

Lecture 4.1 Privacy and Confidentiality, Disclosure and Truth-telling

I: Patient/Clinician

The issues in the first few readings in this course are intimately related to each other: and each of them has at its center the concept of autonomy.

(the autonomy mobile)

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.

(cf. Hippocratic oath; AMA code of ethics; nursing oaths)

(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.

II: 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 need an example of one of those permission slips. If someone taking 680 can provide us with an example of a physician/patient agreement, I'll 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 2005, 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.

Reading SAL: Blackhall: Bioethics in a Different Tongue

Context: end of life care and the ethnically homogeneous physician

Bioethics believes that the problem is too much futile care at the end of life, and the answer is advance directives. But inadequate care is as much (or more) of a problem; and not everyone wants to be involved in end of life decision making.

This paper is an empirical study of EOL attitudes and experiences of 4 ethnic groups on truth telling.

Methods: 200 elderly subjects from each of 4 groups [African Americans, European Americans, Korean Americans and Mexican Americans] were asked about truth-telling of diagnosis and [negative] prognosis.

Results: Preferences on being told varied across the different ethnic groups.

Preference	African-Amerc	European-Amerc	Korean-Amerc	Mexican-Amerc
Tell diagnosis	87%	89%	47%	65%
Tell prognosis	63%	69%	33%	48%

Themes:

- Because it’s me—my body!
- Ah—you know anyway—and ignorance is not bliss.
- Taking care of business (=control)
- Making peace (c God or man)
- It’s cruel to tell (> depression, loss of hope)
- If you know you die faster
- Some people can’t take it (usually said of others, not ones’ self...)

Some cultures are ‘high-context’; others are ‘low-context’; and truth telling varies between the two.

Conclusion: Truth-telling in EOL contexts can be a source of control—or can be cruelly disempowering. Which it is may depend upon the source of self-identity of the individuals involved: their individuality, or their relationships. And our place on that continuum may vary by cultural / ethnic background [*or, feminists tell us, by gender, too*].

We usually think of truth as a bivalent alternative: we either tell the truth, the whole truth or nothing but the truth, or withhold it. But that’s a crude oversimplification of the possibilities of human communication.

Recommendation: try to be sensitive to possible different cultural approaches to truth-telling—without, of course, falling into stereotyping.

How do these various appeals relate? Katz says doctors are to blame for not telling patients their diagnosis/prognosis; but clearly, not all patients want to hear it.

Should I assume, if my patient is Korean, that I should not offer a diagnosis of cancer, or a specific prognosis?