21A.216J Dilemmas in Bio-Medical Ethics
2005/3/2 (W), Week 5, Class 9

Readings
TL Kuther “Medical Decision-Making and Minors: Issues of Consent and Assent.” Adolescence, Vol 38, No 150 (Summer): 343-358
EJ Gordon and CK Daugherty “‘Hitting You Over the Head’: Oncologists’ Disclosure of Prognosis to Advanced Cancer Patients”. Bioethics, Vol 17, No 12 (Apr 2003): 142-168.
Kuhse and Singer. Bioethics: An Anthology pp 515-550

Class Business
Victoria’s presentation, then go over papers. Also comment on alternative medicine work. Definitions of care. Surprised that lower-income, lower-education populations would be interested in “alternative’ therapies. Realm of healing, beyond biomedicine, is regulated by the state.

Student Presentation

“Medical Decision-Making and Minors: Issues of Consent and Assent.”
Background: Kuther researches social cognition and risky activity by adolescents and young adults. She studies youth alcohol consumption, youth violence and victimization, risky behavior, and the ethical issues that arise in research with children and adolescents. Psychologist’s perspective.

Summary:

- Although there is an **egalitarian partnership** between MD and adult patients to make healthcare **decisions**, **children and adolescents** have **little voice** in medical decision-making.
- She discusses issues of “informed consent” and the development literature on youth *to make informed, voluntary, rational medical decisions.* (Based on presumption that adults do this, too…?) So can children make good medical decisions? Do they have the capacity? Where do parents and autonomy fit into their medical decisions.
- *Missed out on cultural issues in informed consent, autonomous decision making (truth-telling we covered on Monday)*

Discussion, Arguments and Critiques:

- Kuther claims, according to the Committee on Bioethics, that the physician-patient relationship is now **egalitarian**, **participatory and patient-centered**, where physician and patient make medical decisions together.
  - To what extent does paternalism or doctor-centered approach exist in the medical world?

- She defines **informed consent** as the treatment authorization given by a patient to a physician **knowingly or informed, rationally by a "competent individual" and voluntarily**
- Why does she call informed consent the "Cornerstone of Healthcare"? Clearly, the power of medicine shoulders a moral responsibility. The power embedded in the position of the doctor necessitates in our litigious society that certain checks and balances exist to protect the patient from harm.
    - Based on tradition of western liberalism and rationality: that an autonomous individual can make rational choices in a scientifically controlled environment
- *Definition of informed consent:* An agreement to do something or to allow something to happen, made with **complete knowledge of all relevant facts**, such as the **risks involved** or any available alternatives. A healthcare provider or facility may be held responsible for an injury caused by an undisclosed risk.
- Kuther is concerned about the **voice of the minor or someone under 18 years old as our legal system defines in medical decisions** since they are not necessarily **informed**, **rational**, or **voluntary** with 3 exceptions: emancipated minors, those seeking medical treatment for certain health problems, and mature minors.
    - How the legal status of the "minor" was conceived in the first place, and also cross-cultural perspectives on "adulthood"?
    - Kuther argues that **state legislation** conceived minors as incapable of understanding and making decisions about medical treatment. Minors are allowed to make decisions without parental consent in certain states for certain treatments such as contraception, sexually transmitted diseases, pregnancy, alcohol and drug abuse, and psychiatric problems. But what about adults?
- **There is no way to evaluate 'decision-making skills' or 'competency'**

- Kuther goes in the developmental psychology perspective of minors and informed consent to help determine when minors are mature enough to provide informed consent. **Standards of competence.**
- Kuther claims that children may be able to understand illness concepts if they are presented in developmentally appropriate ways or if they are subject to frequent medical treatment.
- Kuther also notes how young children tend to comply with authority figures because of perceived social power differences. Kuther notes that conformity peaks at early adolescence at age 11 or 12.
- Claims that those between ages of 11-14 need to have special attention, those under 11 do not have adequate intellectual ability to make decisions, and that those 15 and above are possibly equivalent to adults.
    - **Do you agree/disagree with her argument about the capacity of children and adolescents? Is her argument persuasive?**
- Both the American Medical Association and American Academy of Pediatrics advise that physicians have an ethical duty to promote the autonomy of minor

patients by involving them in the medical decision-making process to a degree commensurate with their abilities.

- *What model of the person is presented in these articles?*
    - Minor belongs to him/herself – issue is not whether minors have a right to know or not, the issue is whether they understand are 'competent'

Consent v Assent

- Ethical Perspectives on Assent: Giving minors a say, and making them feel heard by parents and physicians, will bring all three parties together in shared decision-making in developmentally appropriate ways. **How effective is this so-called "learner's permit" for decision-making and to what extent does it provide 'safety'?**
- **Does open communicate facilitate sense of control and empowerment?**
- As Kunin (1997) argues, "it is not necessary to treat children as autonomous, rational decision makers in order to treat them with respect as autonomous individuals" (p. 45). **Do you agree or disagree?**
- What is "developmentally appropriate" child involvement in decisions and are physicians expected to know this?
- **Kuther asks:** Although participation in decision-making generally increases with age, must minors wait until age 18 to participate fully in decisions? At what age should they be given veto power or the ability to refuse treatment?

- All kids should understand some things, adults should stop over-simplifying for children
- Is it a matter of a culture that 'mythicizes' children? Cross-cultural, different perceptions of children and rationality
- How is this perspective forcing this view of people/minors upon people in other cultures
- Is there another paradigm for treatment? Partially due to the legal system, legalities of health care and treatment systems (philosophical, moral background)

Remaining Issues

- **how to best assess a minor's capacity**
- **how to balance the sometimes conflicting need to promote and respect the autonomy of both minors and parents**
- **how to respond to a minor's refusal of treatment.** How can physicians best promote the autonomy of minors while respecting parental autonomy? How should physicians navigate disagreements between parents and minors?
- how to proceed when parents and minors disagree on treatment.

"'Hitting You Over the Head': Oncologists' Disclosure of Prognosis to Advanced Cancer Patients".

<u>Background</u>: Christopher K. Daugherty, M.D., Assistant Professor, Section of Hematology/Oncology, University of Chicago, Chicago, Ill. Internal Medicine,

Oncologist. Elisa J. Gordon is an Assistant Professor of Bioethics and Health Policy and Assistant Director of Research at the Neiswanger Institute for Bioethics and Health Policy of Loyola University of Chicago. Gordon's research interests cover a broad range of topics in anthropology, bioethics, and medicine. She examines the cultural foundations of theory and practice within biomedicine, science, and bioethics in the United States.

Discussion, Arguments, and Critiques

"'Hitting You Over the Head': Oncologists' Disclosure of Prognosis to Advanced Cancer Patients"

- They argue that disclosure of a terminal prognosis is ethically justified by the principle of self-determination and patient autonomy. They also seek to understand the oncologists' perspective about disclosure
    - Acknowledge that "ethical justification" by "principle of self-determination" and autonomy needed another phrase which was "in the North American cultural context".
- They argue that knowledge/discussion of prognosis help terminally ill manage the process and has been associated with less emotional distress. How much so and what are the cross-cultural implications?
- **How are informed decisions made? What information is necessary? Do they need to understand the disease and its prognosis?**
- **What is the actual encounter like and how is 'bad news' broken? How are doctors trained to provide such information?**
- Given that advanced cancer patients tend to overestimate their long-term survival Patient may perceive treatment as a means to cure—**authors seek to understand how patients acquire inaccurate perceptions of their prognosis?**

Historical and Cultural context of disclosure of cancer diagnosis

- Reluctance to disclose diagnosis, no willingness to discuss prognosis in 50s and 60s
- Improvements in non-surgical methods of evaluation could confirm cancer diagnosis and increased patient compliance. Note *medicine as power/ knowledge.*
- Late 70s full disclosure became the norm. How do practices become the norm in medicine?
- Oncologists only disclose when empirical data is available. Is that beneficial for the patient? Should a doctor disclose his suspicions and hypotheses, even though they may not be final prognoses?
- They also don't disclose for fear of smashing hope of patients. Is the doctors' confidence in the power of hope valid? Are there studies that research the influence of hope on the patient's lifespan?
    - Hope as either or both an ethical and a therapeutic category
    - Intersection of sacred and moral (gray area). *Where is the balance? To what extent should the processes of life, including death and dying – be medicalized? Religion, spirituality also play a role*
    - Quality of life is now an object – objectified by medicine, ex. Pregnancy/childbirth – creates a certain image of the human body

  - Doctors have assumption that patients are coming for hope? Where is this assumption coming from? Split between body and mind? Mind/body planes separate. Doctors have responsibility for the physical body, but the moral/spiritual side is another area, and doctors should not have responsibility for this
    - Prayer studies
- Use of qualitative methods to understand the meanings that patients and physicians attribute to prognosis or perceptions of giving and receiving prognostic information. **Emphasis on the attitude of the physician in prognosis communication—is this a paternalistic attitude?**
- Views it as the debate between fulfilling informed consent/egalitarian relationship versus paternalistic attitude of withholding/disclosing information to maintain hope, individual preferences. How can these two competing ideas be resolved? IS there a resolution or common ground?

Methods

- How they found their research subjects, the physicians
- How they interviewed them (14 of 21 agreed to participate—what about the other 7? 2/3 participation rate—what does that say about the doctors if anything?)
- How did the presence of the anthropologist change the clinical encounter?
- The analysis of data through coding

Findings

- MDs were reluctant, disclosed as "not curable", without use of statistics for lack of question/misinterpretation; patient-dependent communication/relations
- Found that MDs used metaphors to describe how they felt the prognosis was:
  - The prognosis is described as physically violent to the patient→**does that come from the paternalist tradition or tendency that validates or emphasizes the power of the doctor?**
  - The prognosis as something that patients try to elicit out of or pressure doctors to disclose
- What is driving this desire to know statistics or how much longer definitely? Will a number provide certainty and do MDs ever give in to providing them some sense of certainty?
- Is it better that doctors wait for patients to ask questions to the MD in order for them to provide information? What if the patient does not ask? Is it better to provide only the information that patients want to hear? "it's better knowing what they want before blurting it out"
  - "Only give as much as information as is asked or absolutely necessary" model
  - When information given too late, is that the fault of the doctor for not giving or the patient for not asking/not knowing?
  - How necessary is hope and is that really following the principle of beneficence? What constitutes beneficence? Is their assumption that they are coming for hope a valid assumption? And what kind of hope will doctors provide? Why not excessive hope? Why must a MD "beat them over the head" when the patient has excessive hope?

- How invested are MDs in getting clinical trials? Isn't there another ethical issue at hand: a conflict of interest of getting more participants versus doing what is best for patients? Isn't the language of benefit so entrenched in the work of the doctor?

Informed Consent and Patient Autonomy

John Stuart Mill (1806-1873) – knowledge is derived from the senses. Utilitarian theory. Right actions produce the greatest happiness

- On Liberty: argued that state can provide interference with citizens only if it can be proven that it will produce good for others. Prevent harm to others. Children are not capable of making decisions. Certain "races" are also considered incompetent.
- Social power vs. personal autonomy
- Individual is the primary unit of analysis. Idea of the person (white make property owners). There is a hierarchy of rationality, white men have most capacity for thought, have more time for reflection. Women have lesser capacity to reason (women=children).
- Hierarchy of civilizations as well – which ones have the capacity for self-governance?
  - Savages/Barbarians: need to be ruled by others
  - Civilized: usually of European background
  - Debates over nation-states: can they achieve democracy?

Last article: persistent vegetative state (PVS): medical institution felt that it was not their responsibility to maintain her life. Hospital took away husband's right

- How much is medical institution responsible for making decisions of life and death? Who should make decisions if the person is not capable of making a decision?
- Terry Schiavo
  Who has the right to decide what happens?