Syllabus

Readings ▪ Preparatory Assignments ▪ Lecture Outlines
Ethical Competence II
Winter/Spring 2008
GA2-4 PreClinical Science Building

Center for Clinical Bioethics ▪ Georgetown University Medical Center
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An introductory note on the overall goal of Ethical Competence II

Every year, when we begin to plan the next offering of Ethical Competence, Part Two, we re-examine the goals that drive our teaching. And every year, we eventually reaffirm, as our reason for being, the opportunity to contribute to the development of a “refined capacity for moral reflection” in our students – a capacity that the authors of the following quote identify as a required competency for the contemporary practice of medicine and nursing.

The Course Directors and Faculty of Ethical Competence II

If ever there was a Golden Age in which the kindly village doctor knew best and his grateful patients unquestioningly accepted his decisions, it may safely be said that we are no longer in it.

Today’s health care professionals provide care in highly organized and complex surroundings, where they encounter not only patients, but other professionals whose values do not necessarily accord with their own.

These changes in the way the health care system functions have consequences for those who are working in it. To adapt to the new environment, a good professional must not only exhibit the technical proficiency that allows her to do things right—she must also do the right thing.

She needs to be aware of her own professional norms and values; to be able to express them to her colleagues, her patients, and their families; and to work together with these other actors to provide ethically responsible care. In short, if professionals do the right thing, they must develop a refined capacity for moral reflection.

A Note on the Syllabus

**Ethical Competence II** consists of 10 sessions. Session 1 is the introductory session for which there is no preparatory assignment or reading. For Sessions 2 through 10, students will need to complete readings and preparatory assignments prior to each session. The syllabus integrates the readings and preparatory assignments with the lecture outlines for each of these sessions.

For each of the Sessions 2 through 10, students should (1) review the learning objectives; (2) complete the readings; (3) complete the preparatory assignment; (4) attend the lecture; (5) submit your preparatory assignment to your small group leader/facilitator; and (6) participate in, and contribute to the small group activity.

**Ethical Competence, Part Two: At a Glance**

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic &amp; Presenter</th>
<th>Reading</th>
<th>Preparatory Assignment</th>
<th>Small Group Activity</th>
<th>Basic Skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Jan 15</td>
<td>Ethical Competence II Introduction &amp; Course Overview Taylor</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>Recognize the ethical challenges in everyday practice; Distinguish ethics From law, religion, culture, etc. Use ethics work-up</td>
</tr>
<tr>
<td>2 Jan 22</td>
<td>General Ethical Theory</td>
<td>Introduce/ review approaches to informing, justifying, &amp; explaining moral action</td>
<td>The case of Maria: ethical analysis</td>
<td>Discussion of Prep Assignment The Case of Maria</td>
<td>Use effective approaches to inform, justify, and explain moral action</td>
</tr>
<tr>
<td>Date</td>
<td>Session Title</td>
<td>Reading Material</td>
<td>Activity</td>
<td>Notes</td>
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<tr>
<td>Jan 29</td>
<td>Determining Capacity &amp; Eliciting Valid Consent/Refusal</td>
<td>Excerpts from Devettere on capacity and consent; Jones, A Guide to Assessing DMC</td>
<td>Discuss 3 Scenarios</td>
<td>Identify the criteria to evaluate decision making capacity; obtain valid consent/Refusal</td>
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<tr>
<td>Feb 5</td>
<td>Advance Care Planning &amp; Advance Directives</td>
<td>Excerpts from Devettere on advance directives</td>
<td>Role Play Advance Care Planning</td>
<td>Clarify DNR status and treatment goals; Facilitate the preparation of an advance directive</td>
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<tr>
<td>Feb 12</td>
<td>Decision Making for Others</td>
<td>Excerpts from Devettere on deciding for others</td>
<td>Discuss 5 scenarios</td>
<td>Identify “at risk” Populations; Identifying and Supporting Valid surrogates; Applying the Best interests and Substituted Judgment standards</td>
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<tr>
<td>Feb 26</td>
<td>End-of-Life Issues</td>
<td></td>
<td></td>
<td>Complete &amp; bring to class on Feb 26</td>
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</table>

Mid-Course Formative Assessment: Self-, Peer-, & Faculty-Assessment of Student Performance in Small Groups

Honest communication Guidelines for Initiating, withholding & withdrawing LSMT
<table>
<thead>
<tr>
<th>Day</th>
<th>Date</th>
<th>Topic</th>
<th>Reading Material</th>
<th>Literature/Case Analysis</th>
<th>Homework/Projects</th>
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<tbody>
<tr>
<td>7</td>
<td>Mar 25</td>
<td>Medical Futility</td>
<td>Duffy</td>
<td>Prevent and resolve ethical conflict; Identify criteria for medically futile Ts; Participate in an ethics consultation</td>
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<tr>
<td>8</td>
<td>Apr 1</td>
<td>Truth-telling Privacy and Confidentiality</td>
<td>Excerpts from Fletcher’s Introduction to Clinical Ethics</td>
<td>Analyze Privacy/Confidentiality Cases; Analyze Privacy/Confidentiality Cases; Respect the privacy Rights of patients</td>
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<tr>
<td>9</td>
<td>Apr 8</td>
<td>Beginning of Life and other controversial Issues</td>
<td>Duffy</td>
<td>Clarify personal Moral convictions and reflect on how they Influence professional practice</td>
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<tr>
<td>10</td>
<td>Apr 15</td>
<td>Justice, Professionalism &amp; the primacy of the Patient, and the Challenge of Divided Loyalties</td>
<td>Toulmin’s Divided Loyalties &amp; Ambiguous Relationships; Blumenthal’s Doctors &amp; Drug Companies; AMSA &amp; No Free Lunch</td>
<td>Analyze Mini Cases Raising Challenges to Professionalism, ethics &amp; Justice; Analyze Mini Cases Raising Challenges to Professionalism, ethics &amp; Justice; Act fairly (justly); Meet obligations to vulnerable patients; Identify and respond ethically to inappropriate financial Incentives.</td>
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<td></td>
<td>Apr 22</td>
<td>Final Summative Assessment: Self-, Peer- &amp; Faculty Assessment of Student Performance in Small Groups + Final Examination</td>
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</table>
Learning Objectives

By the conclusion of *Ethical Competence, Part Two*, students should be able to:

1. Identify and describe the predominant moral challenges and issues encountered by physicians and nurses in the clinical practice of their professions

2. Assess the ability to effectively respond to common moral challenges encountered by physicians and nurses in the clinical practice of their professions paying attention to moral character and basic ethical skills

3. “Diagnose,” analyze, and resolve moral problems and challenges, methodically and systematically

4. Inform, explain, and justify their moral actions, methodically and reasonably

5. Assess their effectiveness as a contributor to, and participant in a group process of ethical decision making

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...
      i. Intellectual and technical competence in service of cure
      ii. Broader competencies which include ethical competence in service of healing
   b. What’s at stake for the public you serve, for yourselves and for medicine and nursing as professions—especially in the present context

2. Clearly articulating where we [GU faculty] “stand” on the professionalism and ethics debate...

3. Respecting the Jesuit and Catholic identity of Georgetown University

4. Teaching the “right” stuff [addressing everyday, REAL concerns and issues vs. “hot topics”: What you believe matters!]

5. Addressing ’ethics is a matter of opinion” and therefore relative and therefore “ungradable” issue [“I showed up for every class and turned in assignments so why didn’t get Honors/A]

6. Honoring the dynamics of each small group while facilitating a comparable experience for all students.

Note the contrast between an opinion and a reasoned philosophical argument or justification.

Opinion:
I don’t feel anyone should have to suffer more than they want and so support physician- or nurse-assisted suicide.
Or, 
I’m Republican and part of the moral majority and am opposed to assisted suicide.

Reasoned philosophical argument
Nothing is more central to who we are as humans as our ability to make choices in light of human goods. I prize our capacity to be self-determining and support physician- and nurse-assisted suicide. (Principle-based ethics: Respect for autonomy)

I believe that life is a gift and not ours to initiate or terminate—hence I am opposed to assisted suicide. Basically I believe that there are limits to freedom… our autonomy is not absolute. We are created by God free to act and make choices in accord with God’s plan for the world. (Theological Ethics)

Format

- There are ten weekly sessions, beginning Tuesday, January 15 and ending Tuesday, April 15. In addition, there will be a final examination on Tuesday, April 22.

- With the exception of session 1 on January 15th, all subsequent sessions (i.e., January 22nd through April 15th) will begin at 10:00 am and will end by 11:50 am; session 1 on January 16th begins at 11:00 am and ends by 11:50 pm.

- The course will be introduced in Session 1 on January 15th. Each subsequent session will consist of
  - approximately 30 to 40 minutes of lecture, designed to distill and convey the most important concepts, definitions, facts and questions for the given topic
  - followed by approximately 70 to 75 minutes of small group-based activity, i.e., case- or problem-based discussion, role-play, etc.

- All of session 1 and the lecture component of sessions 2 through 10 will occur in GA24 Preclinical Sciences Building; students will be assigned to small groups for the small group-based activities.

Course Requirements and Criteria for Student Assessment

Student assessment in Ethical Competence II permits recognition of meritorious performance in the course. The graduate nursing and medical schools use nominally
different — but substantively equivalent — grading systems. Neither group of students (i.e., neither graduate nursing nor medical students) has an advantage or disadvantage with regard to the criteria for student assessment in this course.

<table>
<thead>
<tr>
<th>Graduate Nursing Student Grades</th>
<th>Points</th>
<th>Medical Student Grades</th>
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<tbody>
<tr>
<td>A</td>
<td>≥ 93</td>
<td>Honors</td>
</tr>
<tr>
<td>A-</td>
<td>90 – 92</td>
<td>High Pass</td>
</tr>
<tr>
<td>B+</td>
<td>87 – 89</td>
<td>Pass</td>
</tr>
<tr>
<td>B</td>
<td>83 – 86</td>
<td>Low Pass</td>
</tr>
<tr>
<td>B-</td>
<td>80 – 82</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>70 – 79</td>
<td>Fail</td>
</tr>
<tr>
<td>F</td>
<td>&lt; 70</td>
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</tbody>
</table>

A student can earn up to 100 points for his/her performance in *Ethical Competence, Part Two*:

- Up to 40 points will be derived from the small group instructor’s assessment of a student’s preparation for, and participation and performance in the small group-based activities. At two junctures in the course – at the course’s mid-point in February (i.e., after Session 5 on February 12th) and at the course’s end – each student will complete a self-assessment and submit it to the small group instructor; and, the student’s small group peers will complete assessments of his/her performance and submit them to the small group instructor. The assessments conducted at the course’s mid-point are intended to provide each student with *formative* feedback so that, if need be, improvements in performance in the small group activities can be made. In the small group instructor’s formulation of the final, *summative* assessment of a student’s performance in the small group-based activities, the student’s self-assessment and peer assessments will play a strictly *advisory* role.

- Up to 27 points will be derived from the student’s weekly preparatory exercises (each week’s assignment can merit a maximum of 3 points)

- Up to 33 points will be derived from the assessment of a student’s performance on the *written segment* of the final examination.

*Please be sure to read the following requirements and criteria carefully.* Any questions or concerns should be directed to the course directors, Doctors Duffy and Taylor. The small group-based activities (i.e., for sessions 2 through 10) have the following requirements and criteria for assessment:
Attendance at each of the nine small group-based activities is required. If a student must be absent (e.g., due to illness or emergency), s/he MUST give advance notice (i.e., prior to the session) to the small group instructor (either via phone or e-mail). Unexcused absences will have an adverse impact on the portion of the final grade that is based on student performance in the small group-based activities.

Prior to the small group-based activities, students are required to complete the readings and the preparatory assignments. Students should submit their completed preparatory assignments to their small group instructors. IF A STUDENT’S HANDWRITING IS NOT CLEARLY LEGIBLE, S/HE SHOULD TYPE HIS/HER RESPONSES. ILLEGIBLE SUBMISSIONS WILL BE RETURNED UNGRADED TO THE STUDENT. Small group instructors will review the submitted preparatory assignments and utilize a simple system to provide feedback on the quality of the submission:

- a “-” sign (i.e., a minus sign) indicates deficient preparation (in which case a student should probably have a brief chat with the small group instructor); A minus sign merits one point.

- an “=” sign (i.e., an equals sign) indicates adequate preparation and merits two points; and,

- a “+” sign (i.e., a plus sign) indicates more than adequate preparation and merits three points.

For the self-, peer- and faculty-assessments of student performance in the small group-based activities, the criteria on the following page will be utilized. Using these criteria, a student’s performance in the small group activities may be assessed by self, peers, and faculty at a point (or points) along the range from “persistently inadequate” (for which 0 to 1 point may be assigned) to “consistently excellent” (for which 9 to 10 points may be assigned). Assessments of better than “persistently inadequate” but less than “consistently excellent” may be assigned points ranging from 2 to 8.
<table>
<thead>
<tr>
<th>Criteria</th>
<th>Persistently Inadequate Contribution to Small Group Activity 0 – 1 point</th>
<th>Consistently Excellent Contribution to Small Group Activity 9–10 points</th>
</tr>
</thead>
</table>
| **Excellence & Scholarship**  
Commitment to attaining & sharing knowledge, preparation & lifelong learning | • 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 | • Well prepared for sessions  
• Preparatory assignments of high, outstanding quality  
• Provides knowledge and well-supported information to help group’s progress  
• Effective and creative with problem solving  
• Committed to excellence  
• Able to advance and defend a philosophical justification for positions taken in class  
• Constructively criticizes positions of others |
| **Respect, Acceptance of Differences, Caring & Compassion**  
Commitment to acceptance of individual & diverse opinions & differences, as well as respect for others & empathy | • Seemingly intolerant of or insensitive to differing opinions or cultural, ethnic, or individual differences distracting sidebars/disrupting group, distant or guarded  
• Uncaring or lacking compassion | • Respectful of individual differences in faculty and peers  
• Works well in team  
• Empathetic, caring, and compassionate |
| **Responsibility, Accountability, & Leadership**  
Commitment to accomplishing the work of the team, behavior that befits a professional, & building & maintaining a culture that promotes professionalism | • Defensive or fails to respond to feedback  
• Consistently late for sessions  
• Arrogant  
• Lacks initiative or leadership qualities  
• Failure to conduct self and peer assessment with requisite discrimination and seriousness | • Takes responsibility for appropriate share of team work, as well as for own learning and that of other team members  
• Responsive to feedback and offers feedback  
• Asks for help when needed  
• Provides leadership  
• Took self- and peer assessments seriously; provided discriminating assessments of self and others |
| **Communication**  
Effective oral communication, including listening skills | • Unable to communicate clearly  
• Dominates/does not listen to others | • Communicates well orally  
• Demonstrates attentive listening |
As previously noted, self-, peer- and faculty-assessments in small groups will be conducted twice during *Ethical Competence II*:

- **First**, at the mid-point of the course, i.e., after Session 5 on February 12th: these assessments will be *formative* and serve the sole purpose of providing each student with feedback to guide subsequent efforts, especially if improvement is needed.

- **And then**, at the end of the course, i.e., after Session 10 on April 15th: these assessments will be *summative*. Small group faculty will assess student performance in the small groups, assigning up to 40 points for a given student’s performance and utilizing the self- and peer-assessments of that student in the process of determining this segment of the student’s final grade in the course.

**Written Take Home Final Examination**

> The written take home examination will provide an opportunity for students to use the ethics work-up to demonstrate their assimilation of course content and include a brief reflection on the dispositions and skills they have developed during the semester and the self-knowledge they gained. The maximum number of points to be awarded for the written final examination is 33. Students will meet on April 22nd in their small groups to hand in their exams and evaluate course learnings.

**Small Groups**

*Ethical Competence, Part Two* has its “center of gravity” in the small group activities that follow the lectures: it is here that the real “work” of the course is accomplished, collectively and in dialogue – hence, the significance placed on self-, peer- and faculty-assessment in the small groups. Student assignments to the small groups are found on the following pages. Students with questions or concerns about small group assignments – especially students whose names do not appear on the following group rosters – should contact Drs. Duffy or Taylor.

Students are encouraged to get to the small group locations as soon as possible after the conclusion of the lectures; faculty are reminded that the small group activities should be concluded and students dismissed by 11:50 a.m.
<table>
<thead>
<tr>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
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<td>Montbertrand</td>
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<td><a href="mailto:Jlynch7376@verizon.net">Jlynch7376@verizon.net</a></td>
<td><a href="mailto:losmp@earthlink.net">losmp@earthlink.net</a></td>
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<td>Building D 172</td>
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<td>Building D 301</td>
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<table>
<thead>
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<tr>
<td>Abdi, Tsion</td>
<td>AchirIMofor, Ngwe</td>
<td>Acord, Michael</td>
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<td>Gex, Saskia</td>
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<td>Taff, Jessica</td>
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<td>Drop, Krysta</td>
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<td>Millard, Kathleen</td>
<td>Murphy, Erin</td>
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<td>Group 7</td>
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## Small Group Instructors, Student Assignments, and Rooms

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15
**Moral Agency**—the ability to be counted on to do the right thing for the right reasons: Questions for Reflection & Self Assessment

| **Moral character:** | To every new moral challenge, the physician or nurse brings a certain set of habitual predispositions, that is, she brings the virtues and the vices that she has acquired through her experience of previous moral challenges – of life itself; in other words, she brings her **character**.  

What are my distinctive virtues and vices? What do they suggest, perhaps predict, about my behavior in response to the moral challenge? How does a given virtue or vice enable or constrain the exercise of my moral agency? |
|---|---|
| **Moral valuing:** | To every new moral challenge, the physician or nurse brings his **values**. In other words, his response to that challenge will be shaped, in part, by his own experiential process of investing such “objects” as life, or happiness, or pleasure, or material success with importance and significance.  

| **Moral sensibility:** | To every new moral challenge, the physician or nurse brings her **moral sensibility**, i.e., her capacity for recognizing the very existence of the challenge and for grasping its significance.  

What is the ethical challenge? What are the specific questions? What values are at stake? For whom is the challenge a challenge? |
| **Moral responsiveness:** | Every moral challenge beckons each involved individual to be responsive to it, to take it up and be engaged by it. Such **responsiveness** often depends upon courage, which is often a pivotal virtue in moral agency (and thus is, as well, an important aspect of another element of moral agency, character).  

How willing am I to intervene in, to get actively engaged with this challenge? What within me inclines or disinclines me? What traits of mine are on display in my responsiveness – or my lack of responsiveness – to this challenge? |
**Moral reasoning:** Every moral challenge also demands that we meet it **reasonably** and **methodically**, if we are to realize, fully, the distinctively human capacity for justifying and explaining our actions.

What is the appropriate methodical approach to the given challenge? How does the moral challenge appear through the lens of different moral perspectives? What does each moral perspective have to offer to my effort to answer such compelling questions as: What should be done? What should I do? What should I be or become in the face of this challenge?

**Moral discernment:** Every moral challenge ultimately demands that a physician or nurse **discern** and take the decisive action needed to meet the challenge – and to do so in ways that are consistent not only with our character and our values, but also with reason.

Which course of action is a right and good healing action for this patient – a good, right or just action in this moral situation?

**Moral accountability:** In meeting the challenge, a physician or nurse is also called to be **accountable** for the decisions and choices made and the actions taken in meeting the challenge.

What are the likely consequences of this course of action and how prepared am I to “own” – to cope with and be accountable for – these consequences?

**Moral advocacy and leadership:** And finally (and this has particular relevance in health care), every moral challenge challenges a physician or nurse to look beyond the immediacy of the situation in which it arises and to explore and address any systemic factors that may contribute to the genesis of the challenge -- to be an **advocate for, and leader of change for the good of patients and society**.

Does the moral challenge in this dilemma, this problem, this situation, originate in something systemic, e.g., the culture of the institution, an unresponsive bureaucracy, etc. How can these causes be addressed, their effects diminished? What is my role in addressing these causes and diminishing their effects?
Basic Ethical Skills

Week 1. Ethical Competence II: Introduction and Course Overview
  - Recognize ethical challenges in everyday practice
  - Distinguish ethics from law, religion, culture
  - Use a systematic ethics work-up to facilitate good ethical decisionmaking

Week 2. General Ethical Theory
  - Use effective approached to inform, justify and explain moral action

Week 3. Determining Capacity and Eliciting Valid Consent/Refusal
  - Respect others
  - Identify criteria to evaluate decision making capacity
  - Obtain valid consent or refusal

Week 4. Advance Care Planning & Advance Directives
  - Respect
  - Honest communication
  - Ability to clarify DNR status and treatment goals
  - Ability to facilitate the preparation of an advance directive

Week 5. Deciding for Others
  - Respect
  - Honest communication
  - Identifying “at risk” populations
  - Identifying and supporting valid surrogates
  - Applying the best interests and substituted judgment standards

Week 6. End-of-Life Issues
  - Honest communication
  - Guidelines for initiating, withholding & withdrawing LSMT

Week 7. Medical Futility
  - Prevent and resolve ethical conflict
  - Identify criteria for medically futile treatment
  - Participate in an ethics consultation

Week 8. Truth-Telling, Privacy and Confidentiality
  - Respect
  - Honest communication
  - Trustworthiness
  - Meeting the privacy and confidentiality needs of patients
Week 9. Beginning of Life and Other Controversial Topics
- Clarify personal moral convictions and reflect on how they influence professional practice

Week 10. Justice, Professionalism & the Primacy of the Patient, and the Challenge of Divided Loyalties
- Act fairly (justly)
- Meet obligations to vulnerable patients
- Identify and respond ethically to inappropriate financial incentives

Ethical Competence II: Philosophy, Goals, and Assessment

A note from the course directors

This is our tenth year of directing and teaching Clinical Ethics, Part 2. The gift of doing something like this, year in and year out, year after year, is two-fold: one, we gain experience and two, along with this experience, we gain a little more clarity about why we do what we do. Our goals are, in one respect, not unlike those that animate other courses, including courses in the basic sciences: we aim to impart to students a specialized “body of knowledge,” to equip them with one of the defining features of their membership in collectives for which we reserve the word, “profession.” But we have other perhaps more ambitious goals: we want to create a space in which our students can cultivate a refined capacity for moral reflection. That is, we want to be an impetus to the growth, the strengthening, of the moral agency of our students.

Moral agency. For us, moral agency – seeking the good, the right, the just thing to do when faced with a moral dilemma or challenge – consists in several interrelated capacities, i.e., capacities for determining the crux of the challenge, for bringing one’s own history and values to bear on one’s actions, for being willing to respond to the challenge and to be held accountable for one’s response. We developed this concept after thinking about, as well as observing and experiencing the various ways in which we can fail to seek the good, the right, and the just. We can fail in our moral sensibility and misunderstand the moral challenge at hand; in our moral responsiveness, being either indifferent to the problem or fearful of the consequences of addressing it; or in our moral advocacy and leadership by being unaware of, or refusing to address the often systemic factors that generate this as well as other moral dilemmas. We have had students ask us why we do not just concentrate on what physicians and nurses need to know: because knowing is not enough for effective moral agency in the realities of clinical practice. It is our job to prepare you for those realities – hence, the broader focus on moral agency.

Ethical skills. This semester we are including a new focusing on the ethical skills which equate with ethical competence. Each week’s content will highlight new skills and build on the skills of the preceding week. Our hope is that students will be
reflective about the natural strengths and deficiencies they bring to practice and then more intentional about cultivating the dispositions and skills needed to be excellent in their practice.

*Ethics begins in conversation.* It is possible to learn many of the disciplines constitutive of medicine and nursing on one’s own – to be alone with one’s books and notes and other aids for study. It is *not* possible to “learn” professional and clinical ethics on one’s own. We can certainly think, in solitary contemplation, about seeking the good, the right, the just thing to do; but if we choose actually to seek the good, the right, and the just, we will necessarily become involved and engaged with others. We hope that you experience this simple, but quite profound truth throughout the course, particularly in your small groups.

*Moral accountability.* In health care, moral accountability is multi-directional. Clinicians are accountable to their patients, to their colleagues and organizations, to their professions and society – and to their families and to themselves. Although *what* they are accountable for in each of these complex relationships is a subject of ongoing debate and controversy, there is no denying the experience every physician and nurse has of being held accountable by others and holding others accountable for their words and actions. How can we generate this experience of moral accountability among our students? For the last four years, we have sought to do this with a process of self-, peer- and faculty-assessment; in response to student feedback we have modified the criteria and the relative significance of the self- and peer-assessments. Although the process is, no doubt, difficult, we believe it to be necessary, if we are to replicate, in the educational setting, something of the day-to-day reality of clinical practice.

During the course and particularly at its end, when students will have the chance to provide feedback via an online survey, we invite questions, concerns, or suggestions for improving our teaching – and the learning of our students.
Session 1
Tuesday, January 15, 2008 – 11:00 am to 12:00 noon

Ethical Competence II: Introduction and Course Overview • Course Objectives • Topics and Format • Methods of Teaching and Learning • Requirements and Criteria for Student Assessment • The Ethics Work-Up

Learning Objectives:

After this session, students should be able to:

1. identify the overall course objectives
2. understand the requirements and criteria for student assessment
3. Distinguish ethics from law, religion, culture
4. Describe the five steps in a clinical ethics workup and their significance
5. Utilize the ethics work-up in case discussions and ethics consultations

Reading:
None.

Preparatory Assignment:
None.

Lecture Outline:
Follows on next page.

Small Group Activity:
None.
I. Everyday Ethical Challenges and Ethical Competence

II. Ethical Competence II
   A. Our Educational Philosophy and Goals
      • From Ethical and Cultural Competence I to Ethical Competence II
      • Interdisciplinarity
   B. New changes based on student feedback
      • Newly streamlined
      • Focus on character and basic ethical skills
      • New course content
      • Grading
   C. Learning objectives
   D. Criteria and requirements for student assessment
   E. Format

III. An Ethics Work-Up
   [The following pages reprint the ethics work-up in its entirety and can be
   separated from this syllabus to facilitate use during case discussions and ethics
   consultations.]
   1. What are the facts?
   2. What is/are the issue/s?
   3. How should the issue/s be framed?
   4. What can be done? What should be done?: Deciding the prudential question
   5. What are the advantages and disadvantages of this decision? How do others view the issues? How would other decide?
   6. Can you implement your decision?
   7. What can be done at the level of individuals, institutions and society to prevent the recurrence of this problem?
THE ETHICS WORKUP

Georgetown University Center for Clinical Bioethics

The ability to workup the ethical aspects of a case is an essential part of clinical reasoning. The emphasis in the ethics workup is on a sensible progression from the facts of the case to a morally sound decision. An ethics workup (this one or a similar version) may be used by a variety of health professionals, such as physicians, nurses, social workers, etc. With some adjustments, it may also be used by lay persons. Using the five principal steps of the ethics workup, health professionals holding a variety of philosophical and religious positions regarding ethics can share a basic framework for thinking about and discussing morally troubling cases:

1. **WHAT ARE THE FACTS?** It is vitally important to clarify the facts of the case in order to anchor the decision. These facts are both medical and social. For example, both an estimate of prognosis and an understanding of the patient’s home situation are often relevant to an ethical decision.

   - Persons involved (who?)
   - Diagnosis, prognosis, therapeutic options (what?)
   - Patient preferences, beliefs, values (what?)
   - Chronology of events, time constraints on decision (when?)
   - Medical setting (where?)
   - Reasons supporting claims, goals of current care (why?)

   Nurses and social workers may be instrumental in ensuring that the patient/family and other nonmedical health professionals understand the medical facts and that the health care team understands pertinent nonmedical information about the patient and family.

2. **WHAT IS THE ISSUE?** Is there a conflict at the personal, interpersonal, institutional or societal level? Is there a question that arises either at the level of thought or feeling? Does the question have a moral or ethical component? Why? (e.g., does it raise issues of rights, moral character, etc.). The issue may not be ethical, but rather a diagnostic problem or a simple miscommunication.

3. **FRAME THE ISSUE:** Some health professionals will explore the issue using only one moral approach. Others will eclectically employ a variety of approaches. But no matter what one’s underlying moral orientation, the ethical issue at stake in a given case can be framed in terms of several broad areas of concern, representing aspects of the case which may be in ethical conflict. It is therefore useful, if somewhat artificial, to dissect the case apart along the lines of the following areas of concern:

   **a. Identify the appropriate Decision maker(s).**

   **There are three rules of thumb for health care decision-making.**

   - Patients with intact **decision-making capacity** make their own decisions. Decision-making capacity entails the ability to 1) understand the information necessary to make this particular decision (task specific), 2) reason in accord with relatively consistent values, and 3) communicate a preference.
   - Surrogates make health care decisions for incapacitated patients with a prior history of capacity by using the **substituted judgment standard**. To the extent that the patient’s values and preferences are known they should direct decision-making. The surrogate asks, “what would the patient choose if able to make and communicate a preference?” not “What would I choose if the choice were mine?”
   - Surrogates of patients who never possessed decision-making capacity: infants, small children and profoundly retarded adults, make decisions using the **best interests**
**standard.** The surrogate asks, “Which option is most likely to benefit and to not harm the patient?” and considers relief of suffering, preservation and restoration of function, and the quality and extent of the life sustained

b. **Apply the criteria to be used in reaching clinical decisions.**

1) **The specific biomedical good of the patient:** One should ask, what will advance the biomedical good of the patient? What are the medical options and likely outcomes? Determine the **effectiveness** of proposed interventions

[A treatment is effective to the degree that it reverses or ameliorates the natural progression of the disease]. **This is an objective medical determination** [to the degree that this is possible]

2) **The broader goods and interests of the patient:** One should ask, what broader aspects of the patient's good, i.e., the patient's dignity, religious faith, other valued beliefs, relationships, and the particular good of the patient's choice, are pertinent to the decision at hand?

Use a **benefit-burden analysis** to determine if the benefits of the proposed intervention outweigh the burdens. **This is a subjective determination** which can only be made by the patient or by those who know the patient well.

3) **The goods and interests of other parties:** Health professionals must also be attentive to the goods and interests of others, e.g., in the distribution of resources. One should ask, what are the concerns of other parties (family, health care professionals, health care institution, law, society, etc.) and what differences do they make, morally, in the decisions that need to be made about this case? In deciding about an individual case, however, these concerns should generally not be given as much importance as that afforded the good of the individual patient whom health professionals have pledged to serve.

The physician explains the medical options to the patient/surrogates and if indicated makes a recommendation. The patient/surrogate makes an uncoerced, informed decision. Limits to patient/surrogate autonomy include the bounds of rational medicine/nursing/social work, the probability of direct harm to identifiable third parties, and violation of the consciences of involved health care professionals. In problematic cases the interdisciplinary team may meet to ensure consistency in their recommendations to the patient/surrogate(s).

c. **Establish the health care professionals' moral/professional obligations.**

Each health care professional must decide what she/he owes the patient, herself/himself, the health care team, the health care institution, and other third parties. Conflicts may present.

4. **IDENTIFY AND WEIGH ALTERNATIVE COURSES OF ACTION AND THEN DECIDE:** In clinical ethics, as in all other aspects of clinical care, a decision must be made. There is no simple formula. The answer will require clinical judgment, practical wisdom, and moral argument. The health care professional must ask herself/himself, “What should I do? Where can I get help?” She/he must analyze the data, reflect on it morally, and draw a
conclusion. She/he must be prepared to explain her decision and the moral reasons for it. Sources of justification include:

a. The nature of the health care professional-patient relationship; compatibility of recommended course of action with aims of profession [internal morality of profession].

b. Approaches to ethical inquiry: principle-based ethics, virtue-based ethics, an ethics of duty or obligation, an ethics of right, an ethics of care, an ethics of consequences, a feminist ethics

c. Grounding and source of ethics: philosophical (based in reason), theological (based in faith), socio-cultural (based in custom)

d. Ethically relevant considerations:
   1) Balancing benefits and harms in the care of patients
   2) Disclosure, informed consent, and shared decision making
   3) The norms of family life
   4) The relationships between clinicians and patients
   5) The professional integrity of clinicians
   6) Cost-effectiveness and allocation
   7) Issues of cultural and religious variation
   8) Considerations of power (Fletcher, Brody, Miller & Spencer)

5. CRITIQUE: It is important to be able to critique the decision that has been made by considering its major objections and then either responding adequately to them or changing one’s decision. The health care professional should also seek her/his colleagues’ input when time permits. Some cases can even be taken to an ethics committee for further reflection. Retrospective analysis is also useful in preparing “for the next time” such a situation is encountered.

6. CAN YOU IMPLEMENT YOUR DECISION? If you find yourself or your team unable to do what you believe is the morally right thing to do, it may be because your ethical competence is deficient (you may lack the courage or skill to do what needs to be done), or external variables may prevent your doing the ethically right thing (moral distress), or some combination of the above. At this point careful reflection is needed to resolve what ethically defensible options are available.

7. PREVENTIVE ETHICS: It is also important to the extent that the case represents recurring challenges/problems, that analysis focus on how individuals, the system and society need to change to prevent the recurrence of the problem. There is often a natural link between clinical and organizational ethics.
General Ethical Theory

Learning Objectives:

After this session, students should be able to:

1. Describe the basic philosophical claims of virtue ethics, deontology, and utilitarianism.
2. Analyze a case using the case method presented in the previous class.
3. Identify which ethical theories are espoused by the physician, patient, surrogate, and others in a case.
4. Begin the defense of your ethical position from opposing views

Reading:
General Ethics
Review the Ethics Workup from last week

Preparatory Assignment:
The case of Maria: Ethical Analysis

Lecture Outline:
Follows the preparatory reading

Small Group Activity:
Discussion of the case of Maria
Application of the ethics work-up
The following eight sections demonstrate the more common approaches to ethical reasoning that a healthcare provider might see in today’s world. The first three represent those Western approaches with a significant degree of philosophical argumentation substantiating their grounds. This “ground” will be the subject of the lecture. The remaining approaches often reference the earlier three, but do not feel the need to justify the “ground” of their claims. They are normally considered “self-evident” to people within their faith, culture, or time period.

1. An ethics of virtue

Redirects attention to the character of the moral agent and focuses on attitudes, dispositions, or character traits that enable us to be and to act in ways that develop our human potential. Examples include such virtues as honesty, courage, faithfulness, trustworthiness, and integrity.

**Advantages**
- Challenges notion that ethics needs only concern itself with moral action; i.e., insists that the character of individuals is as important – if not more so – than what they do or do not do
- Recaptures the ancient tradition of ethics
- Encourages identification and cultivation of the human excellences that are prerequisites of the practice of good science, medicine, nursing, etc.
- Compatible with principles, e.g., the principle of beneficence and the virtue of benevolence

**Limitations**
- Lack of consensus regarding essential "virtues"
- Needs to be anchored in prior theory of the right and the good and of human nature in light of which virtues can be defined
- Personal nature of virtue
- The ancient problem of "Can virtue be taught?" (and the more modern concern of “How can character be assessed?”)

2. An ethics of duty or obligation

Often known as “Kantian” ethics, after Immanuel Kant, the German idealist philosopher whose thought has had a decisive influence on this form of moral reasoning. According to this ethic, **one must act not only in accordance with, but for the sake of the obligation.** One should and must tell the truth because telling the truth is morally right
in and of itself. If I do so out of fear of the consequences of not telling the truth or because I take pleasure in telling the truth, then my action is not morally sound.

Advantages
- Consistency, i.e., if a particular action is morally required under these circumstances, then that action is also morally required in relevantly similar circumstances
- Relative clarity and simplicity of systems of duty or obligation

Limitations
- The problem of conflicting obligations
- Neglect of relationships
- The empty formalism of such concepts as “humanity” and the ensuring problem of practicality

3. An ethics of consequences (the best known example of which is utilitarianism)

Focuses on the consequences that actions or policies have on the well-being (“utility”) of all persons directly or indirectly affected by the action or policy. Consequences are often assessed as beneficent or nonmaleficent. The guiding precept is that, of any two actions, the most ethical one will produce the greatest balance of benefits over harms.

Advantages
- Familiar form of reasoning, arguing that acts are right or wrong according to their consequences
- All parties receive an impartial good
- Offers an acceptable norm for public policy

Limitations
- Appears to sanction or permit immoral actions
- Demands too much by making persons as responsible for consequences they fail to prevent as for consequences they directly cause, even when the former are not of their own doing
- The interests of the majority can override the rights of minorities

4. A theological ethics

Examines the moral life from the viewpoint of theistic beliefs, attitudes, and precepts; argues that such beliefs, attitudes, and precepts are fundamental to informing, explaining and justifying ethical decisions and actions.
Advantages

- Contributes the accumulated wisdom and knowledge that are the fruit of long-established religious traditions
- The practical dilemmas of bioethics often presuppose common questions of meaning about human nature, suffering, dying, and human destiny that are central to religious traditions

Limitations

- Religious pluralism prevents the widespread acceptance of any particular theological ethics
- Ethical arguments which appeal to a set of religious convictions not widely shared will have limited usefulness

5. **An ethics of principle**

Appeals to four *prima facie* principles -- non-maleficence, beneficence, respect for autonomy, and justice -- as overarching guides to ethical decision making and action.

Advantages

- Compatibility with deontological (i.e., duty- or obligation-based) and consequentialist (i.e., utilitarian) theories
- Fairly specific action guidelines
- Relevance to bioethics and clinical ethics

Limitations

- Lack of unifying moral theory
- Reduces ethics to "hard cases" (quandary ethics)
- Devalues everyday ethical concerns, e.g., about relationships, the concrete particularity of persons and circumstances
- Communicates false notion that all actions justified by a principle are equally "correct"

6. **An ethics of right**

Identifies certain interests or activities that our behavior must respect, especially those areas of our lives that are of such value to us that they merit protection from others. Each person has a fundamental right to be respected and treated as a free and equal rational being capable of making his or her own decisions (respect for autonomy). This implies other rights (e.g., privacy, free consent, freedom of conscience, etc.) that must be protected if a person is to have the freedom to direct his or her own life. "An action or policy is morally right only if those persons affected by the decision are not used merely as instruments for advancing some goal, but are fully informed and treated only as they have freely and knowingly consented to be treated."
Advantages

- Offers a bulwark against oppression, inequity, intolerance, and arbitrary invasions of privacy
- Well established in the vocabulary of the Anglo-American West
- Addresses questions of what must be done as well as what must not be done
- Compatible with deontological or duty- or obligation-based ethical theory

Limitations

- An exclusive emphasis on rights may entail a narrow understanding of morality, leaving out such matters as motive or intention, virtues, etc.
- Tends to be highly individualistic, neglecting “supra-individual” or communal goods
- An ethic of rights may inject an adversarial note into dialogue and debate about ethics and morality

7. An ethics of care

Fundamental tenets include: the source of the moral life is in the human capacity to extend care to others, to nurture relationships and to develop the communication, psychological skills and responsibility needed to sustain these networks of care; moral problems arise out of disruptions in or conflicts between responsibilities to self and others and they require a type of thinking which is contextual and narrative. Moreover, what is ethical is what best responds to the individualized needs of those with whom I live in relationship, people with unique life narratives and plans.

Focuses on the centrality of the caring relationship, which is asymmetrical in the professional patient relationship, on the promotion of the dignity and respect of patients as people, on the recognition and acceptance of particular patient and professional variables (e.g., beliefs, values, relationships) as morally relevant factors in ethical decision making, and on the norms of responsiveness and responsibility

Advantages

- Challenges the rote application of ethical systems grounded in the principles of universalizability, impartiality, and autonomy
- Challenges a reductionistic-mechanistic approach to health care and health care ethics which "objectifies" patients
- Directs attention to the reality of particular patients viewed in the context of their life narratives

Limitations

- Underdevelopment of caring as concept (Conceptualizations include caring as a human trait, caring as moral imperative, caring as affect, caring as interpersonal interaction, and caring as intervention)
• Caring's "dark side": the clinician’s need for detachment, continuing harsh abuse of patient autonomy, limits of self-sacrifice.
• The privileging of particulars

8. **A feminist ethic**

A feminist ethic views the moral life and the challenges of moral decision making and action through the lens of gender. It argues that, in general and by tendency, there are gendered – i.e., male as distinguished from female – ways of viewing the moral life, understanding its significance, and choosing, deciding, and acting. It seeks to be sensitive, especially, to how differences in power (whether due to gender or some other characteristic of human beings) shape and inform moral life and decision making. Finally, it argues that the female voice and vision have something distinctive to contribute to our understanding of moral life – and to the rationale for our decisions and actions.

**Advantages**
• Surfaces the significance of power – and of differences in power – in the various relationships in health care (e.g., between physician and nurse, between professional and patient, between students and practicing clinicians, etc.)
• Focuses attention on the important role of affect or emotion in morality

**Disadvantages**
• There can be tendencies to over-generalize (e.g., concerning the attributes of men and women)
1. Go to the Course Documents on Blackboard for this Ethics course.
2. Watch the movie clip, *Maria: Who is she? Whose is she?*
3. Imagine that you are on the healthcare team caring for Maria in the first few days of her arrival to the hospice.
4. Using the Ethics Workup Template discussed in the first class, review the case. Pay particular attention to 4b (the subject of Session 2).
5. After you complete the workup, “step back” and identify which ethical method you have used to analyze your case (virtue ethics, deontology, utilitarianism or one of the other methods in the reading: theological, principilism, right, care, or feminist).
6. In the clip, the ethics committee demonstrates a whole range of differing methods to decide whether or not to place the PEG (feeding tube). Identify the arguments of the opposing view. How would you defend your position from opposing views, using your method?
7. A template for this Assignment will be found in the Course Documents folder of Blackboard. You will be discussing the results of this Prep Assignment in Small Group and will be handing in the assignment at the end of class.
Session 3
Tuesday, January 29, 2008 – 10:00 am to 12:00 noon

Determining Capacity & the Process of Valid Consent/Refusal

Learning Objectives:

After Session 3, students should be able to:

1. Identify four consensus principles and three unresolved issues that currently exist in the United States concerning the patient’s right to self-determination in health care decision making.

2. Identify the four essential elements of valid consent/refusal:
   a. Describe the four elements of disclosure, standards of disclosure, and exceptions to disclosure requirements.
   b. Define capacity and identify and critique the common standards used to determine patient decision making capacity.
   c. Identify the most reliable indicator of capacity.
   d. Identify health care professional and other variables that may constrain voluntariness.

3. Identify the ethical perspectives and frameworks that are critical in informing and justifying professional decisions with regards to capacity determination and informed, valid decision making.

Reading:

Preparatory Assignment:
Considering 3 Scenarios of Consent/Refusal

Lecture Outline:
See pages following the preparatory assignment. The Powerpoint version of the lecture will be posted on Blackboard.

Small Group Activity:
Discussing the 3 Scenarios of Consent/Refusal
Session 3 ★ Determining Capacity & the Process of Eliciting Valid Consent to or Refusal of Treatment ★ Lecture Outline

A Framing Case:
In 1996, California resident Joe Foster agreed to participate in an experiment testing a new blood pressure drug. Lured by the promise of free medical care, the 58-year-old was told to stop taking his regular hypertension medication so he could test the effectiveness of the new drug. What Foster didn’t realize was that the pills he began taking weren’t medicine but useless placebos that were given to patients who make up the experimental control group. Six days later, Foster had a major heart attack followed by a debilitating stroke. Researchers say Foster signed a consent form describing the experiment’s risks. But Foster, who told Congress about his case last spring, says he never would have agreed to take part in the drug trial if he’d understood the grave dangers involved. The Anaheim Heart and Research Institute’s newspaper ad that Foster saw, and which had been approved by a for-hire ethics board in Ohio, offered: “Free office visits with a board-certified cardiologist. Free study medication. Free lab tests and EKGs. …Patient reimbursement,” which Foster learned was $75 a visit. From Foster’s perspective, he was being offered cutting-edge care by great doctors. But something else also was happening: Foster was volunteering his body to test a new drug. There was no guarantee that he would get the drug, nor any promise that it was safe and effective. [USA Today, June 8, 1998].

I. Introduction

A. From “informed consent” to “informed consent or refusal” to “valid decision making”

II. The Patient’s Right to Self-Determination in Health Care Decision Making [William F. Tuerk]

A. Consensus Principles

1. All competent patients have the right to consent to – or to decline – any and all presented (i.e., medically indicated) treatment options;

2. Incapacity does not, of itself, cause patients to lose that right;

3. If the incapacitated patient's wishes are known—e.g., through a written advance directive or equally through oral discussions, those wishes must be honored;

4. The above principles apply whether or not the patient is "terminal," and they apply to all forms of medical treatment including, e.g., nutrition and hydration "by tube."
B. Unresolved Issues

1. Who makes decisions (and on what basis) for patients when they lack decision making capacity and have not left "clear and convincing evidence" of their wishes;

2. The right of patients and surrogate decision makers to demand treatment that health care professionals are reluctant to provide--e.g., because of its perceived medical futility, scarcity, cost;

3. The right of clinicians to limit (medically futile) life-sustaining interventions without the valid consent of the patient or surrogate.

III. The Moral Foundation of Valid Consent/Refusal

A. Consequentialist Justification: Patient Well-Being (Beneficence)

B. Deontological Justification: Respect for Self-Determination (Autonomy)

C. Evolving Models

1. Paternalism Rooted in Hippocratic Ethic (Beneficence)

2. Noninterference Model/Patient Sovereignty (Autonomy)

3. Authentic Autonomy Model/Shared Decision Making
   a. Role of Virtue
   b. Care Perspective

IV. Elements of Valid Consent/Refusal

A. This is a process, NOT an event: Faden/Beauchamp Model of Autonomous Action: “X acts autonomously only if X acts 1) intentionally, 2) with understanding, and 3) without controlling influences”

   a. Event model: clinician meets the patient, explains the procedure, obtains the patient’s consent (“consents the patient”) and signature
   b. Process model: patient and clinician(s) establish individual responsibilities. In the process model the patient’s problem is defined in dialogue between the clinician and the patient. Does the patient agree with the what the clinician thinks the problem is? They set goals, such as curing the disease or treating a symptom. Finally, they select appropriate therapy.
B. Duty of Disclosure

1. Elements of Disclosure:
   a. The nature of the proposed intervention
   b. The purpose
   c. The risks and consequences
   d. The benefits
   e. The probability that the intervention will be successful
   f. The feasible alternatives; and
   g. The prognosis if the intervention/therapy is not given

2. Standards of Disclosure
   a. Professional
   b. Patient-Oriented

3. Exceptions to Disclosure Requirement and the Requirement for Informed Consent
   a. Emergency exception: when the patient is in a life-threatening situation and unable to consent
   b. Incapacity: when the patient is unable to consent; the process must then involve the surrogate decision maker
   c. Patient Waiver: when the patient waives the right to know
   d. Therapeutic privilege: when informing poses a significant threat to the patient’s well-being, not because it will make the patient feel upset or depressed; should only be invoked in rare circumstances.
   e. National/state waivers: when the federal or state government waives informed consent for vaccination programs, newborn genetic screening, etc.

C. Legal Competency vs. Decision Making Capacity

1. Standards: outcome-based, category-based, function-based

2. Criteria
   a. ability to understand information necessary to make this decision [task specific],
   b. ability to reason in accord with a relatively consistent set of values, and
   c. ability to communicate preferences
3. Sliding Scale: When a patient’s capacity is being determined it is important to assess the individual abilities of the patient, the requirement of the task at hand and the consequences likely to flow from the decision. Consent for a high-benefit, low-risk treatment demands a lower capacity standard than consent for low-benefit, high-risk treatment which require a higher capacity standard. Similarly, refusals which entail few risks or harms demand a lower capacity standard than refusals with potentially grave consequences (Drane, 1994, pp. 152-154).

4. Depression may alter the patient’s capacity for decision making. In general, life-sustaining therapy should not be withheld until efforts have been made to reverse depression. That said, depressed patients may have the capacity to refuse life-sustaining treatment.

D. Comprehension

Ask patients/surrogates to repeat in their own words what they believe they are consenting to...

E. Voluntariness

Continuum of professional approaches to eliciting valid consent: from persuasion to manipulation to coercion

V. History of the Concept of Informed Consent

A. The Hippocratic Oath does not mention a physician’s obligation to converse with patients. In the Ancient Greeks’ view, cooperation between the physician and patient was important not for the sake of sharing decision-making burdens, but for the sake of friendship, that in turn, led to trust, obedience and then to cure.

B. The doctrine of informed consent began to evolve in the courts after the turn of the 20th century.

a. "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent commits an assault for which he is liable in damages." Judge Cardoza; Schloendorff v. Society of New York Hosp., 211 N.Y. 1125, 105 N.E. 92, 95 (1914)
b. In 1957 the courts began to define the legal requirement for consent. In *Salgo v. Leland Stanford, Jr., University Board of Trustees*, the court declared that uninformed consent is not true consent. “A physician violates his duty to his patient and subjects himself to liability if he withholds any facts necessary to form the basis of an intelligent consent by the patient to the proposed treatment.” This ruling emphasized disclosure and not the right of the patient to make the decision.

C. The 1957 Opinions of the AMA’s Judicial Council provided three specific instructions with respect to disclosure and consent:

a. a surgeon is obligated to disclose all facts relevant to the need and performance of the operation;

b. an experimenter is obligated, when using new drugs or treatments, to obtain the “voluntary” consent of the person; and

c. investigators involved in clinical investigations primarily for treatment must “make relevant disclosure and obtain the voluntary consent of patient.”

D. At present the requirement for “valid decision-making” as an expression of self-determination is supported by the President’s Commission for Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982), The American Hospital Association’s Patient Bill of Rights, the American Nurses Association’s Code for Nurses (2001), the 1992 Code of Medical Ethics, and the American College of Physicians (1992).

VI. Related Obligations of Health Care Professionals

A. Identifying and supporting the decision maker

1. Determining and documenting the patient’s decision making capacity

2. Protecting the right of patients with decision making capacity to be self-determining

   a. Facilitate communication and documentation of the patient's preferences
b. Anticipate the types of treatment decisions that are likely to need to be made

c. Assist in the preparation of advance directives

3. Promoting authentic autonomy; authentic decisions reflect the individual's identity, decisional history, and moral norms

4. Identifying the morally as well as legally valid surrogate decision maker

5. Supporting the surrogate decision maker; clarifying the surrogate decision maker's role

6. Identifying limits to patient/surrogate autonomy and limits to care giver autonomy

B. Promoting patient good

1. Clarifying the goal of therapy: cure and restoration; stabilization of functioning; preparation for a comfortable, dignified death

2. Determining the effectiveness of therapy

3. Weighing the benefits and burdens of therapy

4. Ensuring that all interventions are consistent with the overall goal of therapy

5. Ensuring that the patient's priority needs are addressed (bio-psycho-social-spiritual needs)

6. Ensuring continuity of care as patient is transferred among services, and intra- and inter-institutionally

7. Weighing the moral relevance of third party interests (family, care giver, institutional, societal)

C. Preventing and resolving ethical conflict

1. Establishing that preventing and resolving ethical conflict falls within the authority of all health care professionals engaged in the care of a patient
2. Facilitating timely communication among those involved in decision making: one-on-one meetings; periodic meetings of the patient, family and interdisciplinary team to clarify goals and plan of care; ethics consult or meeting of the institutional ethics committee

3. Developing awareness of and sensitivity to the conscious and unconscious sources of conflict

4. Documenting pertinent information on the patient record
Jan 29 * Session 3 * Determining Capacity & the Process of Valid Consent/Refusal * Prep Assignment/Small Group Activity

Prepare for the small group activity by reading and reflecting on the directions below:

I. Capacity Determinations

Capacity is essentially the ability to make a decision. It is a preconditional absolute in the process of valid decision making. The functional standard is the most widely accepted standard in determining the patient’s capacity. It suggests that capacity is determined by whether a patient can do the following:

1. understand information relevant to the decision
2. communicate with caregivers about the decision
3. reason about relevant alternatives, against a background of reasonably stable personal goals and values.

II. The Process of Valid Consent/Refusal

Valid informed consent/refusal requires the presence of multiple, interrelated elements:

A. Pre-Conditional Elements

1. Capacity (to understand and decide)
2. Voluntariness (in deciding – i.e. freedom from undue duress)

B. Elements of Information Exchange

1. Health Care Provider’s Disclosure
2. Health Care Provider’s Recommendation (Rx plan)
3. Patient’s Understanding/Comprehension (of 1 & 2)

C. The Actual Consent/Refusal

1. The Decision
2. The patient’s formal authorization of the plan – Verbal or Written
III. Nine basic rules for obtaining valid consent or refusal:

1. Identify the appropriate decision maker, either
   a. The patient who has decision making capacity, or
   b. The patient’s morally and legally valid surrogate

2. Sit face-to-face in a private place and have the discussion at a time when the
   patient/surrogate is not distracted or in great pain.

3. Determine that the patient or surrogate is communicating voluntarily

4. Disclose the following:
   a. The nature of the proposed intervention
   b. The purpose
   c. The risks and consequences
   d. The benefits
   e. The probability that the intervention will be successful
   f. The feasible alternatives; and
   g. The prognosis if the intervention/therapy is not given

5. Offer a recommendation.

6. Ensure comprehension. Give the information in “small chunks” and stop
   occasionally to check that the information is being understood; have the decision
   maker describe what he or she believes he was told in his or her own words.

7. Acknowledge any emotional reaction from the patient and respond to that
   reaction with sincerity and empathy.

8. Validate what you take to be the patient/surrogate’s decision.

9. Summarize, ask for questions and have a clear idea of when you will meet again.
IV. Read the following scenarios. For each scenario, you are the health care provider in the case:

1. Decide whether the patient possesses “decision-making capacity” for the decision with which they are faced. Be prepared to defend your assessment.
2. Following the 9 basic rules for obtaining valid consent/refusal, what information must be disclosed, comprehended, and consented?
3. As the case is presented, what factors in the case could undermine a valid consent/refusal? How might you intervene to support the process?

Scenario 1: Jason is a 17-year-old single male with cystic fibrosis. He is brought into the emergency room in respiratory crisis. His girlfriend accompanies him. He refuses to be intubated and his girlfriend supports his decision. She states that his condition has been steadily worsening, they both know he is dying, and he is adamant about not wanting to die in a hospital. When his mother appears she demands that he be intubated in no uncertain terms.

Scenario 2: Mr. Smythe is an 80-year-old male in end stage multiple organ system failure. The clinical consensus is that it is time to withdraw from aggressive management and the attending approaches Mr. Smythe’s wife about writing a comfort measures only order and a decision to withdraw life-sustaining medical interventions. Mr. Smythe has been determined to lack decision making capacity. Staff are undecided about Mrs. Smythe’s capacity. She has carefully avoided every effort to engage her in reasoning about his plan of care. She repeatedly makes statements begging the staff not to let her husband die. “He can’t die.” “I can’t live without him!”

Scenario 3: Jolene is a 16-year-old woman who is 25 weeks pregnant and hospitalized because of pre-term labor and pre-eclampsia. Treatment consists of bed-rest and tocolytics (medicine to stop the premature contractions). Initially excited by all the care that surrounded her hospitalization, Jolene has become increasingly noncompliant over time and is now threatening to walk out of the hospital if she is not discharged immediately. Emotionally young for her 17 years, she seems not to grasp the consequences of her behavior for her unborn fetus.
Advance Care Planning & Advance Directives

Learning Objectives:

After Session 4, students should be able to:
1. Describe critical milestones in the legal and ethical evolution of advance care planning and advance directives
2. Define advance care planning and explain its clinical and ethical significance
3. Describe the respective roles of patients, proxies, physicians, nurses and others in the advance planning process
4. Distinguish between statutory and advisory documents
5. Identify pitfalls and limitations in advance care planning as well as the advantages and disadvantages of differing types of advance directives
6. Describe a systematic process for establishing goals of care and evaluating the therapeutic interventions as the means for achieving goals of care

Reading:
An excerpt on “Advance Directives” from Raymond J. Devettere’s Practical Decision Making in Health Care Ethics: Cases and Concepts

Preparatory Assignment:
Thought Provoking Exercises.

Lecture Outline:
See the pages following the preparatory assignment.

Small Group Activity:
Role play and critique the skill of advance care planning
THOUGHT PROVOKING EXERCISES

On the following pages you will find a series of “Thought Provoking Exercises” that are designed to elicit and throw into relief your values and preferences regarding care, in the event that you suffer a serious, life-threatening or terminal illness. The exercises address different issues:

- What to consider when choosing a spokesperson (proxy or surrogate decision maker)
- Your wishes regarding what makes life worth living
- Your personal and spiritual beliefs that affect medical decision making, and your feelings about hope and risk taking
- Your wishes regarding the way you might spend your last weeks or days if you were dying, and other related matters.

As preparation for Session 4, you are encouraged to complete as many of the exercises as you can. By doing so, you will (1) become intimately familiar with the multiplicity of considerations integral to effective advance care planning and (2) experience – in a more “first-hand” fashion – the challenges that confront patients and families in the difficult process of making health care decisions in the context of serious or terminal illness.

Bring your completed exercises to your small group on February 5th; these will not be reviewed or critiqued by your small group facilitator but s/he will glance at them to ensure that you have completed them and return them to you.

Once your completed exercises have been returned to you, you may:

- Use them to discuss your values with your loved ones and health care providers
- Attach them to your own advance directive(s) as your personal statement. They will provide greater details about your wishes.
- Review them each year – your answers could change with time.

Source: Excerpted from Your Life, Your Choices.
I. INTRODUCTION: MEDICINE, NURSING, AND THE EXPERIENCE OF THE INEVITABLE – that is, THE EXPERIENCE OF HUMAN MORTALITY

A. Thought Provoking Exercises
   1. The importance – and the difficulty – of imagining what may well be unimaginable
   2. A glimpse of the rationale for advance care planning and advance directives: the exercise of prospective autonomy

B. The Experience of Serious Illness; the Experience of Dying: Human Mortality and Morbidity in Clinical and Historical Context
   1. The relatively recent past
   2. The present
   3. The future

II. ADVANCE CARE PLANNING AND ADVANCE DIRECTIVES

A. CRITICAL MILESTONES
   1. In re Quinlan, 1976
   2. Natural Death Act, 1976
   3. President’s Commission, 1983

B. THE PROCESS OF ADVANCE CARE PLANNING
   1. Steps in the process
   2. The ethics of advance care planning
3. The ethical ideal of shared decision making; the processes of establishing goals of care and evaluating therapeutic interventions as the means for achieving goals of care

C. THE OUTCOMES OF THE PROCESS OF ADVANCE CARE PLANNING: ADVANCE DIRECTIVES

1. Types of advance directives
   a. Living wills
   b. Durable powers of attorney for health care decision making

2. Advantages and disadvantages

D. REALITY CHECK: ADVANCE CARE PLANNING AND ADVANCE DIRECTIVES IN CONTEMPORARY HEALTH CARE

1. The troubling findings from SUPPORT

2. Living wills: is enough, enough?
Note to Faculty:  *Please look ahead to next week’s small group activity and assign one of the cases to each student to prepare in advance.*

1. Divide the group into dyads and have each student role play being both the patient and clinician in the following scenario. You are being seen by the clinician at Georgetown University Hospital for your first admission after being diagnosed with cervical/testicular cancer. The clinician should use the forms below to 1) clarify DNR status upon admission and 2) help the patient to complete an advance directive. When playing the role of the patient the student should pay attention to the clinician’s behavior and provide feedback at the end of the experience about what was helpful and not helpful. Each role play should take about 20 minutes.
D.C., Maryland and Virginia

ADVANCE DIRECTIVE
Your Durable Power of Attorney for Health Care,
Living Will and Other Wishes

I. ______________________________ write this document as a directive regarding my medical care.

Put the initials of your name by the choices you want.

PART 1. MY DURABLE POWER OF ATTORNEY FOR HEALTH CARE

I appoint this person to make decisions about my medical care if there ever comes a time when I cannot make those decisions myself:

NAME __________________________ PHONE HOME ______________ WORK ____________

ADDRESS __________________________ ________________________________

If the person above cannot or will not make decisions for me, I appoint this person:

NAME __________________________ PHONE HOME ______________ WORK ____________

ADDRESS __________________________ ________________________________

I have not appointed anyone to make health care decisions for me in this or any other document.

I want the person I have appointed, my doctors, my family, and others to be guided by the decisions I have made below:

PART 2. MY LIVING WILL

These are my wishes for my future medical care if there ever comes a time when I can't make these decisions for myself.

A. These are my wishes if I have a terminal condition:

Life-Sustaining Treatments

____ I do not want life-sustaining treatments (including CPR) started. If life-sustaining treatments are started, I want them stopped.

____ I want life-sustaining treatments that my doctors think are best for me.

____ Other wishes: __________________________

Artificial Nutrition and Hydration

____ I do not want artificial nutrition and hydration started if it would be the main treatment keeping me alive. If artificial nutrition and hydration is started, I want it stopped.

____ I want artificial nutrition and hydration even if it is the main treatment keeping me alive.

____ Other wishes: __________________________

Comfort Care

____ I want to be kept as comfortable and free of pain as possible, even if such care prolongs my dying or shortens my life.

____ Other wishes: __________________________

B. These are my wishes if I am ever in a persistent vegetative state:

Life-Sustaining Treatments

____ I do not want life-sustaining treatments (including CPR) started. If life-sustaining treatments are started, I want them stopped.

____ I want life-sustaining treatments that my doctors think are best for me.

____ Other wishes: __________________________
Artificial Nutrition and Hydration

_____ I do not want artificial nutrition and hydration started if it would be the main treatment keeping me alive. If artificial nutrition and hydration is started, I want it stopped.

_____ I want artificial nutrition and hydration even if it is the main treatment keeping me alive.

_____ Other wishes:

Comfort Care

_____ I want to be kept as comfortable and free of pain as possible even if such care prolongs my dying or shortens by life.

_____ Other wishes:

C. Other Directions

You have the right to be involved in all decisions about your medical care, even those not dealing with terminal conditions or persistent vegetative states. If you have wishes not covered in other parts of this document please indicate them here:

PART 3. OTHER WISHES

A. Organ Donation

_____ I do not wish to donate any of my organs or tissues.

_____ I want to donate all of my organs and tissues.

_____ I only want to donate these organs and tissues:

_____ Other wishes:

Autopsy

_____ I do not want an autopsy.

_____ I agree to an autopsy if my doctors wish it.

_____ Other wishes:

If you wish to say more about any of the above choices, or if you have any other statements to make about your medical care, you may do so on a separate sheet of paper. If you do so, put here the number of pages you are adding: _____

PART 4. SIGNATURE

You and two witnesses must sign this document for it to be legal.

A. Your Signature

By my signature below I show that I understand the purpose and the effect of this document.

NAME ___________________________ DATE _____________

ADDRESS ___________________________

B. Your Witnesses’ Signatures

I believe the person who has signed this advance directive to be of sound mind, that he/she signed or acknowledged this advance directive in my presence, and that he/she appears not to be acting under pressure, duress, fraud or undue influence. I am not related to the person making this advance directive by blood, marriage or adoption, nor, to the best of my knowledge am I named in his/her will. I am not the person appointed in this advance directive. I am not a health care provider or an employee of health care provider who is now, or has been in the past, responsible for the care of the person making this advance directive.

Witness #1

NAME ___________________________ DATE _____________

ADDRESS ___________________________

Witness #2

NAME ___________________________ DATE _____________

ADDRESS ___________________________
2. Use the last twenty minutes of the small group to talk together about the learnings from this experience. What challenges did you encounter in speaking to a prospective patient about his or her preferences for end-of-life treatment. Many clinicians continue to offer as an excuse for not initiating these conversations with patients their belief that patients will become uncomfortable or despairing when the topic is introduced—in spite of research to the contrary. In fact it is more often the discomfort of the clinician—not the patient—that impedes advance care planning!

3. Use the last five minutes of the class to prepare your self-assessment on your perceived competence in 1) clarifying DNR status and treatment goals and 2) facilitating the preparation of an advance directive. What did you learn about yourself through this exercise? What natural strengths can you draw upon moving forward and what dispositions or skills do you need to work on to better accomplish these interventions?

4. Independent Learning. You may wish to think through how you would respond in the following clinical situations after this class.

   a. As a resident or nurse practitioner you report to a patient’s oncologist that the patient wants to talk about writing an advance directive and are told by the oncologist that the topic is premature and will only depress the patient. Moreover, the oncologist, who is Middle Eastern, says that if the patient becomes too weak to speak for herself he can always ask her husband what to do. The patient is 64 and has an advanced leukemia. How do you respond?

   b. An 83-year old woman, Ms. U, was admitted to the hospital from an assisted living facility due to a stroke with left-sided weakness and aphasia. She had a history of Parkinson’s disease, coronary artery disease, and a prior stroke several years ago. She was seen by a neurologist the day after admission who noted dysarthria (i.e., problems of speech articulation due to muscular control disturbance), a severely diminished gag reflex, and that she was not ambulatory. She did respond to right-sided commands. Speech and physical therapy were recommended.

A speech therapist also recommended that Ms. U not ingest anything by mouth due to her swallowing difficulties. A nasogastric tube was inserted for feedings. Ms. U subsequently pulled out the tube twice; the neurologist’s notes indicated she would need a peg tube to survive. At that time, her daughter June, who lived nearby, refused the peg tube but eventually agreed to reinsertion of the nasogastric tube as a temporary measure.
The social worker spoke at length with June. She was initially reluctant to agree to any feeding tube at all because she wanted to follow her mother’s wishes as expressed in her advance directive. This living will was one of the typical forms that are used in Pennsylvania. It was so worded that Ms. U did not want artificial nutrition and hydration if she were in a terminal condition or permanently unconscious. The next day June was still uncertain and was advised to confer with her sister Donna who lived out of town. It was hoped they would clarify their mother’s intent. Ms. U’s family physician also spoke to June and told her that a peg tube was not an extraordinary measure.

Due to uncertainty about the patient’s decision making capacity, a psychiatrist was consulted. He felt the patient was disoriented, lacked insight, had impairments in cognition, and lacked decision making capacity at that time. The social worker again spoke with June. June had spoken with Donna, and they were both in agreement to refuse any type of feeding tube.

The clinicians caring for Ms. U are uncertain about how to proceed, i.e., to honor the refusal of treatment expressed by Ms. U’s daughters, June and Donna, or to insert the peg tube. What would you do in this situation and what is your rationale?
Session 5
Tuesday, February 12, 2008 – 10:00 am to 12:00 noon

Deciding for Others

Learning Objectives:

After Session 5, students should be able to:

1. Identify “at risk” populations for whom capacity determinations may be complex: children, older adults, the homeless, individuals with mental health and psychiatric problems

2. Describe the substituted judgment and best interests standards for surrogate decision making and indications for each

3. Identify the valid proxy decision maker for patients who never possessed decision making capacity (infants, small children, profoundly retarded adults) and patients who no longer possess decision making capacity

4. Describe the order of priority for proxy decision makers in Washington, D.C.

Reading:
An excerpt on “Deciding for Others” from Raymond J. Devettere’s Practical Decision Making in Health Care Ethics: Cases and Concepts.

Preparatory Assignment:
Analysis of assigned case of deciding for others

Lecture Outline:
See the pages following the preparatory assignment.

Small Group Activity:
Discussion of cases of deciding for others using best interests or substituted judgment standards.
Feb 12 ★ Session 5 ★ Deciding for Others ★ Preparatory Assignment

Read the case from the small group activity that you were assigned last week and prepare in writing an answer to the following question: To what extent, if any, are the best interests and substituted judgment standards relevant and how would you respond in this situation. Support your answer using this week’s assigned reading.

Feb 12 ★ Session 5 ★ Deciding for Others ★ Lecture Outline

I. Introduction

The object of all health care decision making is first and primarily to secure the health, wellbeing, or good dying of the patient, and second to do this in a manner that respects the integrity of each participant in the decision making process. Pellegrino’s scientifically right and humanly good criteria.

II. Rules of Thumb for Health Care Decision making

A. Patients with intact decision-making capacity make their own decisions.

B. Surrogates make health care decisions for incapacitated patients with a prior history of capacity by using the substituted judgment standard. When we lose our capacity we do not lose the right to be self-determining. To the extent that the patient’s values and preferences are known they should direct decision-making. The surrogate asks, “what would the patient choose if able to make and communicate a preference?” not “What would I choose if the choice were mine?

1. Challenge A: Patient had a prior history of capacity but no one is present who knows the patient. To what lengths must the treating team go to discover the patient’s beliefs and values.
2. Challenge B: Family unwilling to serve as surrogates and to make decisions for the patient.
3. Challenge C: The patient’s surrogate states that s/he knows that the patient would or would not want “X” treatment but that s/he cannot authorize this.
4. Challenge D: The patient’s surrogates and or treating team believe that honoring the patient’s previously expressed wishes will lead to treatment not in the patient’s best interests.
5. Challenge E: The family acting as surrogates cannot reach consensus about what should be done; may be complicated when the morally and
legally valid surrogate is never identified and team keeps working with different members of the family.

C. Surrogates of patients who never possessed decision-making capacity: infants, small children and profoundly retarded adults, make decisions using the best interests standard. The surrogate asks, “Which option is most likely to benefit and to not harm the patient?” and considers relief of suffering, preservation and restoration of function, and the quality and extent of the life sustained.

1. Challenge A: Surrogates who demand “too much treatment” which the team believes to be medically futile and not in the best interests of the patient (may be cruel and inhumane)
   - Futile Treatment Policies and Palliative Care Protocols
2. Challenge B: Surrogates who want “too little treatment” which the team believes to be in the best interests of the patient.
   - Baby Doe Regulations/Criminal Abuse & Manslaughter
3. Challenge C: Surrogates and team cannot agree about what is in the best interests of the patient.

III. Who speaks for the incapacitated patient in Washington, D.C.?

A. Two qualified, D.C.-licensed physicians, including a psychiatrist, one of which examined the patient within the preceding day, are needed to certify, in the patient record, their opinion and clear evidence as to the cause, nature, extent and probable duration of the incapacity.

B. In a life-threatening emergency the court, on petition, may appoint a temporary guardian if no guardian or other person who appears to have authority presents. The emergency physician has implicit authority to deal with an emergency.

C. If a valid durable attorney for health care party presents and is able and willing to serve, s/he represents the patient. If a valid advance directive is presented clinician’s must defer to the patient’s lawful and medically reasonable stated preferences or transfer the patient.

D. In Washington, D.C. the order of priority for surrogates is as follows:
   1. attorney in fact for health care
   2. court-appointed guardian
   3. patient’s spouse or domestic partner
   4. an adult child of the patient
   5. a parent of the patient
   6. an adult sibling of the patient
7. for the patient in a religious order: religious superior or diocesan priest  
8. close friend, not an involved health care provider  
9. nearest living relative of the patient  
Order of priority creates presumption that may be rebutted if a person or lower priority is found to have better knowledge of the wishes of the patient, or, if the wishes of the patient are unknown and cannot be ascertained, is better able to demonstrate a good-faith belief as to the interests of the patient.  

E. A guardian cannot subject the patient to involuntary commitment or to experimental research without court permission.  

IV. Challenges in communicating the information and providing the support dependent patients and their surrogates need to make “right” and “good” decisions  

A. A quick review of the three models of decision making for incapacitated patients  

1. Paternalistic/Maternalistic: Surrogates are “spared” the burdens of making decisions for others; clinician’s judgment of patient’s previously-expressed preferences or “best interests” trumps  
2. Patient Sovereignty: Full burden of decision rests on surrogate(s); surrogate’s judgment of patient’s previously-expressed preferences or “best interests” trumps  
3. Shared Decisionmaking: Clinicians and surrogates share burdens of decision making and work jointly to identify patient’s preferences or best interests  

B. Should parents and other surrogate decision makers have unlimited autonomy in making health care decisions for patients lacking capacity?  

C. At what age do children have morally as well as legally valid decision making capacity for making health care decisions? What respect should be given the preferences of adolescents who are morally but not legally competent to make health care decisions?  

D. Who is best able to determine what is in a patient’s “best interests” when the patient is unable to speak for him or her self?  

V. Neonatal Issues  

A. Selective Non-Treatment of Newborns
1. Pediatricians Duff and Campbell and Yale-New Haven Hospital’s policy of selective non-treatment that resulted in the deaths of 43 infants over a period of 30 months (reported 1973)

Infants with anencephaly have a “right to die,” that some defective infants need to escape a “wrongful life” characterized by cruel treatment in institutions, and that families need to be spared the chronic sorrow of caring for infants with little or no possibility for meaningful lives.

2. Also in 1973, Shaw, a pediatric surgeon, wrote that the presence of mental retardation and/or severe physical malformations is an important consideration in deciding whether to treat neonates.

3. Surveys at the time indicated that many pediatricians and pediatric surgeons agreed with a policy of selective non-treatment of seriously impaired newborns. Researchers who conducted a 1977 survey of pediatricians in Massachusetts reported that 54% did not recommend surgery for an infant with Down syndrome and duodenal atresia, and 66% would not recommend surgery for an infant with a severe case of spina bifida.

B. Baby Doe Regulations

In April, 1982, the Reagan administration intervened in response to outcry from right-to-life advocates and advocacy groups for people with disabilities over the “Baby Doe” case, which involved forgoing the life-sustaining treatment of an infant. The purpose of these regulations was to ensure that handicapped infants received all potentially efficacious life-saving treatment without consideration of quality of life. The regulations appeared to require maximal treatment in all cases except those in which treatment was futile because the infant was irreversibly and imminently dying.

“Hotline and Baby Doe Squads”

The U. S. Department of Health and Human Services rules which were finalized in January 1984 follow.

1. All such disabled infants must under all circumstances receive appropriate nutrition, hydration and medication.
2. All such disabled infants must be given medically indicated treatment.
3. There are three exceptions to the requirement that all disabled infants must receive treatment, or stated in other terms, three circumstances in which treatment is not considered “medically indicated.” These circumstances are:
a. if the infant is chronically and irreversibly comatose.
b. If the provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or otherwise be futile in terms of the survival of the infant.
c. If the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

4. The physician’s “reasonable medical judgment” concerning the medically indicated treatment must be one that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved. It is not to be based on subjective “quality of life” or other abstract concepts. [U.S. Department of Health and Human Services, “Nondiscrimination on the Basis of Handicaps: Procedures and Guidelines relating to Health Care for Handicapped Infants,” Federal Register 49 (12 January 1984): 622-654.]

C. The Challenges in Brief

a. Parents want too little: Baby Doe Regulations/Criminal Abuse & Manslaughter

b. Parents want too much: Futile Treatment Policies and Palliative Care Protocols

Peter Clark, SJ, PhD: Is it time for a public policy of medical futility in pediatrics which protects the patient’s right to self-determination, the physician’s right of professional integrity, society’s concern for just allocation of medical resources, and which is securely rooted in the ethical tradition of promoting and defending human dignity.

D. Neonatal Resuscitation

Approximately 50% of infants born at less than 1,500 grams survive. Of these, up to 40% are expected to have severe long term neurologic and developmental impairment. Although American physicians have resuscitated smaller and smaller neonates, the question of whether or not this is appropriate has been challenged by ethicists, economists, social scientists, nurses and physicians.

Physicians and nurses who provide delivery room resuscitation have little direction for decision making in the guidelines from the American Academy of Pediatrics’ Neonatal Resuscitation Protocol. There is no suggested protocol for initiating or withholding CPR, no suggested length
of time for continuing a resuscitative effort, no guidelines for when to halt the resuscitation, and no mention of how to comfort parents of neonates for whom resuscitation is ineffective. The algorithm presents no pathway other than full resuscitative effort for all newborns regardless of age, weight, or condition. A. Catlin

The informal US rule is to attempt to resuscitate all neonates who are > 400-500 grams or >23-24 weeks

In contrast to standard resuscitation practice in the U.S., physicians in other developed countries withhold treatment for marginal neonates, based on societal resources and social policies. Canada, e.g, recommends against resuscitation for infants of less than 25 gestational weeks.

**Approaches to Decision Making (Weir)**
- Treat all non-dying neonates
- Terminate the lives of selective non-persons
- Withhold treatment according to parental discretion
- Withhold treatment according to projections about quality of life
- Withhold treatment judged not in the child’s best interest. (Weir)

**Basis for Decision Making**
- Criteria: Medical Indications, Quality of Life, Technical Merit Criteria, Non-maleficence/Best Interest
- Economic Factors in Decision-making
- Certainty/Uncertainty

**Colorado Collective for Medical Decisions**
- Infants who are likely to survive should be given appropriate medical care even if they have mental or physical limitations.
- Infants who are extremely unlikely to survive infancy due to extreme prematurity should receive comfort care instead of aggressive life-sustaining interventions.
- Infants who are extremely unlikely to survive infancy due to a lethal birth defect should receive comfort care instead of aggressive life-sustaining interventions.
- Infants for whom survival offers only a short lifetime filled with significant suffering should receive comfort care instead of aggressive life-sustaining interventions.
- When the outcome of aggressive medical care for an infant is uncertain, the family should be provided with comprehensive information about outcomes.
- When the outcome of aggressive medical care for an infant is uncertain, decisions about life-sustaining interventions should be made jointly by the family and medical team.
The kinds of ethical questions raised here continue to be pondered at the local level by health care providers, ethics committees, and health care administrators, and at the state and federal level by policy makers and society. We feel that the following questions must be raised and debated in an open and honest forum. We present these questions and we invite your comments as we strive to provide extraordinary care for acutely chronically ill children. [Smith, K. & Uphoff, M.E. (2001). Uncharted Terrain: Dilemmas Born in the NICU Grow Up in the PICU. *The Journal of Clinical Ethics*, (2001), 12(3), 231-238.]

- When does routine care become extraordinary care, and when does that extraordinary care become futile care? Who makes this decision, and how is further care or a change in the course of goals of care determined?
- If a child is in need of high-tech or otherwise extraordinary care or procedures, how are his parents evaluated in regard for their ability to care for the child on a long-term and perhaps chronic basis? Who makes this determination? What evaluative tools are used?
- Is the parent who asks us to do everything always acting in the child’s best interests? Can a parent truly make a decision that is in the best interests of the child from a benefit/burden standpoint, when that decision might lead to the loss of the child?
- If it is determined that the child’s parents are unable or unwilling to assume care for the child at some point post-hospitalization, what then? Is it fair or right to embark on a procedure that precludes a child from living with his family of origin? Or, if a child's parents initially appear able and willing, but later prove to be unable to be caregivers, to whom does this responsibility fall? Must we develop a cadre of skilled medical foster parents (currently a scarce resource) to step in and provide such care, even, perhaps, on a respite basis?
- Is the margin for success for procedures like transplants and/or chronic health care maintenance such that the benefit to the child and the family outweigh the (potential) burdens of pain, suffering, fear, family disruption, dysfunction and financial devastation? Has or should a “threshold for success” been determined? Who decides?
- When might the long-suffering child push away the hand of a caregiver and really be respected in saying “enough is enough”?
- How do we, as a society, finance a lifetime of expensive supportive care for a child who has used up the cap on his or her healthcare insurance in the first two years of life? Is it appropriate for a society with so many global pediatric and mental health needs to keep funding the millions of dollars necessary to keep an individual child alive?

**VI. Pediatric Issues**
A. Children as Decision Makers

Recent developments in the understanding of the cognitive development of the child, the desire to enhance the child's autonomy and skill as a decision-maker, and the recognition of the need of the minor patient to know the diagnosis and proposed treatment have all led to an increased role in decision making for the child-patient. Most children and adolescents, however, are not considered legally or ethically fully capable of making health care decisions. Special categories of minors (definitions vary from state to state) include

- **emancipated minors** (minors who are married or not subject to parental control; usually includes pregnant or parent minors),
- **mature minors** (minors who merit respect for their decision-making based on age and maturity), and
- **statutory minors** (minors able to give consent for medical or mental health services involving diagnosis and treatment of venereal or other contagious disease, birth control or pregnancy, or substance abuse or outpatient mental health treatment).

Much attention recently has been focused on giving children/adolescents a greater voice in decision-making in their health care. See the accompanying chronology of adolescent decisionmaking. However, in a rebuttal to the 1995 American Academy of Pediatrics’ recommendations for an increased role of children in health care decision-making, Ross (1997) argues that parents should continue to have the greater say in decisions affecting their child due to their responsibility to pursue family developmental goals, goals which may compete and conflict with the goals of particular family members. In other words, the future and integrity of the family unit as a whole outweighs the autonomy of a single member when there is a conflict of interests. Moreover, studies indicate that younger children tend to think in terms of short-term and hedonistic needs, and that until they develop a higher cognitive maturity level they will be disinclined to comply with an uncomfortable course of treatment. The issue seems far from resolved—especially for those who are involved in these decisions at the bedside on a daily basis.

Chronology of Adolescent Decisionmaking

- Developmental Psychology Supports Increased Role for Adolescent Decisionmaking Comprehensive analysis of the literature in developmental psychology indicated that “generally minors below the ages of 11-13 do not possess many of the cognitive capacities one would associate with the psychological elements of 'intelligent' consent.” By contrast the authors state there “is little evidence that
minors of age 15 and above as a group are any less competent to provide consent than are adults.” They conclude that “minors are entitled to have some form of consent or dissent regarding the things that happen to them in the name of assessment, treatment, or other professional activities that have been determined unilaterally by adults in the minor’s interest” (Grisso & Vierling, 1978, p. 423).

- In the pediatric literature, Sanford Leiken (1983) surveyed the findings of developmental psychologists and observed that while the cognitive development cannot always be equated with chronological age, good evidence exists “that, by age 14 years, many minors attain the cognitive developmental stage associated with the psychological elements of rational consent”. As to other adolescent ages, he concluded that “minors between 11 and 14 years of age appear to be in a transition period...[and] there appear to be no psychological grounds for the assumption that minors 15 years of age or older cannot provide competent consent.”

- Professional Groups (Policy Statements) Support Increased Role for Adolescent Decisionmaking. The Committee on Child Psychiatry from the Group for the Advancement of Psychiatry has produced a lengthy study on children and children in which they examine they report “we would expect that by 14, all potential subjects must give their informed consent separate from their parents”. Other professional groups agree.

- In 1973 the Committee on Youth in the American Academy of Pediatrics (AAP) proposed that all state legislatures enact a “Model Act for Consent of Minors for Health Services” that would clarify and expand the ability of minors to give “self-consent” apart from parental consent in a number of clinical circumstances.

- The Pediatric Bill of Rights, an alternative and considerably more expansive model legislative act was passed the same year by the National Center for the Prevention and Treatment of Child Abuse and Neglect; this model act was adopted in 1974 by the National Association of Children’s Hospitals. The proposed law stated that any minor “who is of sufficient intelligence to appreciate the nature and consequences of the proposed medical care and if such medical care is for his own benefit, may effectively consent to such medical care in doctor-patient confidentiality of the parent”.

- In 1976 and AAP Task Force on Pediatric Research, Informed Consent, and Medical Ethics issues a policy statement on consent. The task force recommended that “a reasonable safeguard for all physicians in all elective cases would be to get the written consent to surgery or
treatment from any minor 13 years of age or older in addition to that of parent.”

- The AAP Committee on Bioethics published a policy statement in 1995 that emphasized the importance of getting the informed consent of patients and research participants who have appropriate decisional capacity and legal empowerment and, otherwise, working with informed permission of parents or other surrogates combined with the assent of younger patients. Since children “frequently have decision-making capacity and the legal authority to accept or reject interventions,” the bioethics committee recommends that pediatricians obtain the informed consent of pediatric patients, with the realization that “no additional requirement to obtain parental permission exists.” Nevertheless, they encourage “parental involvement as appropriate.”

- That same year a multidisciplinary Children’s Rights Task Force sponsored by the Midwest Bioethics Center (MBC) completed a work on a comprehensive new shared decision-making model for health care decisions involving minors. Called “Health Care Treatment Decision Making Guidelines for Minors”, the document indicates “that many minors achieve decisional capacity at much earlier ages than is recognized legally.” Consequently the pediatricians, nurses, child psychologists, ethicists, community representatives, and others on the committee propose, that “all persons with decisional capacity have the right to make health care treatment decisions, i.e., the capacity to engage in the informed consent process.” (p. A/2).

- In 1997 Weir and Peters urged the use of advance directives to give older pediatric patients a say in their care.

- Legislative Bodies Support Increased Role for Adolescent Decision Making Several Canadian provinces have enacted legislation that entitles children to make their own health care decisions and public policy in Great Britain is moving in this direction.


B. Consent/Refusal vs. Assent/Dissent

**Assent:** The term assent was suggested in the mid 1970s by a national commission on human research to distinguish a child’s agreement to treatment from a legally valid consent, which can only be given by a competent adult. The American Academy of Pediatrics suggests that assent should include at least the following elements:
1) Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition;
2) Telling the patient what he or she can expect with tests and treatment;
3) Making a clinical assessment of the patient’s understanding of the situation and the factors influencing how he or she is responding (including whether there is appropriate pressure to accept testing or therapy)

Soliciting an expression of the patient’s willingness to accept the proposed care. Regarding this fine point...no one should solicit a patient’s views without intending to take them seriously. In situations in which the patient will have to receive medical care despite his or her objection, the patient should be told that fact and not deceived

C. Guidelines to Facilitate Decision Making by and for Children

- Ensure that each member of the collaborative team simultaneously respects the preferences and is committed to advancing the best interests of the child/adolescent. Caregivers should be conscious of whether their bias leans toward violating the autonomy of children to secure “better” health outcomes or toward challenging the adolescent’s right to be autonomous to the degree that what may be “poor” or “ill-advised” choices are too “readily” accepted.

- Ground decision making in caring professional relationships with both the child/adolescent and his or her family and with other members of the health care team.

- Use the trust these relationships generate to be sensitive to how developmental, family, cultural, and caregiver variables are influencing the decision-making process and the values that are shaping preferences and behaviors.

- Reject the tendency to restrict what counts as a “good outcome” to perfect compliance with the recommended medical plan of care resulting in the reversal of the progression of the disease. Healing takes many forms, only one of which is cure. Even good dying and death can be transformative experiences for the patient, family and staff.
Feb 12 * Session 5 * Deciding for Others * Small Group Activity

Discuss each case below…not using the ethics work-up, but merely reporting on how you would use the best interests or substituted judgment standards to guide decision making for these patients. Be sure to describe what you believe should be the role of the clinician in the shared decision making model.

**Case A:**
A baby is born to a young couple who expect a healthy infant based on all the prenatal and perinatal indications. Within 24-48 hours after birth the baby refused to eat, becomes lethargic and rapidly lapses into coma at which time hyperammonemia is diagnosed. (This genetic disorder manifests only after the baby is born and the umbilical cord disconnected; the mother's liver detoxifies the ammonia of the baby through the placenta.) The baby needs to go on life support, as hyperammonemia causes brain swelling and, unless rapid therapy is instituted, the baby will die within a few days. The only life-saving procedure is hemodialysis to bring the ammonia down rapidly. Most babies who are treated with effective hemodialysis will survive, but there could be complications such as stroke, obstruction of large vessels, and infections. Once the ammonia has been brought under control, the baby will be treated with severe protein restriction and ammonia scavenging drugs and will be stable for about 2-4 months until the next hyperammonemia episode, usually during the next infection. Recurrent hyperammonemia will then happen frequently and each time additional brain damage occurs.

The neonatology attending of this baby instructs the resident to request an emergency ethics consult. **According to the attending:** When I talk with parents about hemodialysis in the newborn period, the decision has to be made within an hour. Although we try to tell them that having a baby with this condition will change their life and we try to explain this, most parents are not in a condition to be able to comprehend the information. (They are in a very stressful state and look for advice from us which we don't give, just giving them the options the way we see them). In my experience all parents want us to do everything we can to save the life of their baby and this is what we do, which has become the standard of care. At this stage we know that the next several years will be extremely stressful, feeling like having a "time bomb" that can go off suddenly (hyperammonemia) and that would life threatening. Some families can handle this better than others. I have seen families whose lives have been severely disrupted as a result, causing divorce and serious emotional problems of the siblings who would get less attention due to the attention given to the sick baby. Their lives then circle around how to treat the baby, what to give him/her to eat, and how to prevent the high ammonia from returning. Guilt feelings occur frequently. Essentially all the affected infants are mentally retarded and require special ed and other multiple medical services. Liver transplantation can cure the high ammonia which will never return but it is a tradeoff with complications such as a risky procedure with probably
10% perisurgical mortality, organ rejection, life-long immunosuppressive treatment, stunted growth and the long-term out for all thus is still unclear, there may be secondary cancers developed due to long immunosuppression. The procedure is very expensive and may cause economical hardship for the family. The attending wants to recommend against hemodialysis and urge the parents to authorize a palliative approach. One nurse who has worked closely with the baby believes that quality of life considerations should not be considered when deciding about hemodialysis. According to this nurse the federal Baby Doe Regulations demand that this infant receive full medical treatment including hemodialysis. A second nurse shares the attending’s concerns and wants to urge the family not to authorize hemodialysis.

So here is the dilemma as stated by the attending. How should the professional caregiving team approach this issue. Should we incorporate our personal ethical beliefs into the information we give to the parents, knowing that they may be incapable of making a well-informed decision due to their state of mind and due to the fact that they need to decide quickly, as delay in decision would cause the baby to have more severe brain damage or the baby may die. We are here to preserve the life of our patients, but want the life to be of reasonable quality. What is our responsibility to the family, parents, sibs? How do we resolve this conflict?

Case B:
Tyrone is a 17 year old African American male who initially presented with a unilateral neck mass in December. Staging revealed a large (14 x 7 x 5cm) right cervical neck mass extending into the mediastinum. A biopsy revealed Hodgkin’s disease stage IIIA. Two other lesions were noted on CT (on the spleen and a lymph node near the right seminal vesicle). He had no fever, chills, night sweats, loss of appetite or shortness of breath. He was referred to an adult oncologist who began treatment (adriamycin, bleomycin, vincristine, dacarbazine). He completed four out of six cycles but at the end of four cycles refused further chemotherapy due to intolerable nausea and malaise. The neck mass had substantially decreased after four cycles of chemotherapy. Of note, Tyrone and his mom were overheard questioning whether or not they were guinea pigs for the white doctors who wanted to try experimental drugs.

In March when Tyrone refused further treatment there was much discussion with Tyrone, his mother, and the oncologist who attempted to encourage continuing treatment. Tyrone’s mother stated that she would like him to continue treatment but “does not know what to do”. He was not suicidal at the time and had no obvious physical findings except with complaints of nausea. They were going to set up a psychiatric referral but mom called one week later and stated that they would not continue treatment. Tyrone received one month of alternative therapy with 714-X, Laetrile, Vitamin C, Essiac Tea, DSMO and a specialized diet. Tyrone was asymptomatic for one year but after noticing an increase in the right neck mass agreed with this mother to come to Georgetown University Medical Center Pediatric Hematology/Oncology Clinic for an evaluation. Per Tyrone’s report there had been no other change in the interim since his last therapy. His mother was concerned that he
had lost weight. In our clinic in May, 2000 it is noticed that Tyrone had a fullness in his right neck but there was no discrete mass and the remainder of his physical exam is within normal limits. Scans revealed large lymph nodes in the right neck. A gallium scan was also positive for a lesion in the right neck. CT of the check, abdomen and pelvis revealed no evidence of tumor. After much discussion, Tyrone agreed to a lymph node biopsy of the right neck by our surgeon. The pathology revealed Hodgkin’s disease.

Tyrone and his mother were connected with Pediatric Hematology-Oncology Art therapy, social work, chaplain and even introduced to other patients that were similar to him, in an effort to support Tyrone. Tyrone acknowledged to the team and his mother that he had lymphoma (or cancer) and that he realized that he was not feeling well due to the lymphoma, but that “he was not going to get any more chemotherapy”. His mother wants him to get chemotherapy but acknowledges that she cannot “force” him to do anything that he refuses to do. Tyrone frequently appeared in the clinic wearing a Bob Marley T-shirt!

You believe that Tyrone should receive the chemotherapy. What do you do?

**Case C:**
Alice Anderson is a 47-year-old homeless woman who is brought to the emergency room one December evening with frostbite to both lower extremities. The clinical consensus is that she needs a lifesaving bilateral amputation. She flatly refuses the amputation and makes statements like: “God is my doctor, God is my lawyer, let me go...”; she refuses to participate in an interview with a psychiatric resident. The psychiatric resident labels her “paranoid with religious delusions” and the court appoints a guardian. The involved clinicians want permission to do the bilateral amputation and have arranged for follow-up treatment at St. Elizabeth’s, Washington D.C.’s residential facility for psychiatric patients. The guardian believes that Ms. Anderson has the capacity to refuse the life-saving amputation.

**Case D:**
A disheveled woman in her mid-40s was brought to the emergency department by the police at 3:00 a.m. They requested that she be admitted to the psychiatry service. She was, so far as the police knew, homeless, and had been seen sleeping in a city park in recent months. She sometimes used the restroom at a nearby Burger King, but occasionally had been seen voiding amongst bushes in the park. The woman spent her days standing on street corners in the neighborhood and appeared to be hearing and responding to voices. She sometimes frightened pedestrians by yelling at them, but she did not appear truly menacing or dangerous. No one knew anything of her history. The police searched her satchel of belongings, which contained mostly clothes and ripped-out magazine articles. She had about $7.00 in cash and some candy. There was no evidence of legal or illegal drugs. The police had observed her culling food from neighborhood garbage cans.
The woman refused to give her name or to same more that a few words to the clinician who examined her. She appeared reasonably well nourished and her vital signs were within normal limits. She would not say anything about her background. She seemed tense and frightened in the ED, and was obviously having almost continuous auditory hallucinations. She was very angry at one of the policemen, periodically screamed and shook her fist at him. She refused to be admitted to the hospital or even to discuss taking medications. The police brought her in on this particular night because she had been screaming especially loudly for the past two nights, and several occupants of lower-floor apartments had called the police and complained. The policemen strongly urge the attending to involuntarily hospitalize the woman. An ethics consultation is requested. [From, Committee on Medical Education of the Group for the Advancement of Psychiatry (GAP) for A Casebook in Psychiatric Ethics , Brunner/Mazel, 1990, pp. 37-38].

Case E:
A 69 year old African American male needs surgery to resect a tumor pressing on his spine. The patient is profoundly retarded and his two legal guardians are his sisters. Both sisters are Jehovah witnesses and they will not authorize the administration of blood products during surgery. The surgeon won’t operate unless he can use blood products if necessary.
End of Life Issues

Learning Objectives:

After Session 6, students should be able to:

1. Formulate a working definition of what constitutes a life sustaining medical intervention.
2. Describe the various consensus principles that have been established to guide the initiation, withholding and withdrawing of life sustaining medical interventions.
3. Describe the mild nuances that come into play with end of life decision-making via a proxy/surrogate.

Reading:


Preparatory Assignment:

Antonia’s Gangrene – Use Case Method Template on Blackboard

Lecture Outline:

Posted on Blackboard

Small Group Activity:

Discuss the Preparatory Assignment’s Case

NB: SMALL GROUP LEADERS: DURING THIS SMALL GROUP SESSION, PLEASE ALSO DIVIDE/ASSIGN STUDENTS TO VARIOUS GROUPS AS DESCRIBED IN THE SMALL GROUP ACTIVITY FOR SESSION 7
Life-Sustaining Surgical Interventions

Seventy-nine-year-old Antonia came to the United States from Italy in the 1930’s. She had married, had a family, and was living independently in her own home at the time of her case. She had been relatively melancholic since her husband’s death 10 years earlier, and had suffered from hypertension, diabetes, and hypercholesterolemia for over twenty years. She had a 20 pack year smoking history (Quit 10 years ago). Her relationship with her children (a daughter and four sons) was marked by a degree of conflict. She had previously announced to the family that she really did not want to live with any of them. Nonetheless, her daughter and one son have dutifully shuttled their mother to her doctor’s appointments, done the shopping, etc. making it possible for Antonia to live “independently.”

Struggling against gangrene in her extremities, she had consented to the amputation of a toe in 2000 and to a part of her foot in November 2003. During her surgery in 2003, she suffered a mild stroke that resulted in residual weakness of her right arm. With intensive physical and occupational therapy, she was able to return to living in her apartment safely.

In April, 2007, gangrene was found in the remainder of her foot, and she consented to an amputation of her lower leg. On the morning of the surgery she changed her mind and the operation was cancelled. She was discharged to her daughter’s home. Around May 9, after encouragement from her primary care physician she had known for years, she again consented to the amputation, but then reversed her decision a second time in the surgical suite.

It was clear from her testimony, and from the testimony of others, that she was confused on the risks and benefits of the proposed surgery (amputation). Her train of thought wandered on occasion, and her conception of time was distorted. She was sometimes hostile with certain physicians and combative when questioned about the possibility of surgery. She repeatedly expressed a desire to get well and return to her apartment but, discouraged by the failure of the earlier amputations to stem the gangrene, she was afraid the amputation of her lower leg would not be successful in controlling the problem. Her opposition to the surgery soon became definitive. She was quite clear on this point and gave every indication that she understood the consequences of declining the amputation (overwhelming infection, sepsis, death).

Her daughter was understandably upset over her mother’s refusal of the life-sustaining surgery. She asked the probate court to appoint her the guardian for her mother with the authority to give consent for the surgery.

For your consideration/discussion:

1. Does Antonia demonstrate decision making capacity for the decision of amputation?

2. What questions would you ask her as her clinician to guarantee that she demonstrates capacity?

3. As the ethics consultant called to comment on this case, use the case method template to work through this case and decide whether you would recommend to the surgical team to proceed with the amputation or to forgo the surgery. You will hand in your case analysis at the end of the Small Group Activity.
Session 7
Tuesday, March 25, 2008 – 10:00 am to 12:00 noon

Futility

Learning Objectives:

After Session 7, students should be able to:

1. Describe established as well as controversial practices in caring for patients with serious and/or terminal illness
2. Describe critical milestones in the ethical and legal evolution of the “problem” of futility
3. Describe and distinguish between different definitions of futility
4. Describe the ethical dilemmas encountered in cases that present clinicians with the “problem” of futility
5. Describe and utilize a “relational” concept of futility

Reading:
An excerpt from Lawrence J. Schneiderman and Nancy S. Jecker’s Wrong Medicine: Doctors, Patients, and Futile Treatment (Baltimore, MD: Johns Hopkins University Press, 1995)


Preparatory Assignment:
Case Analysis of “Mr. X”

Lecture Outline:
Posted on Blackboard and below

Small Group Activity:
Mr. X – Ethics Committee
Each student should prepare for the class by evaluating the case using the case method template. This will be handed in at the end of the small group activity.

In the previous class, your small group leader will have divided the class into the Director of the Health Care Ethics Committee, the members of the Health Care Ethics Committee, members of the health care team, and specialists. The Director of the Committee will coordinate and facilitate the discussion.

The goal of the class is to work the complexity of the case and to determine whether the health care team should/must comply with the family’s wishes for aggressive treatment.

Mr. X is the 97-year-old patriarch of a large Iranian-American Muslim family. He was well with controlled hypertension and mild heart failure until 7 years ago when he had a stroke. At that time he lost function of his right leg and had some speech impairment, which partially resolved. His wife died soon thereafter and his children insisted that he live with them. He then split his time between his two sons’ houses. He also had two daughters. One, who had a family of her own, would visit him often. The other was mildly developmentally disabled and unmarried. She was always at his side and dependent upon her father for support.

Despite close attention and careful medical care, he had several subsequent strokes with associated cognitive decline and worsened ability to complete daily activities. He was hospitalized several times for heart failure exacerbations and each time was discharged to a nursing home where his family was omnipresent and visibly unhappy with the level of care. They were distressed that his renal function, which was failing, was not being checked often enough and that his myriad medications were not always given on schedule. The physicians during hospitalizations and in the nursing facility attempted on numerous occasions to try to outline a plan of care for the patient with a palliative bent, but were met with resistance and anger. Physicians’ attempts to speak with the patient about this topic were thwarted by his poor command of English, the family’s view that the physicians should communicate only with them, and the patient’s cognitive impairment. On one occasion when a social worker attempted to bring the patient’s religious views into consideration, the family consulted with the imam who told them that any withdrawal of care would violate their religious beliefs. Another time, when a translator was present and the family was not, the translator felt that the patient could answer simple questions, but did not meaningfully respond to physicians’ questions about preferences for current and future health states.

The patient became short of breath in the nursing home and was brought back to the hospital once again. He was found to have had a myocardial infarction and was in heart failure. Despite medical therapy, he was unstable and the family asked that an angiogram be performed so that the patient might receive angioplasty or perhaps a bypass surgery. The cardiologists were reluctant because they felt that the patient was unlikely to benefit from the procedure and because he would become dialysis dependent after the procedure. The heart surgeons declared that he was not a surgical candidate. The family pressed for the patient to be moved to the ICU, dialyzed and taken for the cardiac procedure. The ethics committee is consulted by the health care team concerning whether they must comply with the family’s wishes.
I. CARING FOR PATIENTS WITH SERIOUS AND/OR TERMINAL ILLNESS: ESTABLISHED AND CONTROVERSIAL PRACTICES

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<thead>
<tr>
<th>Ethically and Legally Established Practices</th>
<th>Controversial Practices</th>
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<td>Patient’s or Surrogate’s (Informed, Voluntary) Refusal of Treatment / Advance Care Planning</td>
<td>Patient/Surrogate Demands for Treatments Deemed by Clinicians to be Futile</td>
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<td>Providing – or by contrast, Withholding or Withdrawing – Life-Sustaining Treatment / Advance Care Planning</td>
<td>Clinician Insistence on Providing Life-Sustaining Treatments Deemed Futile by Patients/Surrogates</td>
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<td>Palliative and Hospice Care / Advance Care Planning</td>
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II. CRITICAL MILESTONES
A. Helga Wanglie, 1991
B. Baby K, 1994
C. Gilgunn v. MGH, 1995

III. THE TROUBLED CONCEPT OF FUTILITY: HOW TO DEFINE FUTILITY? HOW TO DETERMINE WHO DECIDES WHAT TREATMENTS ARE OR ARE NOT FUTILE?
A. Quantitative or physiologic futility
B. Qualitative futility
C. Other definitions

IV. THE TROUBLED CONCEPT OF FUTILITY: ETHICAL DILEMMAS

V. FUTILITY AS A RELATIONAL CONCEPT
A. Effectiveness
B. Benefit
C. Burden
Session 8  
Tuesday, April 1, 2008– 10:00 am to 12:00 noon

Truth-Telling, Privacy and Confidentiality

Reading:  
Chapter 7 and 8, “Privacy and Confidentiality” and “Communicating, Truth-telling and Disclosure, from Flether’s Introduction to Clinical Ethics, 3rd ed.

Preparatory Assignment:  
Use the assigned readings to reflect on two mini cases involving privacy and confidentiality and prepare answers to three questions.

Lecture Outline:  
See pages following preparatory assignment.

Small Group Activity:  
Discussion of the case of David Collins, using the ethics work-up.

Apr 1 ✪ Session 8 ✪ Truth telling, Privacy and Confidentiality ✪ Readings
A. Read the following two cases, utilizing the ethics work-up and focusing on the prudential question: What should – or should not – be done for this patient? Write your answers to the following questions and support your answers with the assigned reading.

1. If the end of the healing relationship is a right and good healing action for this patient, what would the right action – the scientifically and clinically sound action – be? What would the good action be?
2. From the perspective of the professional morality of medicine and nursing, what course of action would be ethical? What is the ethical justification for your decision?
3. In complying with the surrogat’s/patient’s wishes, whom or what would the clinician benefit? Whom or what would the clinician harm?

Case One:
A woman originally from the Middle East calls us and tells us that her 16-year old son has both HIV-infection and is recovering from chemotherapy for lymphoma at NIH. He is no longer on protocol and needs a new Peds Infectious Disease Specialist to follow him. Her question to us is: Would we agree to treat this young man without telling him he is HIV infected? He knows about the cancer but not the HIV infection acquired by transfusion as a newborn in the US.

Case Two:
A 42 year male patient scheduled for a knee arthroscopic procedure presents for preadmission testing and tells the nurse practitioner doing his history that he is HIV + but he does not, for any reason, want this fact documented in his record. He tells the nurse practitioner that she is at liberty to communicate this fact orally to any team member who has the need to know but he does not want this recorded in his chart.

B. Then prepare for your small group activity by reflecting on that case and the questions above.
I. The Relationship between a Patient and a Health Care Professional/Clinician

A. What’s the goal? What’s the aim? What’s the end?

B. And, in that light, what should the nature of this relationship be? How should it be conducted or pursued? Which of the clinical virtues should professionals/clinicians exhibit in the relationship, so conceived?

II. Medicine and Nursing as Healing/Fiduciary Relationships Oriented to the End of a Right and Good Action for the Patient

A. Healing: the relationship is grounded in the shared desire to restore the patient, in some sense, to wholeness

B. Fiduciary – i.e., trust-based: the relationship is grounded in mutual trust

C. Right: the decision is clinically, scientifically sound

D. Good: the decision is in accord with the preferences and values of the patient and of the professional(s)/clinician(s)

III. Complicating Realities

A. Differences between professional(s)/clinician(s) and patients

   ➢ Aesculapian power: the clinician’s knowledge and skill
   ➢ Illness and the diminishment of patient autonomy
   ➢ Gender, race/ethnicity, socioeconomic status, age

B. Differences between/among members of the health care team

   ➢ Knowledge, skill, experience
   ➢ Culture and hierarchy in health care

IV. Establishing, Cultivating, and Preserving Trust: The Critical Importance of Respecting Privacy, Maintaining Confidentiality, and Telling the Truth

A. The ethical problem: the problem of the professional’s power to control communication and patient-related information

B. The durability of the traditional commitment to respect privacy and maintain confidentiality

C. By contrast: the checkered history of truth telling

V. Respecting Privacy and Maintaining Confidentiality
A. Rationales and justifications

- Duty-based – absolute or conditional?
- Virtue-based
- In deference to the principle of respect for autonomy? Rights to privacy?
- The care perspective
- The viewpoint of the common good

B. Exceptions: justifications for breaching confidentiality

C. HIPAA

VII. Truth Telling

A. On not telling the truth: omissions and commissions
B. Rationales and justifications
Read and discuss the following case, utilizing the ethics work-up and focusing on the prudential question: What should – or should not – be done for this patient? In the course of your discussion, collectively consider and address the following questions:

1. If the end of the – of this – healing relationship is a right and good healing action for this patient, what would the right action – the scientifically and clinically sound action – be? What would the good action be?
2. From the perspective of the (codified) professional morality of medicine and nursing, what course of action would be ethical?
3. In complying with the patient’s wishes, whom or what would the clinician benefit? Whom or what would the clinician harm?

You are a physician or nurse practitioner working for Omnicare, a large managed care organization in the northwest U.S. Omnicare provides health care on a contractual basis for the area’s large military and civilian population. You practice in one of Omnicare’s primary care groups. You refer patients who need specialty care to several of the major medical centers in the community that have contracted with Omnicare. All medical records, including those of military personnel, are maintained in Omnicare’s electronic database.

For the past two years you have been treating David Collins, a 39-year old active duty Army officer, for mild hyperlipidemia. David is an intelligence officer who plans to retire from the military in three years and work for the State Department. He is an engaging, quick-witted man whom you have come to know well. You look forward to his appointments as a break in the often monotonous clinical routine.

Today, as you enter the examining room, you notice that David is quiet and withdrawn. His posture is uncharacteristically slumped and his eyes, normally twinkling, are surrounded by darkened circles. He answers questions with monosyllabic responses and frequently asks you to repeat your questions.

You comment on David’s unusual demeanor and ask if there is anything he would like to discuss. At first he stumbles, but soon reveals that a loved one has recently died. Upon further inquiry, David confesses that the “loved one” was his male partner with whom he shared a relationship for the past 12 months.

His companion died in an auto accident four months ago. David, aware of the Army’s policy on same-sex relationships, feels he must remain silent to his supervisors about his loss. He tells you that if you disclose the situation to his supervisor, he could forfeit his current position (and perhaps his pension) and would also almost surely jeopardize future employment at the State Department. In fact, he has spoken to no one about his loss.

He expresses relief that he can finally unburden himself to you because you are a civilian health care professional. He explains that he has experienced changes in his weight and appetite, felt excessive guilt and experienced intrusive passive suicidal ideation.
You suspect that David is suffering from a major depressive disorder and that he might benefit from both antidepressant medication and psychotherapy. David, however, flatly refuses the latter.

You try to reassure him that the medical record is confidential and that his supervisors are not routinely entitled to information in it. David shakes his head sadly and lets out a sigh. “I can’t believe you are so naive,” he says. “I’m in Army intelligence. I can promise you that there are 10 ways I could breach the confidentiality of the medical record system right now if I wanted.”

Although David agrees to try an antidepressant and to see you more frequently, he asks you to refrain from writing anything about the depression in his chart. He also asks you to write his prescription on a paper pad and not enter it into the computer system as you would ordinarily. Finally, David says he will pay for the medication himself rather than risk having a record of it in the Omnicare’s prescription benefit database.

You know you have an obligation to protect David’s sensitive personal and medical information; you believe wholeheartedly that medical records should be kept confidential. However, you also believe that David is justified in his skepticism about how well confidentiality is safeguarded. Nevertheless, you are uncomfortable with the idea of prescribing a psychotropic medication without at least some note of it in the record. On the other hand, you fear that David will object to the treatment if you insist on even the barest of documentation. Untreated, he could very easily become much more depressed, even suicidal.

How should you proceed? Do you have an obligation to record the content and clinical plan of this clinic visit?

Source: Adapted from The Annals of Internal Medicine/American College of Physicians
Session 9  
Tuesday, April 8, 2008 – 10:00 am to 12:00 noon

Decision Making at the Beginning of Life

Learning Objectives:

*After Session 9, students should be able to:*

1. Analyze the relationship between personal and societal beliefs and values about human life and reproduction and clinical decision making.

2. Self-evaluate the grounds of their personal beliefs regarding beginning of life issues, and begin to learn how to speak to others who might disagree with their position in a civil manner.

3. Contrast the implications of using different ethical perspectives and frameworks (i.e., strict traditionalism, modern traditionalism or radical liberty) to inform and justify assisted reproduction decision making.

4. Use the methodical approach to ethical decision making to facilitate conflict resolution about treatment options at the beginning of life.

**Reading:**

**Preparatory Assignment:**
1. Personally defend one of three different ethical/philosophical stances toward the meaning and significance of human reproduction, parenting, and the status of offspring, etc.: a) strict traditionalism, b) modern traditionalism, and c) radical liberty.

2. As a group assignment, use the case method to analyze one of two cases assigned in the previous class.

**Lecture Outline:**
Posted on Blackboard

**Small Group Activity:**
Discuss the Preparatory Assignment in a civil manner
1. The reading for this session, the article “Procreative Liberty in the Era of Genomics” by John Robertson, describes three different ethical/philosophical stances toward the meaning and significance of human reproduction, parenting, and the status of offspring, etc.: 1) **strict traditionalism**, 2) **modern traditionalism**, and 3) **radical liberty**. In a one page defense, argue for one of the three stances.

2. In the previous class, your preceptor should have divided the class in two groups and assigned each group to one of the two following scenarios. Each group should meet briefly prior to the class and work through your assigned case using the case method template. You can hand in a Common Case Method Analysis for the entire group. During the small group activity your group will be charged with leading the discussion of the case and the manner in which your group resolved the issue.

**Scenario One:** Adapted from *A World of Their Own* (In the eyes of his parents, if Gauvin Hughes McCullough turns out to be deaf, that will be just perfect ...) by **Liza Mundy**

*The Washington Post Magazine*, March 31, 2002; Page W22 (Full article posted on Blackboard)

Sharon Dinges and Candace McCullough are a young lesbian, deaf couple who fell in love at Gallaudet University in Washington, DC. Liberated from the predominantly “hearing” culture of the United States, they have come to embrace their deafness as a gift, not a disability. In their attempt to raise a family within the deaf subculture, they specifically chose a sperm donor, whose family was deaf for several generations. Their first daughter, Jehanne, is profoundly deaf and has been signing ASL (American Sign Language) since birth. Although Jehanne has a speech therapy class at her local kindergarten, neither parent is interested in forcing her to speak according to “hearing standards,” which have represented a source of pain and embarrassment throughout Sharon and Candace’s lives.

Their second child, Gauvin, was born at home with the assistance of a midwife. Born at 6#, 5 oz with an Apgar score of 9/10 in one minute, he appears to be a healthy baby boy. A few days later, they take Gauvin to their pediatrician and undergo the normal perinatal care of a young child.

At three months, Gauvin undergoes extensive hearing tests. His left ear does not seem to register hearing at greater than 95 decibels (profound hearing loss). His right ear registers a spike at 75 decibels (significant hearing loss).

The pediatric clinician provides them the results of the study. The clinician explains that if there is any chance at all for Gauvin to begin hearing sounds that are necessary for speech development, his right ear will have to be fitted with a hearing aid. Therefore, a hearing aid was recommended to Sharon and Candy. They listen attentively, but decide to forgo the hearing aid. They explain that if Gauvin wants to have a hearing aid in the future, they will permit him to do so. By the time he is of the age to make such a decision, his capacity to vocalize speech in the “hearing” world will be greatly limited.

Happily, they leave your office. Gauvin may not be as profoundly deaf as his sister Jehanne, but he is quite deaf enough.

The pediatric clinician is uncomfortable with this course of action. He/She calls you, as the ethics consultant, and asks the question: Are Gauvin’s parents (the natural surrogates for Gauvin) acting according to the best interests standard? Do I have any further obligation to Gauvin to maximize his ability to vocalize speech?
**Scenario Two:** A 19 year old woman named Ayesha Madyun is in labor with her first child. Her “water broke” before she arrived at the hospital. Seventy hours have passed since the breaking of her waters and she is three quarters dilated, but making no further progress. In other words, the baby is “stuck.” The hospital’s obstetrical residents have been taught that infection, which can kill the baby or cause severe brain damage without warning, threatens any woman who has not delivered within 24 hours of “breaking her water”. As time passes the obstetricians have been strongly advising Madyun that she must have a cesarean section to “pull the baby out” before an infection takes hold and her delivery has catastrophic consequences. Madyun, convinced that she will deliver naturally and safely if left alone, refuses to let them operate.

She argues that this is her baby, she says, her body. Her religion teaches that the decision must be hers. Should the obstetricians honor her instructions and hope that both the baby and mother survive? What if you were her midwife managing her home birth and she refused your counsel to be moved to the hospital after your best efforts to move her along failed. Should the involved clinicians call for a court order and then operate without her consent? If you get a court order and she fights the procedure would you hold her down? Would you anesthetize her or administer any drugs with the intent of making her more relaxed and cooperative? Would it matter if her reason for refusing the cesarean was linked to vanity and wanting her abdomen to be free of scars? What if she gave no reason at all--simply sat up in her bed, a competent adult fully informed of the consequences, and looked her obstetrician/midwife in the eye, and said, no? (Adapted from The New York Times, December 13, 1988]
I. Introduction: Human Life and Reproduction – Relating Personal and Societal Beliefs and Values to Clinical Decision Making

II. The Challenges for Decision makers and Health Care Professionals

   A. Challenge to Competency: Professional obligation to keep abreast of scientific and technological advances
   B. Obligation to Critique Scientific Advances in Light of Their Potential to Influence Human Well-being
   C. The ideal of shared decision making
      1. Do parents have unlimited autonomy regarding reproductive decision making?
      2. What rights do the unborn have? What “respect” is owed embryos?
      3. What decision making role ought health care professionals play?
      4. Aim: 1) protect the parent(s)’ rights to self-determination; 2) promote the best interests of future children; 3) promote the clinician’s right of professional integrity; 4) promote a just society; and to do this in a manner securely rooted in the ethical tradition of promoting and defending human dignity
   D. NANDA Diagnosis: Decisional Conflict
      What does it mean to be an advocate for people struggling with beginning-of-life decisions?
      1. Ability to present the options
         1. objective content
         2. subjective content
      2. Sensitivity to how one’s personal beliefs and values influence the process of professional communication and decision making
      3. Goal: authentic autonomy
         Decisions are consistent with the identity, decisional history, and moral norms of the decision maker and consistent with the integrity of the health professions (end of medicine and nursing) and individual health care professionals
      4. Technology transfer and gatekeeper issues
         a. Rapidity of technology transfer from research to clinical application
         b. Role of commercial interests
         c. Accessibility of technology
         d. Heterogeneity of testing sites and providers
         e. Preserving the “traditional” genetic counseling model

III. The Reproductive Revolution: Challenging Basic Notions about Procreation, Parenthood, Family and Children

Technologies to Control the Quality of Offspring
The most widespread form of quality control occurs through prenatal screening of coitally conceived fetuses by means of amniocentesis, chorion-villus sampling, ultrasound, or maternal alphafetal protein testing (maternal blood test of the fetus)
Technology is pushing prenatal screening back to the pre-implantation or embryonic stage of development -> embryos with genetic defects can be discarded, obviating the need for later prenatal diagnosis and abortion

In the future, therapeutic genetic alteration may be possible to treat the affected embryo -> non-therapeutic enhancement of offspring characteristics

Screening techniques that identify a problem in the embryo or fetus may lead to medical indications for medical or surgical procedures to treat the problem in uteri

Increased attention to the health of fetuses has also focused attention on the environmental and behavioral factors that affect the well-being of offspring in uteri.

A. Claims
   1. Parents have a “right” to healthy/genetically-advantaged offspring
   2. Parents have an obligation to utilize all available means to ensure healthy/genetically-advantaged offspring

B. Issues
   1. Are there limits to parental autonomy?
   2. Are parents obligated to act in the best interests of their offspring?
   3. What is society’s role in ensuring the quality of offspring?
   4. Questions about normalcy and potential for discrimination
   5. Justice questions

IV. Stem Cell Research and Human Cloning

V. Clinician Autonomy
Session 10
Tuesday, April 15, 2008 – 10:00 am to 12:00 noon

Justice, Professionalism & the Primacy of the Patient, and the Challenge of Divided Loyalties

Learning Objectives:

After Session 10, students should be able to
1. Identify the core elements of professionalism for physicians and nurses and relate these to everyday ethical challenges in professional practice
2. Describe the clinician’s ethical obligations to difficult patients
3. Develop strategies to justly navigate conflicts involving divided loyalties

Reading:
Toulmin, S. (1986). Divided loyalties and ambiguous relationships. *Social Science and Medicine, 23*(8):783-7

American Medical Students Association: “Does that one slice of pizza matter?”
No Free Lunch: Pharmaceutical Facts and Fallacies

Preparatory Assignment:
Analyze assigned scenario and respond to questions.

Lecture Outline:
See the pages following the preparatory assignment.

Small Group Activity:
Discussion of assigned scenarios
Review your respective code of ethics and relate its provisions to the case you were assigned to discuss in the small group activity. How would a just nurse/physician respond? Write a one page statement which describes how you believe nurses/physicians should respond in this situation (refencing your code) and how you believe most are likely to respond. If these are different please explain.

**ANA Code of Ethics for Nurses (2001)**

1. The nurse, in all professional relationships, practices with compassion and respect for the inherent dignity, worth, and uniqueness of every individual, unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems.
2. The nurse’s primary commitment is to the patient, whether an individual, family, group or community.
3. The nurse promotes, advocates for, and strives to protect the health, safety and rights of the patient.
4. The nurse is responsible and accountable for individual nursing practice and determines the appropriate delegation of tasks consistent with the nurse’s obligation to provide optimum patient care.
5. The nurse owes the same duties to self as to others; including the responsibility to preserve integrity, to maintain competence and to continue personal and professional growth.
6. The nurse participates in establishing, maintaining and improving health care environments and conditions of employment conducive to the provision of quality health care and consistent with the values of the profession through individual and collective action.
7. The nurse participates in the advancement of the profession through contributions to practice, education, administration, and knowledge development.
8. The nurse collaborates with other health professionals and with the public in promoting community, national and international efforts to meet health needs.
9. The profession of nursing, as represented by associations and their members, is responsible for the articulating of nursing values, for maintaining the integrity of the profession and its practice, and for shaping social policy.

Voted on and accepted by the ANA House of Delegates on June 30, 2001.


**AMA Principles of medical ethics**

Preamble

The medical profession has long subscribed to a body of ethical statements developed primarily for the benefit of the patient. As a member of this profession, a physician must recognize responsibility to patients first and foremost, as well as to society, to other health professionals, and to self. The following Principles adopted by the American
Medical Association are not laws, but standards of conduct which define the essentials of honorable behavior for the physician.

Principles of medical ethics

I. A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights.

II. A physician shall uphold the standards of professionalism, be honest in all professional interactions, and strive to report physicians deficient in character or competence, or engaging in fraud or deception, to appropriate entities.

III. A physician shall respect the law and also recognize a responsibility to seek changes in those requirements which are contrary to the best interests of the patient.

IV. A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy within the constraints of the law.

V. A physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, make relevant information available to patients, colleagues, and the public, obtain consultation, and use the talents of other health professionals when indicated.

VI. A physician shall, in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical care.

VII. A physician shall recognize a responsibility to participate in activities contributing to the improvement of the community and the betterment of public health.

VIII. A physician shall, while caring for a patient, regard responsibility to the patient as paramount.

IX. A physician shall support access to medical care for all people.

Adopted by the AMA's House of Delegates June 17, 2001.

Last updated: Nov 06, 2006
Content provided by: Ethics-CEJA
I. Professionalism and Nursing and Medicine

Central to all definitions of professionalism is the primacy of patient welfare.

**Code of Professionalism**

*Students of Georgetown University School of Medicine*

**Preamble:** What virtues, values, and principles are essential to the formation and sustenance of therapeutic relationships between patients and their physicians? To effective collaboration between physicians and other health care professionals? To the cultivation of a profession worthy of the public trust? As students at Georgetown University School of Medicine, we are embarking on our path to the profession at a time when these and other related questions have become the focus of unprecedented interest and concern. The result has been a provocative, wide-ranging and in-depth dialogue about the ultimate ends of medicine – and about what current and future physicians should do, as well as be, in order to ensure the achievement of these ends.

**Our Values, Virtues, and Principles**

With an understanding that the following ideals are central to the practice of medicine, we, as members of the community of Georgetown University School of Medicine, will strive to

- **Respect the dignity and intrinsic value of every individual.** Regardless of race, ethnicity, national origin, age, gender, socioeconomic background, sexual orientation, religious belief or political affiliation, we will strive to respect our teachers, fellow students, patients, and other members of the medical school community.

- **Be altruistic.** We will strive to place the interests and needs of others, especially the sick and the disadvantaged, above our own self-interest.

- **Be compassionate toward others.** We realize that the ability to share in the experiences of others – especially, the suffering of the sick – is critical to the work of healing.

- **Act and speak with integrity.** We will seek to speak and to act in ways that testify to, and support our values and principles.

- **Be collaborative and collegial.** We realize that care for patients and ourselves demands the integration and coordination of the talents, knowledge, and skills of all members of the health care team.
- **Be responsible and accountable.** We will be willing to accept and acknowledge our shortcomings, as well as our successes. We will also commit ourselves to responsibility and accountability for our own learning.

- **Seek excellence.** We will endeavor to improve our knowledge and skill, both within and beyond the learning environment.

- **Practice humility.** We acknowledge the limits of our science and our practice, as well as our personal limits in knowledge and skill.

- **Be worthy of the trust** of our patients, teachers, and fellow students.

- **Be honest,** speaking and acting with truth.

**II. The Concept of Justice**

A. Justice: A Principle and a Virtue

   Common to all theories of justice is a minimal formal requirement traditionally attributed to Aristotle: Equals must be treated equally, and unequals must be treated unequally (Aristotle, Book V, *Ethics*)

   This principle of formal justice is “formal” because it identifies no particular respects in which equals ought to be treated equally and provides no criteria for determining whether two or more individuals are in fact equals.

2. *Material Principles of Justice:*
   Principles that specify the relevant characteristics for equal treatment are called material because they identify the substantive properties for distribution. Philosophers and others have proposed each of the following principles as a valid material principle of distributive justice.

   - To each person an equal share
   - To each person according to need
   - To each person according to effort
   - To each person according to contribution
   - To each person according to merit
   - To each person according to free-market exchanges

Macro and Micro Allocation

*Macroallocation* decisions determine the funds to be expended and the goods made available, as well as the methods of distribution.
Microallocation decisions determine who will receive particular scarce resources.

Norman Daniels argues that the scope and design of basic health care institutions involve allocation decisions to determine the following:

- What kinds of health care services will exist in a society?
- Who will receive them, and on what basis?
- Who will deliver them?
- How will the burdens of financing them be distributed?
- How will the power and control of those services be distributed?


B. Justice at the bedside

1. Commutative vs. distributive justice
2. Legitimate vs. illegitimate roles of HCPs

III. Divided Loyalties

A. Conflicts of obligations

Conflicts of obligation are inherent in all medical practice and cannot be resolved by balancing claims, but only by choosing one obligation over another.

B. Conflicts of loyalty

Conflicts of loyalty result when a clinician's relationships "to two or more individuals, or to two or more institutions, become irreconcilable in ways that force him to choose between them." Along the spectrum of loyalties lie multiple loyalties and ambiguous loyalties, and the latter, if unresolved, create moral ambiguities.

IV. Divided Loyalties and the Personal and Professional Integrity of the Clinician

V. Test Case: Abu Ghraib and Guantánomo
The abuses at Abu Ghraib and Guantanamo were medically, legally and ethically unjustified. They violated every major international human rights convention and the four basic principles of medical ethics. However, these incidents, while deplorable, can “serve as an eleventh hour wake-up call for the western world to rediscover and live by the values enshrined in its international treaties and democratic constitutions.” The United States government and American medical professionals lost a great deal of international credibility in its fight to uphold human rights worldwide as a result of these abuses. Only through immediate needed reforms will this credibility ever be restored. Failure to restore this credibility has the potential to allow the basic human rights of the most vulnerable in the world to be violated in an ever greater way. [Clark, P. (2006). Medical Ethics at Guantanamo Bay and Abu Ghraib: The Problem of Dual Loyalty. The Journal of Law, Medicine & Ethics, 34(3), 570-580.]
Discuss each of the scenarios below which represent challenges to professionalism and medical and nursing ethics and JUSTICE. Having reviewed your respective code of ethics and related its provisions to the scenario you were assigned, discuss how you believe nurses/physicians should respond in this situation (refencing your code) and how you believe most are likely to respond. If there are differences please explain.

Scenario One: Residents talking about “frequent flyers” in the emergency room
The Fat Man [resident] gathered us around the electric gomer ["Get out of my emergency room"] bed containing my patient, Mr. Rokitansky. Fats explained how the goal of the [in]tern was to have as few patients as possible. This was opposite the goal of the Privates, the Slurpers, and the House Administration. Since, according to LAW NUMBER ONE: GOMERS DON'T DIE, the gomers would not be leaving the tern's service by way of death, the tern had to find other ways to TURF them. The delivery of medical care consisted of a patient coming in and being TURFED out. It was the concept of the revolving door. The problem with the TURF was that the patient might BOUNCE, i.e., get TURFED back. For example, a gomer who was TURFED TO UROLOGY because he couldn't urinate past his swollen prostate might BOUNCE back to medicine after the urology intern with his filiform probes and flexible followers had managed to produce a total body septicemia, requiring medical care. The secret of the professional TURF that did not BOUNCE, said the Fat Man, was the BUFF...

“Like BUFFING a car,” said Fats. “You gotta BUFF the gomers, so that when you TURF them elsewhere, they don't BOUNCE back. Because you gotta always remember: you're not the only one trying to TURF. Every tern and resident in the House of God is lying awake at night thinking about how to BUFF and TURF these gomers somewhere else. Gath, the surgical resident downstairs, is probably giving his terns the same lecture at this very moment, about how to produce heart attacks in gomers to TURF TO MEDICINE.” The House of God, by Samuel Shem. pp. 49-50.

A homeless man well known to the ER staff is complaining of “100” on a scale of 1-10 “belly pain” and you are instructed to do a quick work up and discharge—since he has a history of drug-seeking. A known alcoholic, the patient is dirty, smelly, disheveled, and verbally abusive. What do you owe him?

Scenario Two: No free lunch
We (No free lunch) are health care providers who believe that pharmaceutical promotion should not guide clinical practice. Our mission is to encourage health care providers to practice medicine on the basis of scientific evidence rather than on the basis of pharmaceutical promotion. We discourage the acceptance of all gifts from industry by health care providers, trainees, and students. Our goal is improved patient care.

One of your colleagues is passionate about preventing pharmaceutical promotion and suggests that your class get involved in some of NO FREE LUNCH’s recommended activities.

- at your own institution, hospital, or practice. Voice your displeasure about drug company sponsored lunches and conferences. Talk to your Department Chair, Program Director, or Medical Director. Cite the evidence that pharmaceutical promotion works, and often does not promote good
practice. If you see reps flouting policies at your hospital or practice (e.g., accessing off-limit areas, cornering residents or students, leaving materials (or gifts) behind where they shouldn’t, let someone know about it. If you attend drug lunches, ask for evidence. If you must eat, avoid uncooked fish; and please, no pens (if it’s pens you need, please let us know). Encourage residents to do the same. Your role modeling-- particularly regarding the non-acceptance and non-usage of gifts--can go a long way. Talk to your office staff (who are a major target of drug reps); explain to them why this is not a trivial issue, and why they too should just say no!

How should individuals in your class and your class as a whole respond to the fact that research confirms that marketing by pharmaceutical companies influences clinician prescribing practices in ways that may be harmful to patients?

Scenario Three: Sports Medicine

You have been hired by Georgetown University to provide health care to the men and women’s basketball teams. You are frequently troubled by your competing allegiances to individual players and to the university’s need to have successful teams! Like most cautious clinicians you are smart enough not to recommend steroids or other drug enhancements to players. But now university officials are suggesting that new synthetic genes which can last for years, producing high amounts of naturally occurring muscle-building chemicals may be the way to go! Should you participate? Would a clinical trial be appropriate?

“This kind of gene therapy could transform the lives of the elderly and people with muscular dystrophy. Unfortunately, it is also a dream come true for an athlete bent on doping. The chemicals are indistinguishable from their natural counterparts and are only generated locally in the muscle tissue. Nothing enters the bloodstream, so officials will have nothing to detect in a blood or urine test. The World Anti-Doping Agency (WADA) has already asked scientists to help find ways to prevent gene therapy from becoming the newest means of doping. But as these treatments enter clinical trials and, eventually, widespread use, preventing athletes from gaining access to them could become impossible. “

On a smaller scale, at every game there are troubling decisions about when to take a player off the court. Oftentimes even the players want to play when a muscle or joint needs rest. How do you balance meeting the players’ needs as well as the team’s needs?

Scenario Four: Physicians and nurses working in for-profit managed care organizations where the goal is to maximize profit by limiting covered benefits

“I wish to begin by making a public confession: In the spring of 1987, as a physician, I caused the death of a man. Although this was known to many people, I have not been taken before any court of law or called to account for this in any professional or public forum. In fact, just the opposite occurred: I was "rewarded" for this. It bought me an improved reputation in my job, and contributed to my advancement afterwards. Not only did I demonstrate I could indeed
do what was expected of me, I exemplified the "good" company doctor: I saved a half million dollars!

Since that day, I have lived with this act, and many others, eating into my heart and soul. For me, a physician is a professional charged with the care, or healing, of his or her fellow human beings. The primary ethical norm is: do no harm. I did worse: I caused a death. Instead of using a clumsy, bloody weapon, I used the simplest, cleanest of tools: my words. The man died because I denied him a necessary operation to save his heart. I felt little pain or remorse at the time. The man's faceless distance soothed my conscience. Like a skilled soldier, I was trained for this moment. When any moral qualms arose, I was to remember: I am not denying care; I am only denying payment.

Nothing in my education as a physician prepared me for what I experienced as an "executive doctor." I thought I could easily translate my professional code of ethics as a physician to my work in the business of health care... Later, my work...convinced me that the place made no difference. Whether it was non-profit or for-profit, whether it was a health plan or hospital, I had a common task: using my medical expertise for the financial benefit of the organization, often at great harm and potentially death, to some patients.”


Are there ever companies for whom a just and ethical clinician should not work?