**Week 4: Medicine, Medical ethics and Physician Responsibilities (Sept 22)**

**Housekeeping:**

Next week (Week 5) we will talk about privacy, confidentiality, truthtelling and disclosure. Week 6, next week, and Week 7, the week after that, we will devote to talking about the right side of the autonomy mobile: the importance of informed consent for treatment plans, and the role of patient capacity in deciding who should make decisions about (and give consent for) treatments of incapable patients. There will be a midterm in week 7 (October 13). The midterm will consist of a short-answer section, administered in class—and an essay, probably another 3 pager, to be e-mailed to me before the 20th. It’s required for BOTH journalers and traditional students.

Some good background reading for this lecture:

On bioethics:
- David Rothman: *Stranger at the Bedside* (1991)

On cultural issues:
- Ann Fadiman: *The Spirit Catches You and You Fall Down*

**The Story of Aesclepius:**

According to legend, the first physician, Aesclepius, was the child of a mortal and a god. His father was Apollo. His mother was the daughter of a king of Thessaly. Coronis was unfaithful to Apollo, and Artemis, Apollo's twin sister, killed her for her unfaithfulness. Coronis was placed upon a funeral pyre. As her body started to burn, Apollo felt sorrow for his unborn son and snatched the child Aesclepius from his mother's corpse, saving him from death. Apollo then handed Aesclepius to a Centaur (Chiron) who became his tutor and mentor.

Chiron taught Aesclepius the art of healing. Aesclepius also acquired the knowledge of surgery, the use of drugs, love potions and incantations, and according to one source, Athena gave Aesclepius a magic potion made from the blood of the Gorgon. Legend tells that the blood of the Gorgon has a different effect depending from which side the blood was taken. If taken from the right side of the Gorgon, it has a miraculous effect and is said to be able to bring the dead back to life, but taken from the left side it is a deadly poison.

With these gifts Aesclepius exceeded the fringes of human knowledge, and cured many illnesses. But one day he offended the high god, Zeus by accepting money in exchange for transgressing the limits of his practice, by raising the dead. In the eyes of Zeus, Aesclepius' action upset the natural order of the universe - a mere mortal helping man evade death. Zeus sent down a thunderbolt, killing Aesclepius.

At the same time, Zeus realised the good Aesclepius had brought to man. So he made him into a god, placing him among the stars, transforming Aesclepius into the constellation Ophiuchus (the serpent-bearer). The snake was used in the healing ritual; non-poisonous snakes were left in the dormitory where the sick slept overnight on the bare ground.

The cult of Aesclepius became very popular during the 4th century BC and the cult centers (known as an
Asclepieion) were used by priests to cure the sick. Invalids also came to the shrines of Asclepius to find cures for their ailments (in the same fashion pilgrims visit Lourdes today.) It is believed that Hippocrates, a great doctor of antiquity, plied his trade on the island of Cos, where many Asclepieions were located. It is also said that Hippocrates was a descendant of Asclepius.

I: Medicine and Professional Ethics

It is safe to say that at the beginning of the 20th century, the physician dominated health care like a colossus. The ethics of healthcare for the majority of the century was medical ethics, with a long and distinguished history. The Hippocratic oath dates to the 5th century BC; and Hippocrates himself, myth tells us, was the descendent of a child of the gods. Insofar as medicine takes Hippocrates as its founder and guiding spirit, it is a 2500 year old tradition.

As I mentioned last week, the turn of the century physician had complete control of the treatments and therapies available to the patient. As more complex treatments became available because of the scientific and technological advances in medicine, the hospital began to assume a larger role in medical treatment. Both birth and death (as well as increasingly complex diagnostic, therapeutic, surgical or life-supporting interventions) gradually migrated into institutional settings. (Recent calculations suggest that in the US 90% of births and 80% of deaths took place in institutions by the end of the 20th century.) But even with the growth in importance of the hospital, the physician remained dominant; he was the source of patients for the hospitals, gatekeeper for their services. He practiced in hospitals which for the most part he ran. Nurses carried out his orders, and other health professionals reported to him and provided services at his discretion. Even today the role in hospital administration of the medical board (the physicians with admitting privileges to a given community hospital) remains strong.

The physician was a professional—indeed, the very model of a professional. When sociologists began trying to define professions and establish criteria for what it meant to be a member of a profession, the physician, along with the judge and the priest, was the example to which they looked. Medicine was a “calling” that demanded of its practitioners a publicly-declared vow of dedication or devotion to a way of life: the relief of human suffering as their highest duty, and a fiduciary relationship to their patients.

Characteristics of a profession:

The following characteristics are very important in understanding the extent to which the physician is a professional.

Expertise: It is his command of a special expertise which justifies admission to membership in a profession. Medical education in early America was an apprenticeship: you learned how to be a doctor by following an older, respected, physician around for a number of years; and modern medical education maintains this apprenticeship aspect, added in on top of the information-content courses. Since the time of Hippocrates medicine has been considered a specialized body of knowledge which must be mastered and is handed down only to selected novitiates, rather than being general knowledge. Continuing education, to keep abreast of advances in the field, is an important contemporary
requirement of maintaining that expertise.

**Licensure:** After the Flexner report was published in 1910, medicine systematized medical education in a limited number of medical schools, accredited by organized medicine. Admission to the profession is controlled by the profession. In order to practice, you must attend one of the accredited schools and pass appropriate exams. The granting (and suspending) of license to practice is in the hands of the profession itself. Medicine as a profession is self-regulating and self-policing.

**Control over an area of practice:** Standards of care are set by the profession as a whole, and adherence to them is the responsibility of individual professionals, as judged and enforced by their peers. The professional model is not comfortably responsive to outside regulation, whether moral, legal or bureaucratic. In the body of many of the court cases we will discuss in the course of the term, judges explicitly defer to their fellow professionals in determining what counts as professional practice and standard of care.

**Code of ethics:** Medicine as a social institution and profession is established as such by the larger society. A territory is thus staked out within which the strictest standards of behavior are constrained. Integrity and character are the major determinants of the ideal physician in the classical model, and the profession is defined by its internal ethics, especially the ethics of human service.

This is a really important point, and it needs to be underlined, I think. To be a physician is to have a code of ethics, and to have an ethical position of a certain sort.

Professional ethics is one variety of agent-centered ethics. The physician by accepting that role has acquired ethical obligations determined by that role, which constrain his behavior in various ways. Compassion and care for the patient are central to the physician’s personal identity as well as his social role.

We often talk about this as “professional autonomy” or “professional integrity.” In exchange for being allowed exclusive access to a realm of practice, the medical professional agrees to abide scrupulously by the ethical obligations of that practice. His failure to do so is a failure not only to himself as an individual, but also to the profession which he represents—indeed, embodies.

The ‘code of ethics’ of medicine has changed over the centuries. Compare the AMA’s 1996 version with the Hippocratic oath; there are some interesting differences.

**Hippocratic Oath, translated into English:**

I swear by Apollo, Asclepius, Hygieia, and Panacea, and I take to witness all the gods, all the goddesses, to keep according to my ability and my judgment, the following Oath.

To consider dear to me, as my parents, him who taught me this art; to live in common with him and, if necessary, to share my goods with him; To look upon his children as my own brothers, to teach them this art.

I will prescribe regimens for the good of my patients according to my ability and my judgment and never do harm to anyone.

I will not give a lethal drug to anyone if I am asked, nor will I advise such a plan; and similarly I will not give a
woman a pessary to cause an abortion. (=prohibition of euthanasia and abortion)

But I will preserve the purity of my life and my arts.

I will not cut for stone, even for patients in whom the disease is manifest; I will leave this operation to be performed by practitioners, specialists in this art. (medicine v. surgery)

In every house where I come I will enter only for the good of my patients, keeping myself far from all intentional ill-doing and all seduction and especially from the pleasures of love with women or with men, be they free or slaves. (= don't sleep with patients!!)

All that may come to my knowledge in the exercise of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal. (=medical confidentiality)

If I keep this oath faithfully, may I enjoy my life and practice my art, respected by all men and in all times; but if I swerve from it or violate it, may the reverse be my lot.

American Medical Association’s Principles of Medical Ethics (1996)

I: A physician shall be dedicated to providing competent medical services with compassion and respect for human dignity.

II: A physician shall deal honestly with patients and colleagues, and strive to expose those physicians deficient in character or competence, or who engage in fraud or deception. (= self-policing)

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. (=advocacy for patients)

IV: A physician shall respect the rights of patients, or colleagues, and of other health professionals, and shall safeguard patient confidences within the constraint of the law. (= confidentiality)

V: A physician shall continue to study, apply and advance scientific knowledge, make relevant information available to patients, colleagues and the public, obtain consultation, and use the talents of other health professionals when indicated. (= advancement of medical science)

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 services. (= basis for ‘fee for service’ medicine in US)

VII: A physician shall recognize a responsibility to participate in activities contributing to an improved community.
II: The Birth of Bioethics

I want to make a big point of the continuity and the long-standing tradition of medicine, as well as the differences between the two oaths, because it is important for understanding the last quarter of a century, and the birth of bioethics.

1. Historical preconditions:

   a. Medical research: became a large scale enterprise during WW2. (Indeed, war has always been a great boon to medical science; with the invention of new weapons, like the introduction of napalm in the Vietnam War, treatment of burns has greatly improved world-wide; we’re hoping for improvements in the treatment of brain injuries with the proliferation of headwounds in Iraq…)

   b. Since Flexner’s attempts to put medicine on a scientific footing, with his reform of medical education in 1910, there has been increasing pressure on medicine to advance medical knowledge (resulting in what amounts to an institutionalized conflict of interest—what I refer to (in an article on the main webside) as the ‘Janus-face’ of medicine)

   c. The NIH were established in 1945 c budget of $700,000: federally funded source of medical research money, iff federal regulations are adhered to.

   With the gradual development of medical technology, it turns out that docs can do more than just offer comfort.

   In the second half of the last Century, medicine began to find itself more and more implicated in, and indeed, sometimes in the center of, various social transitions:

   changes in practice of medicine: specialization, hospitals, class isolation
   social climate of the ‘60s: civil rights, feminism, Our Bodies Our Selves

The mutual involvement of responsibility and authority is greatly complicated by an idiosyncratic national tradition (discussed in sympathetic detail by Atul Gawande in a recent New Yorker article): the tradition of reimbursing the cost of medical treatment through employee-based medical insurance (conjoined c rising costs): (= NO national health system)

2. Research Ethics 1966—1976

It is the same training that prepares a person for medical practice, and for medical research, the advancement of medical science. So thinking about health care ethics means considering not only the requirements of physician patient relationships—but considering as well the sometimes different conditions that surround medical research.
In the 1960s there began to be heightened attention paid to ways in which medical research practices were at odds with therapeutic medical practices:

- Beecher’s article in the NEJM about abuse of patients in research (1966)
- Jewish Chronic Disease Hospital (1963)
- Tuskegee syphilis study (1932-1972)
- Human radiation experiments
- Nuremberg Trials in 1946

Results: federal regulation on human experimentation
  - (issued the Belmont Report)
  - Formal process of informed consent
  - Mandated prior group review of all research protocols by IRBs

3. The Courts and Medical Decision Making:

In the 70s courts began to get involved to define rights of patients and surrogates to make decisions re end of life care and life sustaining treatments (see “Cases” sheets)

- 1976: the case of Karen Ann Quinlan
  California passed the first legislation authorizing living wills

- 1982: Baby Doe laws passed (and quickly retracted)

The “Birth of Bioethics” represented several fundamental changes.

Much of what physicians had done as prerogatives of their professional role began to be questioned by non-physicians, the “strangers at the bedside” of Rothman’s title. Decisions that had been the prerogative of the medical community were increasingly subjected to public scrutiny, legal review, and wide publicity.

The public—in the form of federal commissions as well as of consumerist activism—began to react in ways that reduced physician autonomy: laws and regulations, but also more questions to doctors.

As philosophers, theologians, lawyers, sociologists, anthropologists, historians began to adopt a more critical stance on medical practice, standards and patterns of ethical judgment were introduced and began to gain currency that were NOT reducible to agent-centered, role-determined, professional ethics.

Medicine, the ethical heir of Aesclepius, son of Apollo, was challenged by what is now at MOST a 30 year old upstart. The relation between the two is not always an easy one. In this course we do not adopt the subject-position of the physician completely—nor do we want to be oblivious to the position of the caregivers, individual and institutional. So we end up talking, often, about the ideal (from one perspective or another--) and talking about the obstacles to meeting that ‘ideal.’
III: So what ARE the professional obligations of the physician?

Privacy and Confidentiality, Disclosure and Truth-telling

[autonomy mobile]

Now what the readings on the syllabus talk about is basically physician attitude, under the heading of physician paternalism. But this week we should talk about ALL of section 2—not just the initial part, about paternalism, which was assigned. The majority of the reading in this section is about cases—cases which illustrate, in various ways, obstacles to the ideal of the Hippocratic patient.

So that means talking about the whole left side of the Autonomy Mobile: (1) the importance, in this society, of patient autonomy; (2) the relation of autonomy to privacy; (3) the importance, in any physician / patient dyad, of the ability to receive information from the patient about what is going on, in order to propose a plan of treatment; and (4) the consequent obligation of the physician (and indeed, the health care system as a whole) to keep patient information confidential.

1: Paternalism and the Patient/Clinician Relationship

The issues in the readings in SAL’s Section II are intimately related to each other: and each of them has at its center the concept of autonomy.

I think the main purpose of the section on paternalism is to acknowledge the historical, cultural, professional weight that the physician, by his role, carries.

What is paternalism? It is NOT disclosing diagnosis, or prognosis. It is NOT informing patients. It is treating patients according to best medical judgment—regardless of the preferences or wishes of the patient; it is ignoring things that may be very important to the patient, or to the family of the patient but less important, or less salient, or less known, to the medical professionals dealing with the patient.

A relevant book: Ann Fadiman, The Spirit Catches You and You Fall Down

As we have said several times already: this is a society which values very highly the individual and the individual’s right to self-determination. We have been exposed to Kant’s emphasis on the autonomous, self-legislating, rational agent as the model for what it is to be a moral grow-up; and that is well and good for most settings.

But: we are talking about ethics in the context of health care. And that usually means someone who is not feeling particularly grown up; at best, it’s someone who is consulting an expert about h/h health; at worst, it means someone who is scared, angry, confused, weakened by illness—and sometimes unconscious.
So: what does the idea of our self-legislating rational chooser have to do with our context? After all—if it were up to us, none of us would choose to have anything at all to do with the social arena of healthcare, unless we were looking for a job there.

How our autonomous agent enters health care primarily is as one participant in a dyadic conversation of patient and clinician—in the first instance a physician. That is the **physician patient relationship**. This is a role that is characterized by two major qualifications:

* It features an inequality of participants. We aren’t on the same footing here: the patient wants and needs something that the professional controls. This is (in our feral society) a position of weakness that needs special bolstering up, special protections. Patients (like children, like the aged infirm) are a vulnerable population.

* It is a professional relationship. The professional role is a fiduciary role: the stronger party is responsible for the weaker party. Our protections come through professional (and legal) limits on the power of the stronger party. The professional duties of confidentiality, truth telling and disclosure are some of those limits.

A: Privacy

Privacy is the acknowledgment of the parameters of individuality. I own or control access to my person, my life, my life history, my decisions, my intentions—and by extension, to INFORMATION about any of those things. For instance: Unconsented touching is a tort. And misuse of information is often legally proscribed.

If I own my body, the content of my mind, including information about myself, and even images of myself, you can have access to it only on my terms. I lend it to you, I don't give it to you; and you can use it for my advantage IFF you respect my privacy as I would have it respected.

My privacy is your obligation to confidentiality.

B: Confidentiality

Confidentiality is the professional duty and legal obligation to recognize the privacy rights of others.

The stakes are higher in the medical context.

(1) The medical professions have an unusually strong need for access to the person and to information about the person, to assure adequate medical treatment. For that reason, they offer unusually strong professional guarantees of confidentiality, and always have.

(2) The information obtained may possibly be sensitive and potentially stigmatizing: ie, STDs, mental illnesses, genetic diseases. So the patient is not necessarily anxious to reveal it; but the
patient in many cases is not only the best source of the information needed by the health system--but the only source. TRUST is the best guarantor of the patient's willingness to confide.

We make a big fuss about the ethical obligation to respect patient confidentiality, because the legal status is unclear, or variable.

(1) Doctor/patient communications, with the possible exception of psychiatrists, are not strictly speaking privileged in the legal sense. Doctor/patient privilege exists only in those states (21 states) where it is legislated; it is not a federal matter.

And it’s complicated. For instance, I own the information in my medical chart; but the hospital owns the physical chart itself. It will give me access to it, if I ask and pay for Xeroxing and wait until they can work it up on the priority list…but that doesn’t mean I can read it in the hospital.

(2) There are regulatory and legal restrictions and limits on the obligation of the physician to respect confidentiality. A very graphic example of the limitations is instanced in some of our most sensitive information: eg: HIV infection. On HIV we have legal regulation of BOTH the strong confidentiality expectation, and the equally strong requirements to pass on this most sensitive and stigmatizing information.

(3) And there are legally mandated reporting requirements, as well: some for public health reasons, some for public safety reasons…Reporting of threats to vulnerable populations; public health risks; gunshot wounds; and lots of requirements about statistical information, ideally stripped of identifiers, but…sometimes it works, sometimes it doesn’t.

Confidentiality in Institutions

Today health care delivery is institutionalized. It is not just the physician and the patient on a greek island (if it ever was)-- or even, often, in an office.

* it is done by teams
* it occurs in clinics, in hospitals, in academic medical centers.
* extramural third parties: payors; insurance companies; employers; government agencies -- often have an interest in, and access to, patient information.

In a 1982 article Mark Seigler speaks of confidentiality as a "decrepit" concept, and refers to the fact that in his organization, over 125 different people have a legitimate need to access to patient information in order to deliver health care.

This may be a bit pessimistic. A more USEFUL way to look at it: confidentiality must become more EXPLICIT --

. you can't presuppose that I understand current conditions of practice; and
. you can't assume you know my clinical expectations-- and more NEGOTIATED.
. you have an obligation to convey legal restrictions on your capacity to respect confidentiality
you have an obligation to get (as far as possible) patient consent to pass on information

There are illegitimate breaches of confidentiality, but there are also increasingly common legitimate or even required breaches of confidentiality created by contemporary conditions of h/c practice which represent changing demands upon h/c providers.

There are two issues which have become quite urgent because of the current conditions of medical delivery by HMOs, and have been recently widely publicized. One is the question of the effect of computerization and information sharing on who has access to medical records; and the other is a subset of the general medical records question: the status of genetic information.

There has been a great deal of discussion of genetic privacy; it is important to notice that insurance companies have been very clear about the fact that they consider genetic information on the same footing as any other medical information and do not consider it appropriate to give it special protection. More about that in the course of the semester.

III: Disclosure and truth-telling

We have general standards in the society about truth-telling. Mother’s voice tells us “don’t lie.” There are legal penalties for lying under oath; habitual liars get a bad rep and aren’t trusted in society at large.

Further, if I go to a physician to find out what is wrong with me, I expect him to tell me. I don’t go to him to give HIM information—I go to him to get information for myself.

But: is the only reason I go to a physician to get information? Don’t I also want him or her to help me? To fix what’s wrong. To make me better. To make me feel better.

There is more going on in THIS relationship than just information exchange.

[That’s what the Emanuel / Emanuel article is about.]

There’s also more going on in this relationship than what I as a patient want [or expect, or can expect].

This is a contractual relationship. When you walk into a doctor’s office, or into an emergency room—when you enter in any way into the healthcare system—you sign something. That piece of paper tells you what your part of the agreement is—and what you can expect happens to any of the information you give your provider.

1. We have an example of one of those permission slips. I will put it up on the website.
2. And the conventions of the institution of health care are historically conditioned—they change over time.

A survey of physicians in a particularly tricky area—cancer—shows the difference in the
attitude of physicians to disclosure of diagnosis over the last 30 years:

In 1961 88% of physicians favored not revealing a diagnosis of cancer.
In 1979 90% of physicians favored revealing that diagnosis.

3. The conventions are to some extent culturally determined as well. Even if it is now 2009, and disclosure of diagnosis is widely accepted in US medicine, not all of us are 7th generation Americans. Some of us come from cultures that have very strong conventions against revealing—and revealing that diagnosis in particular. [The Blackhall article is about that.]

4. Content of the disclosure: One of the problems with this issue is that we create physicians; we support them with social support; we tell them that their relationship with their patients is crucial—and if we DO that—we can’t get too authoritarian about what they tell their patients, when and how.

The content of what they are disclosing is an important factor in the physician’s judgment about what to disclose. If it is something small, no problem. If it’s BIG—problems. Some things we get tested for are stigmatizing. Some things we test for make a huge difference to other relationships. Some things we test for are life and death issues. Some things make a difference to others.