the sciences ethics does not offer "2+2 = 4" type of "right answers."
- Ethics requires prudential reasoning in situation that are often complex ambiguous.
- The fact that good people can reason differently about what ought to be done does NOT mean that all responses are equally right and good. Challenge is to discern the one BEST response. This may require careful reflection and discourse.

ii. Ethos and mores

iii. Culture

*Culture* is an integrated pattern of human behavior which includes but is not limited to thought, communication, languages, beliefs, values, practices, customs, courtesies, rituals, manners of interacting, roles, relationships, and expected behaviors of a *racial, ethnic, religious, social or political group*; the ability to transmit the above to succeeding generations; dynamic in nature.

iv. Competence

B) Ethical and cultural competence: the elements

**Ethically competent health care professionals:**

1. are clinically competent
2. can be trusted to act in ways that advance the best interests of the patients entrusted to their care
3. hold themselves and their colleagues accountable for their practice
4. work collaboratively to advocate for patients, families, and communities
5. mediate ethical conflict among the patient, significant others, the health care team, and other interested parties
6. recognize the ethical dimensions of practice and identify and respond to ethical problems
7. critique new health care technologies and changes in the way we define, administer, deliver and finance health care in light of their potential to influence human wellbeing
LEARNING OBJECTIVES

The word patient is derived from the Latin “patior”- to suffer; thus the patient is literally “... the one who suffers”. The focus of this session is to understand how disease injury infirmity and illness impact the person that is a patient. The class will develop meaningful understandings of concepts as disease illness and malady to address how being a patient renders a person vulnerable and affects multiple dimensions of their existence. We will discuss how the relationship with the person is important to defining the role of the physician. Through film (“Whose Life Is It Anyway”), readings and discussions we will attempt to gain insight to the predicament of disease, illness and malady and the experience of “patienthood”.

Specific Objectives:
1. Analyze the concepts of disease and illness as described by Boorse, Nordenfelt, Gert et al., and Cassell.
2. Describe how these definitions each contribute to what Pellegrino refers to as the "fact of illness".
3. Evaluate how these "define" what it is to be a patient.
4. Describe how the objective and subjective nature of the patient might contribute to or define the role and moral obligations of the physician?

READINGS


Recommended:

The film: Whose life is it anyway?
PREPARATORY ASSIGNMENT

Interview someone who is or who was recently a patient. Ideally this will be someone with a chronic illness or serious/life threatening illness. You may use a family member, friend, neighbor or acquaintance. Think about what sort of questions you might ask to elicit from this individual a rich sense of what being a patient means to him/her. What are the vulnerabilities experienced in relationship to disease/injury/illness. What has been his/her experience of health care professions and their sensitivities to and responsiveness to human vulnerability. Type a one to two page report of your findings.

LECTURE OUTLINE

I. The objective and subjective domains of disease, illness and malady
   A. Definitions and meanings
   B. Relevance to patients and physicians

II. The experience of “patienthood”
   A. Dimensions of vulnerability
   B. Subjective knowledge
   C. Inequity
   D. Expectations

III. The clinical encounter
   A. As exchange of knowledge
   B. As reconciliation of meaning
   C. As bridge between “world of patient” and “world of physician”

Before General Session ends prepare students for next two classes and for the preparatory activity.
Class on 9/25 will be all in small groups.

SMALL GROUP ACTIVITY

[Note to faculty: Review the small group activity for next week’s class (9/25) and be sure that at least one student is assigned to research and be prepared to report on how each of the following cultures may facilitate or constrain the practice of professional (good?) medicine in the next class: 1) Georgetown University Hospital, 2) Walker Whitman Clinic in Washington, D.C., 3) Doctors without Borders in Lebanon, 4) Kaiser Permanente, 5) Mayo Clinic, 6) Military Medicine: Abu Ghraib, Guantanamo, 7) Sports Medicine (Redskins physician), 8) Boutique Medicine, 9) Urgent Care Center, 10) For Profit Plastic Surgery Center, 11) Fertility Center, 12) Family Practice Clinic, 13) Medicine in Nazi Germany, 14) clinical researcher for Pfizer, 15) Virginia jail.]
A. General Discussion

- Discussion of personal experiences of patienthood
- How did any personal experience relate to impression of film and readings?
- How do such impressions affect current perception of role as physician?
- Discussion of meaning of patient-centered care as relevant to student’s personal experience and its potential and problems in contemporary medicine.

B. Share Gross Anatomy Reflections

Reflections

Imagine yourself in each of the following situations. Write a brief reflection on each scenario about what you would be thinking or feeling in each situation. What do you expect of the physicians treating you in each scenario? Would your thoughts and/or feelings change if you were not the patient, but if you were there with a loved one who was the patient in each situation.

Conclude with a written reflection on the nature of the relationship between “patients” and medical students who “learn their craft” by using the bodies and pathologies of the ill. What do you as a medical student owe each of the patients/individuals described below?

1. Picture yourself on a Saturday afternoon in a busy Emergency Department with a fractured ankle after a pick up soccer game. You have been waiting for two hours to be seen by the doctor. The first person you meet is a medical student.

2. Picture yourself in a bed, in a double room on a hospital ward recovering from your first heart attack. You are listening to the rounding team discuss your progress (outside the open door), and the intern is supposed to come back later this afternoon to talk to you about diet, exercise and smoking cessation. The team does not come into the room.

3. Picture yourself in an ICU bed. You are comatose after a severe head injury. A medical student is learning how to do a neurological assessment. S/he is testing your responsiveness to deep pain stimuli.

4. You now reside in a nursing home dementia unit. Your limbs are contracted and you can’t feed yourself, bathe yourself, or speak. A nursing assistant drops you during a difficult transfer and you find yourself in the emergency department with a fractured hip. You are cold and frightened. The E.R. resident instructs a medical student to examine you.
5. You are in the emergency room, newly deceased. A senior resident is delaying calling the code so that the new residents will gain more experience. After the code is called someone asks to practice intubation.

6. Picture yourself as a cadaver on a table in an anatomy lab. Five students with scalps are poised to cut.

For further reflection, what is the relationship between health care professionals and the patient in each scenario? What are the responsibilities of each? What allows you to violate the taboo against mutilating the dead in the pursuit of your education? What do you owe to your cadaver.

C. Optional Case Discussion

Read a patient’s account of her illness and then respond to the questions which follow.

When my doctor first told me that I was going to die from my disease, the image that came floating to my mind was this: I would just be going along living as usual, and living a little more, then I would just fall into a big hole in life (opened up just for me) and be dead. It was a shocking thing--thinking of being dead. Thinking about it now, that first image--fall in, be dead, sounds pretty dang naive and optimistic.

My real life dying is turning out to be a whole lot harder than that. Lots slower and lots more demanding. I'm going in bits. I mourn each individual piece as I lose it.

The first thing to go was my equilibrium. I lost it the moment my prognosis seeped through the haze and into my head. I lost that sense I had when I woke up in the morning that the world was in balance and that my spot in it was solid and secure. Then I lost that feeling of being all in one piece. Body, mind, spirit. Be. Body had created such a breach. Breach of trust. Breach of faith. Breach of peace. My peace. It was hard to know what to trust if I couldn't trust my own body.

After that, my mind demonstrated to me its limitations. I had always believed that I could rely on my mind to overpower any frailty of body or spirit. Then one day, it couldn't. I walked myself into the bathroom at work and when I was finished in there, I simply could not get my legs to stand back up. I tried for hours. I sat there, deep toilet grooves around my bottom in disbelief. I had walked to the absolute end of my strength.

Then my bones started breaking. I stood up using my crutches and my arm broke. When that healed, I stood again and my leg broke. Five times my arm or leg broke within a few seconds of my standing. Hello wheelchair. The worse consequence of being in a wheelchair is that I can't go visit friends at their homes. Almost none of them have accessible housing. They come to visit me, and I'm very glad that they do, but I really miss getting to see them in their own places. Back to bones. Breaking. Now a cough or a
sneeze can break a rib. Roll over wrong while I'm asleep and I can wake up with a broken foot. Or arm. Or....

Now my body is getting too spent for chemo. Chemo used to lay me low for four days. Then it stretched to five and now it is usually six. Then comes my nadir. How low can you go? Pretty dang low. Nurses come twice a day to give me lasix transfusions to keep some blood in me. It's not enough. Blood leaks out of me everywhere. I try to ignore it, but it's bright and scary.

The tumors in my head have grown. They say they're benign. Let's see...what does benign mean? "Gentle or kindly, tender, compassionate." Well, these kindly tumors grew enough so that they created pressure in my head. Then, when my platelets bottomed out, I had a head bleed. Now my left side works only when I think hard about it. Concentrate. Don't neglect that left arm. Leg.

That happened two months ago. Last nadir. Now it's this nadir. I've been home for five days. Waiting to see how low I can go. To see if I bleed, if I break. Waiting.

I have learned so many forms that mourning can take. The form seems to be connected more to what shape I'm in than to the severity of the loss. I have cried over very small losses and have furrowed my brow and moved on over some pretty significant ones.

If, when my doctor told me I was going to die, she had told me it would be bit by bit, I would have thought, "Thank God! What a mercy. Not all at once. Bit by bit." Now I sometimes find myself wondering what will be next. How many more losses can I stand? How much less can I be and still be alive and counted?

If I saw that hole in life that I first imagined, I don't know if I'd fall through it on purpose or not. I'm not looking for it, but if it just appeared in front of me...I don't know. Tonight I'm tired and sick and glad I don't see the hole so I don't have to decide.

1. Am I the type of person who would elicit this story? What kind of persons (healers?) do we need to be to elicit the telling of such stories?

2. If this woman was entrusted to my care, what would my clinical priorities be? Do I possess the broad-based clinical competencies which would allow me to be responsive to the broad human needs of this woman?
   Is it reasonable to expect health care professionals to pay attention to human suffering?

3. How does the system need to change in order for us to be more responsive to individuals like this woman? In what ways do her vulnerabilities create moral obligations for her physicians?
"If one seeks to influence, shape, direct, heal, elevate, and enrich a complex industrial democracy, it cannot be done simply by integrity of individual witness. It is done by institutions that lay hands on life at the critical points where life can be injured or fostered, where people are born and die, where they learn and teach, where they are cured and healed, and where they are assisted when in trouble.” [Rev. J. Bryan Hehir]

**Changing individual behavior is difficult, but changing an organization or culture is potentially a greater challenge—and often is a precondition for individual change. Deficiencies in care often reflect flaws in how the health care system functions, which means that correcting problems will require change at the system level. [AMA]**

4. If I want to be a person of integrity, how should my religious beliefs and faith commitments influence my care of the seriously ill and dying?

5. What are the societal forces which are impeding and facilitating quality end-of-life care?
LEARNING OBJECTIVES

With the conclusion of this class, students should be able to:

1. Describe what it is (personal oath, public declaration, personal sense of vocation, social vocation) that makes a person a professional and identify key features of a profession.

2. Develop personal answers to Ozar’s nine categories of questions about professional obligation.

3. Articulate a personal code of ethics.

4. Analyze positive and negative ways that cultures influence individual and collective expressions of the medical profession using the student’s.

READINGS


PREPARATORY EXERCISE

A. After reading Ozar’s essay reflect on YOUR answers to the nine categories of questions about professional obligation.

   1. Who is (are) the medical profession’s chief clients?
   2. What are the central values of this profession?
   3. What is the ideal relationship between a member of this profession and a client?
   4. What sacrifices are required of members of this profession and in what respects do the obligations of this profession take priority over the other morally relevant considerations affecting its members?
   5. What are the norms of competence for this profession?
   6. What is the ideal relationship between the members of this profession and co-professionals?
7. What is the ideal relationship between the members of this profession and the larger community?
8. What ought the members of this profession do to make access to the profession’s services available to everyone who needs them?
9. What are the members of this profession obligated to do to preserve the integrity of their commitment to its values and to education others about them?
10. Are there any non-negotiable, universal moral obligations binding on all physicians? [This question has been added to Ozar’s list.]

B. Draft your personal code of ethics. Submit a one-two page typed personal statement. When you approach patients saying, “may I help you?” what will you implicitly be “professing” by virtue of being present to them as a physician?

C. Reflect on how different cultures influence individual and collective expressions of the profession of medicine. Come to your small group prepared to discuss the effect your assigned culture has had or is likely to have on individual physicians. You may need to do a little research before you can begin your reflection. To what degree are positive and negative expressions of the profession a result of culture versus individual choice? [N.B. You may need to research your assigned practice setting if you are not familiar with its characteristics.]


**SMALL GROUP ACTIVITY**

A. Work through the first three exercises briefly to allow time to discuss B and C below.

- See if the group can agree upon “necessary and sufficient” criteria of professions. How well does medicine as you know it today meet these criteria?

- Share individual responses to the question “what is it (personal oath, public declaration, personal sense of vocation, social vocation) that makes a person a professional”?

- Share individual responses to Ozar’s nine categories of questions about professional obligation.
LEARNING OBJECTIVES

With the conclusion of this class, students should be able to:

1. Identify the principal themes and concepts used to describe and justify professional morality

2. Describe the moral authority in codes of ethics.

3. Describe the three phenomena that ground Medicine’s moral obligations according to Dr. Pellegrino.

4. Explain why you do or do not agree with Dr. Pellegrino’s claim that it is time to reconstruct medical morality on a sound philosophic base—the base that is unique to medicine: the physician patient relationship.

5. Develop and defend an argument against or on behalf of the claim that there are non-negotiable, universal moral obligations binding on all physicians.

READINGS

Hippocratic Oath


Codes of Medical Ethics: Ethical Analysis

- What is the “source of authority” for this particular expression of professional morality?
- According to each, what are the cardinal virtues of the professional? What character traits should professionals exemplify?
- As for prescribed and proscribed actions or activities, what should physicians and nurses do? What should these health professionals NOT do?
- What rationale for the prescriptions and/or proscriptions is offered? Are physicians or nurses urged or constrained to do or not do certain things out of deference to duty? Principle? A particular right and if so, whose right? A value?
- What concepts are dominant in these codes, oaths, statements, and charters as explanatory or justificatory devices for moral choices and decisions?
- As statements of the morality of contemporary medicine and nursing, what are their strengths and weaknesses? Advantages and disadvantages?

- Do you agree or disagree with Dr. Pellegrino’s claims regarding medicine’s moral obligations and their justification?

B. If you found yourself practicing medicine in a culture where you believe one or several of your peers are acting unethically, illegally, incompetently, or unprofessionally how do your think you should respond and how do you think you would respond? Is it sufficient to hold ourselves accountable to the norms of the profession or are we also responsible for one another?

C. Do you think it is a good idea to prevent physician patient conflicts in the manner described in the Washington Post article,”Medical Practices Blend Health and Faith”?

D. Now, consider this question – what is morally negotiable and/or morally non-negotiable in medicine– by reflecting on the following six scenarios:
Scenario One: The dreaded avian flu pandemic is here and now and GUH is ordering all physicians (and other health care professionals) to mobilize. When someone protests, quoting the CDC statement on virulent epidemics (class reading) that “the phrase ‘duty of care’ is at best too vague and at worst, ethically dangerous” and s/he needs to get home to be with her children who are her “first priority” she is told she is unprofessional. What is it reasonable to expect of physicians in epidemics? Should each physician be allowed to determine what risks they are willing to accept or should certain obligations be mandated for all?

Scenario Two: Boutique medicine is all the rage! Why put up with all the hassles in health care today, when you can start your own boutique practice for those who can afford a hefty initiation fee and high price tags on diagnostic and therapeutic options. This way you can spend as much time as you like with each patient and make sure that your commitment to quality isn’t compromised. More and more practitioners seem to be finding this to be a reasonable option. Is there any pro bono obligation for health care professionals?

Scenario Three: You have a colleague who is terrified of “catching TB” who absolutely refuses to care for anyone with diagnosed TB. She is also careful to limit her contact with anyone who might be at risk for TB. She asks what you think about her way of handling her fears.

Scenario Four: (From a student’s reflections on the “greatest past challenge to my moral agency...”): “I was deployed with the United States Air Force to a developing country as the head operating room nurse. Our primary mission was to support the United States and the United Nations troops in the country but, by far, the bulk of our time was spent doing humanitarian surgeries for indigents. One late afternoon as we were wrapping up our day of surgeries in a very remote location, a 37-year-old male limped into the clinic in obvious distress. He had walked almost ten miles to get there. Our head surgeon made the preliminary diagnosis of incarcerated intussusception, which is life-threatening in the best of circumstances. In this country it was a death sentence. The surgical team was required by the commander of the base to be back “inside the wire,” safe at camp, by dark every day. We had already used all of the sterile supplies we had brought with us that day and were ill-prepared to start another surgery. I suggested to the surgeon we take the patient back to our tent hospital and do the surgery there. We were refused permission to bring the patient back with us, and if we were to be back “inside the wire” by dark, we would have to leave right then. At stake were the man’s life, the treating team’s safety, and literally, the military careers of the surgeon and team.
**Scenario Five:** You have been working in the psychiatric unit for one month (as a medical or advanced practice nursing student) when a 37-year-old schizophrenic man whom you know fairly well again asks, “Why should I continue to care about what happens to me? No one else does.” You have to agree that his prospects are pretty bleak. He has no family to speak of and generally moves from one shelter to another when not hospitalized. Drug and alcohol dependencies have complicated his adherence to therapeutic regimens. When he tells you that he wants to end his life and asks for your help so “he will be successful this time” how do you respond? You find it difficult to challenge his claim that “the world would be better without me – and I’d be better without this world.”

**Scenario Six:** Your practice continues to lose revenues and your financial manager tells everyone to “Stop seeing Medicare/Medicaid patients (or worse still, “self-pay” patients) STAT!” You know that there aren’t many options for these patients in your local community. What, if anything, do you, your practice, and medicine/nursing as professions, owe vulnerable populations?

**Scenario Seven:** You are asked to administer a lethal injection to a prisoner on death row. You work for the correctional institution.
LEARNING OBJECTIVES

At the end of this lecture the learner will be able to:

1. Define shared decision making in the context of patient –centered communication.
2. Explain the ethical basis of shared decision making grounded in patient autonomy and beneficence.
3. Apply a model of shared decision making to a clinical encounter.

READINGS

Required:

Ubel, P.A. “Is information always a good thing? Helping patients make “good” decisions.” Med Care 40 (9Suppl) V39-44.


Optional:

PREPARATORY ACTIVITY

Type a one page statement describing the role you believe physicians should play in helping patients make “good” decisions. Cite the readings as appropriate.

LECTURE OUTLINE

I. Communication in the patient-professional (physician) relationship.
   a. Patient centered communication and the spectrum.
   b. Adaptive models of communication.
OBJECTIVES

At the end of this lecture the learner will be able to:
  1. Contrast the three elements of the healing encounter (science, art and ethics).
  2. Identify personal strengths and growth opportunities to practice good medicine.
  3. Critique medicine as it is practiced today in the U.S.

READINGS


Young, R., Ed. (2000). A piece of my mind. Chicago: AMA Press. [Greengold, N.L. By the numbers; Verrees, M. Touch me; Keene, N. He lifted his eyes; Schmidt, S.A. When you come into my room]


PREPARATORY EXERCISE

A series of reflections to prepare you for your conversation in the small groups.

A. After reading the series of brief physician and patient essays and reviewing the chart below contrasting the science, art and ethics of the healing encounter reflect on: 1) descriptors of “good” clinical encounters, e.g., honesty on both sides or ability to use human touch appropriately; 2) the clinical skills or cultivated dispositions/virtues which correlate positively with good clinical encounters, e.g., therapeutic attentiveness; and 3) factors in society which constrain the science, art and ethics of history-taking, e.g., today’s emphasis on efficiency and cost-containment.

B. To the extent that your know yourself, reflect on your natural and cultivated abilities to practice the science, art and ethics of medicine. Identify strengths and growth opportunities.
C. Do you think it is possible to practice good medicine in the U.S. today—based on your current knowledge of the culture of medicine and health care.

D. What is at stake for physicians and patients in the healing encounter?

### Comparative Matrix: The Science, Art, and Ethics of the clinical encounter

<table>
<thead>
<tr>
<th></th>
<th>Outcomes</th>
<th>Processes</th>
<th>Related Skills &amp; Dispositions</th>
<th>Pitfalls</th>
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<tr>
<td><strong>The Science</strong></td>
<td>Accurate and comprehensive history that provides a basis for scientific (evidence-based) practice</td>
<td>Uses a systematic &amp; comprehensive framework (e.g., body systems) to identify medical problems</td>
<td><em>Clinical reasoning skills</em></td>
<td>Focusing on self rather than the patient</td>
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<td><em>Systematic and comprehensive approach</em></td>
<td><em>Ability to check accuracy and reliability of data; draw valid conclusions; distinguish relevant from irrelevant data; recognize inconsistencies; identify patterns; identify missing information; promote health by identifying and managing risk factors; diagnose actual and potential problems; set priorities</em></td>
<td>Failing to allot sufficient time Preconceived (and erroneous) ideas about the patient’s condition and needs</td>
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<td><em>Technical competence</em></td>
<td><em>Reflective intelligence</em></td>
<td>Disorganization</td>
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<td><strong>The Art</strong></td>
<td>History communicates a “real sense” of the patient that makes individualized care possible</td>
<td>Sufficient time spent getting to know the patient prior to beginning the actual history to ensure the patient’s comfort (physical and emotional) and ability/willingness to participate fully and to allow the patient to participate fully and to allow the patient to participate fully</td>
<td><em>Clarify personal values, beliefs and needs to ensure these do not interfere with meeting needs of the patient</em></td>
<td>Rote application of history-taking skills</td>
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<td><em>Attentiveness to what makes the patient unique: age, race/ethnicity, culture, religion, health/disease state,</em></td>
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<td>Inability or unwillingness to focus on the reality of this unique individual at this point in time</td>
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<td><em>Practical wisdom</em></td>
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<td>Lack of comfort with some patients</td>
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<td>Outcomes</td>
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<td>Related Skills &amp; Dispositions</td>
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<td>physician to use appropriate language and individualized strategies to gain needed information. Strategies which engage the patient and facilitate the telling of her/his story</td>
<td>level of education, emotional status, social status, roles, previous experiences with health care, etc.</td>
<td>Bias, stereotyping, discrimination Belief that certain patients are not worthy of good care</td>
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<td>The Ethics</td>
<td>Experience of history-taking 1) validates the integrity and dignity of the patient (RESPECT IS KEY) and 2) builds trust in the physician’s—and health care team’s ability to appropriately care for the patient</td>
<td>Attentiveness to the vulnerabilities of the patient and the promise physicians make not only to be competent but to use that competence to secure the interests of the patient translates into profound (validating) respect for the patient and the commitment to use the history to gain whatever data is needed to identify medical priorities and meet the patient’s needs. End goal: excellent</td>
<td>Insufficient valuing of the ethical dimensions of practice Abuse of power differential in the physician-patient relationship Reduction of patients to objects (jobs to be performed, problems to be solved, revenue-generating commodities) Self-Interest Bias, stereotyping, discrimination Belief that certain patients are not worthy of good care</td>
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**SMALL GROUP ACTIVITY**

**Note to faculty:** assign each student one of the three cases described under small group activity for class on 10/23.

I. Engage in a small group conversation about the reflections engendered by the preparatory reflections.
   a. Do you agree that all three elements of the healing encounter are essential? Are they equally important? Can one be a good physician and neglect the art and ethics of medicine.
   b. To the extent that you know yourself, reflect on your natural and cultivated abilities to practice the science, art and ethics of medicine. Share personal strengths and growth opportunities.
   c. Do you think it is possible to practice good medicine in the U.S. today—based on your current knowledge of the culture of medicine and health care.
   d. What is at stake for physicians and patients in the healing encounter?

II. Divide into groups of three and use the scenarios below. Take turns being the patient, the physician and the observer. Use the chart contrasting the outcomes, processes, related skills and dispositions and pitfalls of the different elements of the healing encounter to critique the different experiences of the healing encounter.

**Scenario 1**
Maria is a 14 year old Latino teenager who comes to the clinic thinking she might get pregnant because she “went too far” with her boyfriend the night before. She wants a prescription for Plan B. She says her father will kill her if she gets pregnant. She doesn’t think the family has insurance. She tells you that she knows good Catholic girls shouldn’t “do it” until they are married.
Scenario 2
Alice Anderson is a single, 67 year old Caucasian nursing home resident who was brought to the hospital emergency room with gangrenous feet. She flatly refuses to cooperate with anyone and makes statements like, “God is my doctor, God is my lawyer, Get out of my face.”

Scenario 3
You are a male physician. Hana Zaer is a Muslim woman newly in the U.S. She is brought to the emergency room with what appears to be a dislocated shoulder. She is accompanied by her husband who refuses to leave her side. He asks if there is a female physician who can see his wife. Quick questioning reveals that a fall caused her shoulder pain. Noticing facial bruising you suspect that more than a fall may have caused her injuries.

Scenario 4
Mr. Kimura, a Japanese American, is brought to the emergency room by his family. He has cancer of the colon with metastasis to the liver and has been filling up with fluid. His abdomen and lower extremities are grossly swollen and he is complaining of pain. His son tells you to be sure not to use the word cancer with the patient because he does not know his diagnosis. He tells you that it is not the custom of the Japanese to be told their diagnoses.

Scenario 5
Ellen is a 14 year old Mormon hospitalized for appendicitis. She is very modest and makes one or two statements that raise the possibility of sexual abuse. She lives in Hurricane, Utah and you know that it is not unusual for a female child to be offered to a family member in some polygamist families.

Scenario 6
David is a homeless man with a long history of alcoholism and abusive behavior. He has been blacklisted from several area shelters because of behavior problems. He presents, again, to the E.R. dehydrated, covered with vomit, and asking for pain meds. It is freezing outside. You suspect he wants to be clean, dry, warm and fed for the evening.

Scenario 7
Jason is a 24 year old single Caucasian accountant in the emergency room with minor injuries following a motor vehicle accident which he is alleged to have caused. He has several scalp lacerations which need suturing and is demanding to see a plastic surgeon. The police want to see Jason because he was reported to be driving his Porsche recklessly at high speeds. They also want to be sure that he is tested for blood alcohol and recreational drug levels. There were two fatalities from another car, a mother and her ten year old son.
LEARNING OBJECTIVES

At the end of this lecture the learner will be able to:

1. Relate cultural competence to ethical decisionmaking for the seriously ill and dying.
2. Describe the role culture plays in determining Pellegrino’s “humanly good” as well as scientifically right “healing acts.”

READINGS

Each student will be assigned one of the three cases described under small group activity. Research the culture of the individuals/families described in your case sufficiently to resolve the clinical challenges.

Recommended:


PREPARATORY ACTIVITY

Research culture of assigned case family and come to class prepared to lead case analysis based on readings.

LECTURE OUTLINE

I. Introduction

A. The object of all clinical decisionmaking is first and primarily to secure the health and wellbeing or good dying of the patient and second to do this in a manner that respects the integrity of all participants in the decisionmaking process.
Reflection:

- What are some of the things which make health care decisions humanly “good” (as opposed to scientifically “right”)?

**Pellegrino’s fourfold notion of patient good ranked from most to least importance:**

1. The Last or Ultimate Good
2. The good of the patient as a human person
3. The patient’s best interests, i.e., the patient’s subjective assessment of the quality of life the intervention might produce and whether or not he deems it consistent with his life plan, goals, and aims
4. Medical, biomedical, or clinical good—the good that can be achieved by medical intervention into a particular disease state.

- What is culture’s role’s in 1) defining “good” and 2) ensuring that the health care team is committed to this “good”?
  
  - What is culture’s role as a source of moral authority? [Does a cultural preference trump other considerations? Does your answer change if the cultural variable is religion?]
  - How should conflicts among patients and their family and professional caregivers which involve cultural issues be resolved? What resources are available to facilitate resolution of these conflicts?
  - How does the system need to change to be more responsive to these issues and concerns?
  - What problems are you encountering and what are you doing about them?

1. Models of Decisionmaking:
   a. Paternalism
   b. Patient Sovereignty
   c. Shared Decisionmaking

2. Necessary Elements of a Profession (John Ladd)
   a. A service orientation that entails a personal relationship between the professional and the one served
   b. Altruistic service intended for the benefit of the one served
   c. A “doctrine” or set of teachings about the aims of the professions, the kinds of services it provides, the procedures that should be followed in pursuing aims, and so forth.
   d. Moral autonomy, self-governance

B. Principles of the *Universal Declaration on Bioethics and Human Rights*

[Adopted by acclamation on 19 October 2005 by the 33rd session of the General Conference of UNESCO]

1. Human dignity and human rights
2. Benefit and harm
3. Autonomy and individual responsibility

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4. Consent
5. Persons without the capacity to consent
6. Respect for human vulnerability and personal integrity
7. Privacy and confidentiality
8. Equality, justice and equity
9. Non-discrimination and non-stigmatization
10. **Respect for cultural diversity and pluralism**
   
   *The importance of cultural diversity and pluralism should be given due regard. However, such considerations are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms, not upon the principles set out in this Declaration, nor to limit their scope.*

11. Solidarity and cooperation
12. Social Responsibility and health
13. Sharing of benefits
14. Protecting future generations
15. Protection of the environment, the biosphere and biodiversity

[http://portal.unesco.org/shs/en/file_download.php/b0f1e8f1dc4a4e8990faff370608c2declaration.pdf; Retrieved October 26, 2005]

**II. Cultural Competence: Review**
[Adapted from the National Center for Cultural Competence, 2004; http://gucchd.georgetown.edu/nccc/]

*Culture* is an integrated pattern of human behavior which includes but is not limited to-thought, communication, languages, beliefs, values, practices, customs, courtesies, rituals, manners of interacting, roles, relationships, and expected behaviors of a *racial, ethnic, religious, social or political group*, the ability to transmit the above to succeeding generations; dynamic in nature.

*Cultural Competence* requires that organizations have a clearly defined, congruent set of values and principles, and demonstrate behaviors, attitudes, policies, structures and practices that enable them to work effectively cross-culturally [adapted from Cross, Bazron, Dennis and Isaacs, 1989, Towards a culturally competent system of care. Volume I. Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center]

Five Elements of *Cultural Competence at the Organizational Level*:
- Value diversity
- Conduct cultural self-assessment
- Manage the dynamics of difference
- Acquire and institutionalize cultural knowledge
- Adapt to diversity and cultural contexts of communities served

*Attitudes --- Values --- Structures --- Services --- Policies*
**Cultural Competence Continuum**

- Cultural Proficiency
- Cultural Competence
- Cultural Precompetence
- Cultural Blindness
- Cultural Incapacity
- Cultural Destructiveness

[Think the recent movie: *Crash]*

**Cultural Brokering** is the act of bridging, linking or mediating between groups or persons of different cultural backgrounds for the purpose of reducing conflict or producing change (Jezewki, 1990)

In health care, cultural brokering is a health care intervention through which the professional increasingly uses cultural and health science knowledge and skills to negotiate with the client and the health care system for an effective beneficial health care plan (Wenger, 1995).

A **cultural broker** is a go-between, one who advocates on behalf of another individual or group (Jezewki & Sotnik, 2001). Characteristics and attributes of a cultural broker include:

- Trust and respect of the community
- Knowledge of values, beliefs and health and mental health practices of cultural groups
  
- Understanding of the traditional and indigenous wellness and healing networks of diverse communities
- Experience navigating health and mental health care delivery and support systems.

**Guiding Principles for Cultural Broker Programs**

**Cultural Brokering...**

- Honors and respects cultural differences within communities
- Is community-driven
- Is provided in a safe, non-judgmental and confidential manner
- Involves service delivery that is accessible & tailored to communities served
- Acknowledges reciprocity and transfer of assets between community and health and mental health care settings
Knowledge, Skills and Awareness for Cultural Brokers

Awareness
- Own cultural identity
- Cultural identity of members of diverse communities
- Social, political and economic factors affecting diverse communities

Knowledge
- Values, beliefs and practices related to illness, health, mental health and wellbeing of cultural groups
- Traditional or indigenous health and mental health care networks within diverse communities
- Medical, health care and mental health care systems

Skills
- Communicate in cross-cultural context
- Communicate in two or more languages
- Interpret and/or translate information
- Advocate with and on behalf of children, youth, and families
- Negotiate health, mental health, and other service delivery systems
- Mediate and manage conflict

III. Ethnicity and Attitudes toward Patient Autonomy

Korean-American and Mexican-American subjects were more likely to hold a family-centered model of medical decisionmaking rather than the patient autonomy model favored by most of the African-American and European-American subjects. This finding suggests that physicians should ask their patients if they wish to receive information and make decisions or if they prefer that their families handle such matters.

IV. Ethnicity and Attitudes toward Life-Sustaining Technology

European-Americans were the least likely to both accept and want life-support.

Mexican-Americans were generally more positive about the use of life-support and were more likely to personally want such treatments. Ethnographic interviews revealed that this was due to their belief that life support would not be suggested if a case was truly hopeless.

Compared to European-Americans, Korean-Americans were very positive regarding life-support; however, they did not want such technology personally. Ethnographic interviews revealed that the decision of life support would be made by their family.
Compared to European-Americans, **African-Americans** felt that it was generally acceptable to withhold or withdraw life support but were the most likely to want to be kept alive on life support. Ethnographic interviews documented a deep distrust towards the health care system and a fear that health care was based on one’s ability to pay.

V. **Ethnicity and Advance Care Directives**


**European Americans** had the highest percentage of individuals who possessed an advance directive (40 percent of those with knowledge). By comparison, only 22 percent of the Mexican Americans, 17 percent of the African Americans, and 0 percent of the Korean Americans with knowledge possessed an advance directive.

Compared with European-Americans, **Mexican-Americans** as a group had a relatively negative attitude toward the concept of advance decision-making. They were significantly more likely to endorse items such as “Doctors should not discuss death and dying with their patients because doing so could be harmful to the patient” and “It is not necessary for people to write down their wishes about medical care because their family will know what to do when the time comes.” This finding supports a previous finding using the same proportion of respondents, that demonstrates that Mexican Americans tend to place greater emphasis on family-centered, as opposed to patient-centered decision-making styles.

**Korean-Americans** were almost completely unaware of advance directives, and reported negative reactions toward the concept of advance care planning more generally. ...research shows that Korean-Americans tend to have a negative sentiment toward telling a patient the truth about a diagnosis and prognosis, and believe that the family, not the patient, should make important health care decisions.

Unlike Mexican-Americans and Korean-Americans, **African-Americans** generally tended to have a positive attitude about advance care planning. At the same time, however, relatively few African-Americans had knowledge of advance care documents and the rate of possession among this group was extremely low. One striking finding of our study is the discrepancy in knowledge about advance care documents between African-Americans and European-Americans. Although virtually all of the European-Americans and African-American respondents were born in the U.S. and are native English speakers, 69 percent of the European-Americans were familiar with the concept of advance care directives as compared with only 12 percent of the African-Americans.
SMALL GROUP ACTIVITY

[Note to faculty: assign each student one of the cases described under small group activity for class on 10/30.]

Come to small group having researched the culture of your assigned family and be prepared to discuss all three cases.

Case One

Culturally Competent Care: Who Decides?

The patient was a 79 year old Vietnamese woman who was diagnosed with non-small cell lung cancer about 9 months prior to admission. At presentation with her lung cancer, she had a malignant pleural effusion and was not an operative candidate. The pleural effusion was drained and pleurodesis was performed. She received several courses of chemotherapy but had continued disease progression. She was admitted to the hospital complaining of chest pain and worsening shortness of breath.

Upon admission, she was found to have progression of disease with additional pleural fluid collection. She was given analgesics and the pleural fluid was tapped with some transient improvement in symptoms. The patient’s family was present including two daughters, one of whom flew in from Hawaii. Discussions were held with the patient and family by the oncologist who explained that the disease process was in its final stage, that no further curative options were available, and that palliative care was the best option. Much to the surprise of the oncologist, the patient and family expressed the wish to continue aggressive life support measures including mechanical ventilation. The patient was apparently very fearful of dying and wished her family to try anything possible to keep her alive.

The patient’s condition deteriorated shortly thereafter and she was transferred to the ICU, intubated and placed on mechanical ventilation. She was treated for pneumonia but her condition continued to worsen. The patient was sedated and kept as comfortable as possible. Daily discussions by the treating physicians with the family were held and a tracheostomy per family wishes was performed.

The patient remained on the ventilator with inexorable worsening of her respiratory function. The family seemed to understand clearly that we had no curative treatments for her disease and that she would die. The family, especially the daughter from Hawaii, was articulate, intelligent and seemed to genuinely want what was best for her mother. The daughter asked that since we could not cure her mother, that she be allowed to try alternative treatments and to continue full life support so that the alternative treatments could have time to work. She brought in
a box full of herbal medication of unknown type to put through the NG tube. Our risk management department got involved as well as the pharmacy and the decision was made to allow this alternative treatment to be given. I do not know the reasoning behind this decision. There was obvious concern on the part of the nurses and doctors that we did not know what was being given and how it could interact with the drugs we were giving.

The family also requested to rub garlic on the mother’s feet. This seemed to be a relatively benign request and they were allowed to do so (the nurses did not apply the garlic). After a couple of days of garlic therapy, the nurses brought me into the room (she was not my patient) to show me the patient’s feet. I was stunned to see huge blistering burns on the plantar surfaces of both feet.

In my role as Medical Director of the ICU, I sought advice from the Ethics Department and we met with the daughters in the patient’s room. When we exposed the feet, the daughters were quite excited, saying this was evidence that the treatment was working to draw out the fluid from their mother’s lungs. I expressed my discomfort at doing something that appeared to be causing obvious harm to the patient. This was not their perception and they asked to continue these measures which they believed meant so much to their mother and to them.

Medically, at this time the patient was moribund. She was on pressors, high oxygen concentrations and PEEP, and her kidneys were failing. It was decided to allow the family to proceed as long as we were satisfied that the patient was in no pain. Interestingly, the family did request that the morphine be stopped, but we insisted it continued.

A day or two later, the patient coded in the middle of the night. Full resuscitation efforts were made with the family in attendance, but the patient died. The next morning, I saw the daughters who had been speaking with pastoral care. They came up and hugged me and expressed their gratitude to all the caregivers for being allowed to do what they felt needed to be done.

Case Two

Culturally Competent Care: Who Decides?
[from the GUH file]

Baby Girl “Miracle” was transferred to your PICU at age 15 days suffering from necrotizing enterocolitis (NEC). Surgery was performed and her bowel was so necrotic that the surgeons basically “opened and closed” believing that she would die shortly. It is now day 30 and she is being maintained with multiple life-sustaining interventions including ventilators, hyperalimentation, antibiotics. Both the medical and nursing staffs believe that continued medical and nursing interventions to sustain life are “cruel and inhumane” and needlessly prolonging her dying and recommend a “comfort measures only” order. They believe the goal
of treatment should change from stabilizing her function and keeping her alive to preparing her for a comfortable and dignified death.

Baby Girl "Miracle" is her mother’s fifth child and dad’s first. Her parents are Mexican-American. The mother is at home recuperating from the birth and caring for her other children. The dad is constantly at the hospital. He believes that God will cure her and that the role of health professionals is to keep her alive until God can work a miracle. He believes that she will be "touched by an angel" and cured.

Should the team withhold or withdraw life-sustaining interventions or at the very least write a "Do not attempt to resuscitate order" against the wishes of the father?

Case Three

Culturally Competent Care: Who Decides?
[from the Philadelphia Inquirer]

Born only hours earlier at a distant community hospital in New Jersey, the twins looked surprisingly strong when they arrived by helicopter Sept. 15. They were joined at the chest, and they seemed to be hugging each other, with their wizened newborn faces only a few inches apart. Their respiration rate and their color was comparatively good, indicating that their blood was getting adequate oxygen. ...Special x-ray studies the next day showed that the twin designated Baby Girl B has an essentially normal, four-chambered heart that was fused to the stunted two-chambered heart of her sister, Baby Girl A. The hearts were joined along the walls of the left ventricles, ...The connecting wall was only one-tenth of an inch thick—far too thin to be neatly divided in order to give each twin what belonged to her. And even if this were possible, the stunted heart of Baby Girl A would not be able to support the child for long. The doctors felt that they could not leave the babies the way they were, either. They knew it would be only a matter or time before the overworked one-and-a-half hearts would start to fail, killing both babies. No twins joined at the heart like this had ever lived more than nine months.

The twins had been born to a deeply religious, Orthodox Jewish family of rabbinical scholars. The father himself is a rabbinical student to whom nothing matters more—not even life itself—than God, the teachings of his religion and biblical ethics. One axiom of biblical ethics is the infinite worth of human life. Since this ethic implies that all human life is equal—that one life is worth no more or less than another—would he consider it moral to kill Baby Girl A so that Baby Girl B could live? ...Several rabbis and other learned men met four to five hours every night for 11 days discussing the ethical issues.

...Word spread through Children’s Hospital that the surgeons were planning to sacrifice one of the Siamese twins. The hospital had said little, so the rumors were sometimes inaccurate. Mrs. Jane Barnsteiner, who is Catholic and the associate director for clinical nursing, was asked about the twins by the head nurses as she went about the hospital every day on her rounds. The Catholic nurses, of whom there are many,
were particularly concerned that the surgeons might be doing something that violated the teachings of their church. The word “sacrifice” was used so much by the nurses in discussing the matter that Mrs. Barnsteiner herself became concerned and decided to consult a priest.

At the same time, the nurses in the operating room were becoming particularly uneasy because they knew they would be called upon to participate in the surgery if it took place. Miss Betsch [assistant director of the operating room complex] said that she would consult a priest. A Catholic herself, she would not want to participate in the surgery if it went against her church.

[Donald C. Drake. (October 16, 1977). One must die so the other might live. The Philadelphia Inquirer.]
LEARNING OBJECTIVES

At the end of this lecture the learner will be able to:

1. Describe spiritual health and spiritual care.
2. Describe the role religion and faith beliefs play in determining Pellegrino’s “humanly good” as well as scientifically right “healing acts.”

READINGS


Recommended:

Grids illustrating the beliefs, rituals, practices, etc. of different religions.

PREPARATORY ASSIGNMENT

Perform and type spiritual assessments of two individuals using one of the guidelines below. Come to your small group prepared to describe your experience and your thinking about the importance and ease of incorporating a spiritual assessment into your practice.

Maugens’ (1996) SPIRIT mnemonic highlights important areas to be covered.

S—Spiritual belief system

- What is your formal religious affiliation?
- Name and describe your spiritual belief system.
P—Personal spirituality

- Describe the beliefs and practices of your religion or personal belief system
- Describe the beliefs or practices you do not accept.
- What does your spirituality mean to you?
- What is the importance of spirituality/religion in daily life?

I—Integration

- Do you belong to a spiritual/religious group or community? What is your role or position?
- What importance does this group have to you? Is it a source of support? In what ways?
- Does or could this group provide help in dealing with health issues?

R—Ritualized practices and restrictions

- Are there specific practices that you carry out as part of your religion/spirituality?
- Are there certain lifestyle activities or practices that your religion/spirituality encourages or forbids? Do you comply? What significance do these practices have for you?
- Are there specific elements of medical care that are forbidden on the basis of religious grounds?

I—Implications for care

- What aspects of your religion/spirituality would you like me to keep in mind as I care for you?
- Would you like to discuss religious or spiritual implications of health care?
- What knowledge or understanding would strengthen our relationship as caregiver and client?
- Are there any barriers to our relationship based on religious or spiritual issues?

T—Terminal events planning

- As we plan for end-of-life care, how does your faith affect your decisions?
- Are there particular aspects of care that you wish to forgo or have withheld because of your faith?

A simpler guide is Anandarajah and Hight’s (2001) HOPE acronym:

- **H**—Sources of hope, meaning, comfort, strength, peace, love, and connection
- **O**—Organized religion
- **P**—Personal spirituality and practice
- **E**—Effects on medical care and end-of-life issues
LECTURE OUTLINE

I. Holistic Health

A. The Theory Practice Gap and the Limits of the Bio-Psycho-Social Model of Health

Principles of Holistic Health

1. The person as a whole is made up of body, mind and spirit; the condition of a person’s health or disease is the reflection of the interaction of these facets.
2. Health is a process in which the body is continually at work to maintain a state of wellness and this process occurs in many different ways.
3. Holistic health inherently believes in prevention as fundamental to a person’s wellbeing.
4. Holistic health believes in self-care, in that the person is responsible for his or her own health—without the individual’s personal belief and adherence to a prescription for a healthy self, the efforts of others are often futile. [Solari-Twadell, P.A. & McDermott, M.A. Eds. (1999). Parish nursing: Promoting whole person health within faith communities. Sage Publications)

The Goal/Aim/Telos of Health Care: Health and Human Wellbeing or Good Dying

Galen: Health is that state of integrity/wholeness in which an individual is unimpaired in doing the things that are important to him or her

Health/disease state

\[
\begin{align*}
\text{person him/herself, ability to achieve valued} \\
\text{family goals}
\end{align*}
\]

Increasingly, achieving the goal of health care entails smooth coordination of the health care team’s expertise and energy

B. The difference between “healing” and “curing”

1. Curing: the alleviation of symptoms or the termination or suppression of a disease process through surgical, chemical or mechanical intervention
2. Healing: may be spontaneous but more often it’s a gradual awakening to a deeper sense of self (and of the self in relation to others) in a way
that effects profound change. Healing comes from within and is consistent with a person’s own readiness to grow and to change. A healing attitude is “a belief system that recognizes that all of life’s experiences, including injury, illness, and other setbacks, provides us with opportunities to learn and to grow toward that we are meant to be. Seen in this light, disease is not an enemy but a teacher and motivation. Disease is manifesting, in a physical way, the desire or need of the psyche to reestablish balance and integration through a change of direction in one’s lifestyle, behavior, or attitudes.” [McGlone, M.E. (1990). Healing the spirit. *Holis Nurs Pract, 4*(4), 77-84.

*Healing is the integration of self. People move from a sense of brokenness to a sense of wholeness. C. Puchalski*

**Healing Testimonies:**
Seven years ago I was faced with three life-threatening events in a period of three years. Those life-threatening experiences taught me that it is possible to “heal” and to live fully even when we are in the abyss of suffering. I believe everyone would benefit if we redefined “healing.” Here are elements I now include in my definition.

**HEALING IS:**
- Becoming whole, a life-long journey of becoming fully human, involving the totality of our being: body, mind, emotion, spirit, social and political context, as well as our relationships with others and with the Divine. Healing does not necessarily mean being happy or getting what we think we want out of life; it means growth, often with pain.
- Becoming our authentic self, releasing old unreal self-images, discovering who we really are, not what we think we should be, knowing why we are here and what we really value, restoring our ability to heed our aspirations.
- Reconnecting lost aspects of ourselves, paying attention to buried feelings and places inside us that are distressed or sick, enabling us to express our self in fullness, both the light and shadow sides.
- Being open to change and new possibilities; responding to problems by changing the picture; being willing to let in more life, to open up to what may have been previously closed or destroyed for us and that which holds promise of giving us new life and fulfillment.
- Facing our fears and refusing to be injured or wounded; changing our belief systems; breaking unnecessary taboos; letting go of what is familiar, and stepping into the unknown.
- Accepting that problems, pain, and suffering are part of life and inseparable from us – not a peripheral relationship, not something isolated and avoidable – enabling us to enter into problems and use suffering, pain, and life-threatening events to enrich our lives.
Being empowered by the Divine; discovering meaning in our defects, disorders, problems, and disease; experiencing new degrees of creativity and life forces that we might never have imagined before our difficulty; finding that our pains and fears are transformed into relief and confidence.

Recognizing the value and preciousness of life, knowing that every moment is unique and significant, which usually leads to greater appreciation of the wonder of our minds, bodies, and spirits and of the Divine.

Having faith and hope – important preconditions for mental and physical health; having a belief in the Divine, the meaning of human life, and the universe; helping us to claim our capacity to create and make something new.

Finding inner peace, contentment, and tranquility amid the realities of daily life, including its problems, changes, and chaos; experiencing a sense of fullness that makes the burdens of pain or illness lighter.

Being forgiving of ourselves and others and being forgiven; giving ourselves and others the freedom to let go of rivalry, strife, anger, hatred, fear and limitations.

Feeling connected to one another, a sense of interdependence; knowing we are not isolated or autonomous, giving up the illusions of boundaries in life; taking responsibility, acting justly, and accepting that we share our humanity.

Being loving and loved; loving one’s self and wanting to love and serve others, as well as being capable of receiving love; having an ability to trust, a feeling of aliveness, and a sense of greater participation in life.


II. Healing Presence

A. Healing presence is the condition of being consciously and compassionately in the present moment with another or with others, believing in and affirming their potential for wholeness, wherever they are in life.

Your healing presence can take many forms. You cannot do healing presence—you become healing presence, expressing it gently yet firmly in various ways: Listening, holding, talking, being silent, being still, being in your body, coming home to yourself, being receptive. ...You can deepen your healing presence by slowing down, by doing only one thing at a time, by reminding yourself regularly to come back to the present moment. You can encourage healing presence by being appreciative, forgiving, humble kind. (Miller, E.J. & Cutshall, S.C. 2001. The art of being a healing presence. A guide for those in caring relationships. Willogreen Publishing.)
Living a Lifestyle that Supports Spiritual Care
We cannot give what we don’t have. Unless our own needs are met we will never be able to be truly present to another. Thus the art of being a healing presence requires a lifestyle that supports this.

A happy heart is like good medicine. But a broken spirit drains your strength (dries your bones). Pr: 17.22

The Healer’s Personal Spiritual Care
The healer who wishes to offer spiritual care begins by assessing how well he or she is meeting his/her own spiritual needs. Assessment criteria include:

- Hold spiritual beliefs that meet needs for meaning and purpose, love and relatedness, and forgiveness
- Derive from these beliefs strength for everyday living, especially when confronting pain, suffering, and death in his or her professional practice
- Set aside regular periods to nurture his or her spiritual self
- Demonstrate in interactions with others peace, inner strength, warmth, joy, caring, and creativity
- Respect the spiritual beliefs and practices of others even when they are different from the HEALER’s own
- Increase knowledge of how the spiritual beliefs of others influence their lifestyles, responses to illness, healthcare choices, and treatment options
- Demonstrate sensitivity to the spiritual needs of patients and their family caregivers
- Develop successful strategies to assist patients and their caregivers experiencing spiritual distress

Questions for reflection
1. To what degree do recent recipients of my care experience me as a healing presence?
2. What kind of person must I be to be a “healing presence”?
3. When I am exhausted and “running on empty” how do I renew my spirit and ability to care? What is lifegiving in my life?
4. In what ways might my lifestyle need to change for me to become a better healing presence?
5. What kind of institutional culture, ethos, promotes our being a healing for one another?

III. Spiritual Care: Introduction

...I could scarcely make out the large sitting Buddha near the entrance of the house. But what caught my attention was the metal circle with spokes resembling a wheel, hanging over the figure of the Buddha. ...I asked our host about the wheel. I was told it represented our eternal journey in this life and continuing into the next. Buddha’s teachings say that life is suffering. We cannot avoid suffering as we move around the rim of the wheel, which represents
perpetual change and the transitory nature of life. But the wheel also symbolizes wholeness or completion because the wheel revolves around the center axis that does not move. That center point represents the presence of the divine. If we remain aware of this center point, we are strengthened for whatever lies ahead.

...It is this center point that grounds us in the midst of the many changes in our lives. It is at the center point where we experience the energy and power that turns the wheel. It is at this center point that we connect with the Everywhere Spirit. When we rest in the center point, we find that we have come home again to the place from which we started. But because of the journey, it is as if we had arrived home for the first time. In our journey around the circles of life, we become new persons over and over again. Susan Gregg-Schroeder, The Journal of Fellowship in Prayer, April 1999

A. Spirituality
Spirituality is recognized as a factor that contributes to health in many persons. The concept of spirituality is found in all cultures and societies. It is expressed in an individual's search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, rationalism, humanism and the arts. All these factors can influence how patients and health care professionals perceive health and illness and how they interact with one another. MSOP Report III: Association of American Medical Colleges, 1999

Puchalski's meaning with a capital and small “m”
• Meaning: Values, beliefs, practices, relationships, experiences, that lead you to the awareness of God/divine/transcendence and a sense of ultimate value and purpose in life.
• meaning: Activities, relationships, values that are meaningful to you but don't define the ultimate purpose of your life.

B. Universal Spiritual Needs
1. According to Fish and Shelly (1978) there are three spiritual needs underlying all religious traditions and common to all people: (1) need for meaning and purpose, (2) need for love and relatedness, and (3) need for forgiveness

2. George Gallup (1990) identifies six basic spiritual needs of contemporary Americans:
   a. The need to believe that life is meaningful and has a purpose
   b. The need for a sense of community and deeper relationships
   c. The need to be appreciated and respected
   d. The need to be listened to--to be heard
   e. The need to feel that one is growing in faith
   f. The need for practical help in developing a mature faith

C. Spirituality and Everyday Living
Spiritual beliefs and practices are associated with all aspects of a person's life, including health and illness. Aspects of a person's life commonly influenced by
spirituality and religion include relationships with others, daily living habits, required and prohibited behaviors, and the general frame of reference for thinking about oneself and the world.

Religious influences may be life affirming or life denying. **Life-affirming influences** enhance life, give meaning and purpose to existence, strengthen one’s feelings of self-worth, encourage self-actualization, and are health-giving and life-sustaining. **Life-denying influences** restrict or enclose life patterns, limit experiences and associations, place burdens of guilt on individuals, encourage feelings of unworthiness, and are generally health-denying and life-inhibiting. (Larue, 1981)

**D. Spirituality, Health, and Illness**
Spiritual beliefs are of special importance to clinicians because of the many ways they can influence an individual’s state of health and self-care behaviors: (1) daily living habits, (2) source of support, (3) source of strength and healing, (4) source of conflict

**E. Spiritual Care**
Care that enables individuals to meet basic spiritual needs: (1) need for meaning and purpose, (2) need for love and relatedness, and (3) need for forgiveness

**II. Spiritual Care and the Health Care Professional**

**ASSESSING SPIRITUAL NEEDS**

**History**
Because a person's spirituality and religious beliefs have the potential to influence every aspect of being, an assessment of spiritual needs should be included in each comprehensive health history. Helpful assessment guides are offered by Fish and Shelly (1978), Stoll (1979), and O'Brien (1982). Data are gathered around spiritual beliefs and practices, the effect of these beliefs on everyday living, spiritual distress, and spiritual needs.

The following questions are from O'Brien's (1982) Spiritual Assessment Guide:

**Spiritual pain:** Do you ever feel hurt or pain associated with the spiritual or religious beliefs that you hold? Do you feel pain related to uncertainty or nonbelief?

**Spiritual alienation:** Do you frequently feel far away from God? Does it seem that he is remote and far removed from your everyday life?

**Spiritual anxiety:** Are you afraid that God might not take care of your needs? That he might not be there when you need him?

**Spiritual guilt:** Have you ever done things that God would be angry at you for? Are you feeling badly about things that you have done or failed to do in your life?
**Spiritual anger:** Are you angry at God for allowing you to be ill? Do you ever feel like blaming God for your illness? Do you think God is unfair to you?

**Spiritual loss:** Do you ever feel that you have lost God's love? That you have broken or weakened your relationship with God? Has God turned his back on you?

**Spiritual despair:** Do you ever feel that there is no hope of having God's love? Of pleasing him? That God does not love you anymore? (p. 102)

If someone shares a spiritual problem, remember to use interview questions to determine the specific nature of the problem, its probable causes, related signs and symptoms, when it first began and how often it occurs, how it affects everyday living, the severity of the problem and whether it can be treated independently by nursing or needs to be referred, and how well the individual/family is coping with the problem.

**Observation**
Because many find it difficult to talk about their spiritual beliefs and problems, the HEALER also observes behavior for signs of spiritual distress. A family member or close friend may share significant observations.

**DIAGNOSING**
When assessment data point to a spiritual problem, it receives the label **Spiritual Distress**. This may be further specified as spiritual pain, alienation, anxiety, guilt, anger, loss, or despair (O'Brien, 1982). Common etiologies for spiritual distress include inability to reconcile current life situation (eg, illness, death of loved person, divorce) with spiritual beliefs ("God is all-powerful, all-loving, all-wise and he cares about me") or separation from or rejection of the religious community or supports.

**PLANNING: EXPECTED OUTCOMES**
HEALERS who are sensitive to the role spiritual beliefs play in influencing both a person's thoughts about self and the world and interactions with the world **value spiritual health**. Their interactions with any patient who values spirituality are supportive of the following goals/outcomes. The patient/family will:

- Identify spiritual beliefs that meet needs for meaning and purpose, love and relatedness, and forgiveness
- Derive from these beliefs strength, hope, and comfort when facing the challenge of illness, injury, or other life crisis
- Develop spiritual practices that nurture communion with inner self, with God, and with the world
- Express satisfaction with the compatibility of spiritual beliefs and everyday living.
Goals/expected outcomes for individuals experiencing spiritual distress need to be individualized and may include some of the following. The patient/family will:

- Explore the origin of spiritual beliefs and practices
- Identify factors in life that challenge spiritual beliefs
- Explore alternatives given these challenges: deny, modify, or reaffirm beliefs; develop new beliefs
- Identify spiritual supports (e.g., spiritual reading, faith, community)
- Report or demonstrate a decrease in spiritual distress following successful intervention

IMPLEMENTING
There are a variety of interventions available to the HEALER who wishes to help others meet spiritual needs. Like other clinical skills, these interventions need to be practiced before the HEALER is able to use them confidently, competently, and at the right moment. Specific interventions include: offering supportive presence, facilitating the practice of religion, nurturing spirituality, praying with patients and others, responding to human suffering and engendering hope, spiritual counseling, contacting a spiritual counselor, and resolving conflicts between treatment and spiritual beliefs.

**Offering Supportive Presence.**
*When you made a cross on my forehead with your thumb, it felt very foreign to me. No one has ever done that before. It felt unfamiliar—but perfect. Like a blessing with no conditions—no strings. How liberating. Affirming. Loving. And to think you did it with just your thumb. And your heart. Thank you.*

Human Caring Facilitates Healing. We care first and primarily by being present to others in a manner that is compassionate, affirming, and healing.

**Facilitating the Practice of Religion**

**Nurturing Spirituality**
Some who experience a need to get in touch with their spiritual self and to nurture their spiritual development may look to the HEALER for direction. The person who lives life enmeshed in the action and noises of society may feel strangely uncomfortable when illness forces solitude and self-introspection. The HEALER can be helpful in recommending means to develop a relationship with one's inner world and manifest spiritual energy in one's outer world. Hill & Smith (1990) identify the following ways to develop one's inner world and to manifest this energy to the outside world.
Ways to develop a relationship with one’s inner world

- Prayer
- reflection or “quiet listening to one’s essence
- communion with nature through walks in the park, woods, beach
- enjoyment of music, drama, art, dance
- inner dialogue with oneself or with God
- dream analysis
- spiritual direction

Ways to manifest spiritual energy to one’s outer world

- loving relationships with others
- service to others in need
- forgiveness of others
- empathy, compassion, and hope
- laughter, joyous expression
- participation in church services and activities and social gatherings

Praying With Others

Those accustomed to regular periods of prayer but who feel too ill to pray as they would like or who enjoy praying with others may ask the HEALER to pray with them or hope that the HEALER will suggest this. Because there are many forms of prayer—quiet reflection, silent communion with God, reading or recitation of formal prayers, silent or loud calling on God or conversation with God, or reading the Bible—the HEALER can take the lead from the patient by asking, "How would you like us to pray?" The religious background of the person is considered along with the type of prayers that have been meaningful in the past. It is also helpful to ask the person if there is a particular prayer request.

The HEALER unaccustomed to praying aloud or in public may find it helpful to have a Bible passage or formal prayer readily available. The prayer may also be a simple expression aloud of the person/family’s needs and hopes. A sample follows:

Lord God, our Creator and Healer, I entrust Mrs. Smith and her family to your loving care . . . bring peace to her mind and health and strength to her body. . . . Be with her [as her treatment begins today, as she goes for surgery, and so on] . . . We remember all your blessings to us in the past and thank you . . . We are confident of your help now as we claim your promises.

Loving Kindness Meditation (Source Unknown)

∞ May you be at peace.
∞ May your heart remain open.
∞ May you awaken to the light of your own true nature.
∞ May you know the power of your higher self.
May peace of mind be your only goal and forgiveness your only task.
May you be healed of all pain and hurt.
May you be a source of healing for others.
May you know the inner beauty of the person you truly are.
May you be at peace.

**Responding to Human Suffering and Engendering Hope**

*Hope develops from the basic human need to achieve, to create.* At its root, it embodies the question of the essence of ourselves that will live on after we die, our contribution. The power of this need fuels our will to live: the loss of such a drive leads to feelings of helplessness and despair. *... Hope is the ingredient in life that enables an individual both to consider a future and to actively bring that future into being.* Hope originates in imagination, but must become a valued and realistic possibility for an individual in order to energize action. *Hope has the capacity to embrace the reality of the individual’s suffering without escaping from it (false hope) or being suffocated by it (despair, helplessness, hopelessness).* Hope is unique to each person. During terminal illness, the future being considered will become more focused, yet hope is essential for an individual to transcend despair and complete crucial life tasks. [Ted Creen. Enabling Hope.]

“Suffering has been defined as a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted. It lasts until the threat is gone or integrity is restored. Suffering involves some symptom or process that threatens the patient because of fear, the meaning of the symptom, and concerns about the future. **The meanings and the fear are personal and individual,** so that even if two patients have the same symptoms, their suffering would be different.” --Eric Cassell

...Suffering is the exhibition of the presence in our existence of that which is not under our control,...of an activity operating under another law than ours, it cannot be brought adequately within the spheres of teleological and deontological ethics, the ethics of man-the-maker, or man-the-citizen. Yet it is in response to suffering that many and perhaps all men, individually and in their groups, define themselves, take on character, develop their ethos. --H. Richard Niebuhr

**Responses to Suffering**

**Finding Meaning in Life Experiences**
The concept of suffering in life experience is not new. Nietzsche was one of the first modern philosophers to call attention to this phenomenon: “He who has a ‘why’ to live for can bear almost any ‘how.’” Jaspers confirmed this need of the person to experience meaning: “As soon as an individual wakes he does not merely want to live out the day, but wants to live for something in his life.” Frankl, addressing himself to what he termed today’s “existential vacuum,” developed the conviction that “life holds a meaning for each and every individual,
and even more, it retains this meaning literally to his last breath.” “Whenever one is confronted with an inescapable, unavoidable situation...e.g., an incurable disease... just then is one given a last chance to actualize the highest value, to fulfill the deepest meaning... the meaning of suffering.”

**Counseling the Patient Spiritually**
Those who feel that the HEALER is sensitive to spiritual needs and comfortable in his or her own spirituality may choose to share spiritual concerns with the HEALER rather than with a religious counselor. The HEALER who feels able to counsel assists the individual to:

- Articulate spiritual beliefs
- Explore the origin of spiritual beliefs and practices
- Identify life factors that are challenging spiritual beliefs (causing spiritual distress)
- Explore alternatives given these challenges: modify lifestyle; deny, modify, or reaffirm beliefs; develop new beliefs
- Develop spiritual beliefs that meet needs for meaning and purpose, care and relatedness, forgiveness

To be an effective spiritual counselor, the HEALER must be open to different spiritual beliefs and forms of spiritual expression and supportive of the individual’s efforts to nurture spiritual growth.

**Contacting a Spiritual Counselor**

**Resolving Conflicts Between Spiritual Beliefs and Treatments**
Both the patient and members of the patient's family may experience conflict between a particular spiritual belief or religious law and a proposed medical treatment or health option. The patient may want the HEALER's assistance when conferring with the spiritual adviser about a particular procedure. The HEALER's role is to assist the patient in obtaining the information needed to make an informed decision and to support the patient’s decision making--when this does not violate the HEALER's conscience/moral integrity. Because what the HEALER says and the way it is said may powerfully influence the patient's decision, it is important for the HEALER to maintain objectivity.

**EVALUATING**
The HEALER working with a patient and family to achieve specified goals/outcomes to meet spiritual needs can use each interaction to evaluate the plan of care. Necessary to the evaluation are sensitivity to what the patient is saying and not saying and observation of the patient when alone as well as when interacting with the family and HEALERS.
In general, the HEALER evaluates the ability to:

- Find meaning and purpose in the patient's current condition
- Interact honestly with family, friends, and others who are meeting the need for love and relatedness
- Derive strength and peace from prized spiritual beliefs
- Reconcile any interpersonal differences causing anguish (religious belief or law in conflict with medical therapy)

The HEALER helps the patient to determine if spiritual beliefs are generally life affirming or life denying and if there is harmony between these beliefs and the patient's everyday life experiences.

**SMALL GROUP ACTIVITY**


2. Identify how physicians who are culturally competent could best meet the spiritual needs of the patients in the cases that follow and ensure better outcomes.

**Unmet Spiritual Needs Compromise Clinical Care and Decisionmaking**

Universal Spiritual Needs: love and belonging, forgiveness, meaning and purpose

*Case One.* Mrs. Mendez is a 62-year-old woman with a newly diagnosed breast cancer. She recently has completed surgery and is scheduled for chemotherapy and radiation therapy. The treatment left her with many physical symptoms, including pain, extreme weight loss, and fatigue. Mrs. Mendez recently was forced to move in with her daughter and son-in-law. In a recent home visit, Mrs. Mendez asked her homecare nurse to communicate to her physician that she would like to cancel the chemotherapy and would rather let the cancer take its course and “die rather than prolong my suffering.” On further assessment, the nurse identified many concerns and potential sources of suffering for Mrs. Mendez. The patient said that she cannot sleep at night because of the guilt and anguish that she feels knowing that her three daughters also are destined to have breast cancer and die. She also feels frustrated in her current living situation and has had conflicts with her son-in-law.

Mrs. Mendez always has relied on her cultural beliefs and traditional practices including the use of a healer, herbal remedies, and many religious rituals to face illness. Her son-in-law, however, is not of Hispanic origin and has prohibited these practices in their home, because he believes they are “witchcraft” and he does not want his children exposed to such practices. Mrs. Mendez was divorced approximately 10 years ago and also expresses her belief that this cancer is God’s punishment because, as her family reminds her, divorce is unacceptable within their faith. Over the past two weeks, the homecare nurse has recognized an increased intensity in her suffering and that she has become
more isolated over time. She asked her physician to discontinue her pain medications because she does not feel comfortable having them in the home for the fear that in her present state, she might consider suicide and believes that God would, in fact, further punish her for such an act. She tells the nurse, “I have gone from being the mother of seven children to now being the baby, dependent on my girls to care for me.”


**Discussion.** You are Mrs. Mendez’s oncologist and have arranged for her to visit you following your discussion with her homecare nurse. What do you say to her and why? What are her clinical priorities? What are the limits of your responsibilities as a physician?

**Case Two.** “My father is confused and afraid to die,” Bill Fitzpatrick said, referring to his father in the May 8 Metro article, “Often limited, living wills rarely ensure a simple solution.” The Fitzpatrick family has ended up in a situation all of us hope to avoid. Sadly, the elder Fitzpatrick felt he had made preparations to prevent what is now happening.

According to the article, 75-year-old Frank Fitzpatrick was in Fairfax Hospital following lung cancer surgery. Eight weeks later, he was hooked up to machines to breathe for him and feed him. Three years ago, he had signed a living will stating that if he ever had a terminal condition he did not want his dying artificially prolonged. Recently, he pulled tubes away from his body, seemingly to confirm his wish to die a natural death. But those charged with his medical care asked Mr. Fitzpatrick if he wished them to reconnect his tubes and he said he did.

Meanwhile, the son and his wife are in anguish over the suffering of his father. They evidently had talked his father into the surgery and now feel guilty for encouraging a course of treatment that has left a man unable to live comfortably or die peacefully. As a full-time chaplain in a nursing home for the past decade, I have often seen similar situations. People think they have done all the necessary preparation for a peaceful death. They sign living wills and medical powers of attorney. They talk to their physicians about their health care wishes. But something is missing.

The Post article was almost 50 column inches long, yet it never recognized the emotional and spiritual dimensions of this case. It never once picks up on the most telling of comments—the man is “confused and afraid to die.”

I wonder how the patient’s fear of death is being addressed, other than by reinserting the life-prolonging devices. Physicians are not trained to handle a patient’s fear of death. So they do what they can—continue with a technological solution without addressing this man’s emotional and spiritual anguish.

The mistaken assumption is that the family’s dilemma only involves questions about patient rights, legal documents, ethics, and what is medically
appropriate treatment. In my view, these questions are minor compared with the ultimate questions: **What is the meaning of my life and my death?**

Regrettably, our health care and legal systems do nothing to address this question. The reinsertion of the tubes affirms the patient’s right of self-determination but avoids the emotional and spiritual crisis behind such a request. As long as our public discussion about end-of-life decisions focuses only on law, medicine, ethics and our rights, it will stay far removed from what is really going on. Often it comes down to the question of can I trust in God, or must I hold on to life out of fear?


**Case Three.** After declining for years, the suicide rate among elderly Americans is rising. Experts suggested that the increase resulted from people living longer with chronic illness and from the social isolation of the elderly. Society’s growing acceptance of suicide may also play a role, the experts said. *New York Times*, January 12, 1996.

Only Aunt Millie survives. She is 88 now, a widow with alabaster hair and skin like parchment. Some days she seems more frail than others, and it is on these melancholy days that she begins to muse. Her eyes fill with doubt and she says things like, “Why? Why are the scientists breaking their brains to get us to live longer? I want to know, what’s the point? ...In a thoughtful book called “The Journey of Life: A Cultural History of Aging in America,” a historian named Thomas R. Cole says that in the last 200 years the social and biomedical sciences have thought of old age as only “an engineering problem to be solved or at least ameliorated.” But, by reducing old age to a “problem,” science has impoverished it, Cole says. Science has robbed old age of the rich symbolism and purpose it had for most of our history. In other words, old age no longer stands for anything. It is empty, purposeless, without meaning. And as “spiritual animals, we need meaning, “ Cole says, no less than we need sustenance and health.
...The cure, say humanists like Moody and Cole, is to search for meaning, by which they mean something much more difficult than platitude. They urge the oldest old to think of themselves not as individuals but as part of something larger—a cultural or religious tradition, a family, an idea—anything that would offer “transcendence.” They suggest that the old might effect these ontological and spiritual attachments by going to retreats, taking courses, relearning religion or engaging in what gerontologists call “life review,” a kind of coming to term with the past, its triumphs and failures, its good luck and bad. The problem, on the face of it, is that all this seems a bit thin. “I say to myself, where are the structures for someone to do that,” says David Barnard, chairman of the department of humanities at the Pennsylvania State University College of Medicine. “When you talk about meaning you can’t expect people to come up with it themselves.” [Michael Norman. (January 14, 1996). Living too long. The New York Times, 36, 38.

What role, if any, should medicine (individual physicians) play in helping patients who are searching for meaning?

Reliance on God’s Providence Compromises Medically Appropriate Self-Care

Case Four. Brenda. was a 40 year old single mother of three children ranging in age from four to nine. She was admitted to the oncology unit with a diagnosis of metastatic cancer of the breast. Throughout her one month stay Brenda deteriorated despite aggressive therapy, and wide spread bone metastasis was confirmed by bone scan.

Brenda was a cheerful, optimistic person with a deep religious faith and a strong conviction that her faith would heal all ills. She knew that she had cancer but did not believe that the disease was terminal. Nurses would frequently discuss what was physically happening to her and would encourage open communication, but she selectively listened to what was being said. Toward the end of the month Brenda was told that nothing further could be done. Again, she listened and said that she understood but continued talking unrealistically about cure with positive thoughts and herbal tonics. The future with her children was her lifeline.

Her support system included an elderly uncle who lived in a nearby state and her 35 year old alcoholic sister who was struggling to care for her children in her absence. The sister visited infrequently and complained to the nursing staff about the responsibility involved in taking care of “the little brats.” After a month Brenda insisted upon discharge to be at home with her children, and her sister stated she would do the best she could to take care of the family.

The reluctant decision was made to discharge the patient at her insistence. Prior to the writing of her discharge orders, labs showed that her calcium level was 12.2 (normal 8.5-11.5). She was approached for consent to initiate 3-day IV Didronel therapy, and it was clearly explained that not treating
this at least temporarily reversible condition would result in certain death within days and that treatment might extend her life for many months. She was also told that her insurance would only cover this therapy in the hospital setting—not at home. She listened carefully, refused treatment, and reiterated her demand for discharge.

The next morning her primary nurse noted that she was lethargic, weak and confused. Her calcium level was now 15.4. The interdisciplinary team caring for the patient asked for an immediate ethics consult. They wanted confirmation of their plan to initiate treatment for hypercalcemia immediately “to save her life” on the grounds that she was no longer competent to make a reasoned decision.

1. How would you respond and what justifies this response?
2. How would you respond to Brenda’s “deep religious faith and strong conviction that her faith would heal all ills.”
LEARNING OBJECTIVES

At the end of this session the learner will be able to:

1. Critique health care using the elements of the ethical and cultural competence of the individual physician and the health care environment.

GENERAL SESSION

We will gather as a class to watch the film W;t.

take home final examination—due November 13

After watching the film W;t in class on November 6, prepare a thoughtful 5-6 page typed, double-spaced, paper which analyzes the personal, professional and institutional factors (N.B. use these headings in your paper) which influence the care received by Dr. Vivian Bearing. Grading criteria (see below) include 1) depth and breadth of analysis, 2) through and creative grasp of course content (ethical and cultural competence), and 3) use of cited, supporting literature.

- The honors take home examination critically analyzes the personal (Dr. Vivian Bearing, Drs. Harvey Kelekian and Jason Posner), professional (medicine and clinical research) and institutional (academic health center) factors which affect the care received by Dr. Vivian Bearing in the play, W;t. The comprehensive analysis in the honors essay demonstrates a thorough and creative grasp of course content (ethical and cultural competence) and cites course and additional literature to support judgments.

- The high pass take home examination analyzes the personal (Dr. Vivian Bearing, Drs. Harvey Kelekian and Jason Posner), professional (medicine and clinical research) and institutional (academic health center) factors which affect the care received by Dr. Vivian Bearing in the play, W;t. The comprehensive analysis in the honors essay demonstrates a thorough grasp of course content (ethical and cultural competence) and cites course and at least some additional literature to support judgments.

- The pass take home examination describes the personal (Dr. Vivian Bearing, Drs. Harvey Kelekian and Jason Posner), professional (medicine and clinical research) and institutional (academic health center) factors which affect the care received by Dr. Vivian Bearing in the play, W;t. The analysis in the pass essay demonstrates a basic grasp of course content...
(ethical and cultural competence) and cites course literature to support judgments.

- The *fail* take home examination fails to analyze or describe in more than an erratic manner the *personal* (Dr. Vivian Bearing, Drs. Harvey Kelekian and Jason Posner), *professional* (medicine and clinical research) and *institutional* (academic health center) factors which affect the care received by Dr. Vivian Bearing in the play, *W;t*. This response does not demonstrate the assimilation and ability to use pertinent course content (ethical and cultural competence) and fails to cite course and additional literature to support judgments.
LEARNING OBJECTIVES

At the end of this lecture the learner will be able to:

1. Critique health care using the elements of the ethical and cultural competence of the individual physician and the health care environment.

READINGS:
Review whatever course readings you believe will be helpful for the writing of your examination.

GENERAL SESSION: MASTER CLINICIAN-PATIENT DIALOGUE

SMALL GROUP ACTIVITY
Meet in your small groups to submit your final examination and to share your critique of both the film, W;t, and the master clinician-patient encounter.