

PROFESSIONAL-PATIENT RELATIONSHIPS

Bioethics: Course Notes | Brendan Shea, PhD (Brendan.Shea@rctc.edu)

Learning Outcomes. We have now finished discussing all four principles of the common morality: autonomy, nonmaleficence, benevolence, and justice. We'll now take a more detailed question at how these principles can help us answer more specific questions:

1. What are the moral obligations of medical and research staff toward their patients, especially as these relate to issues such as truth-telling and respecting confidentiality?
2. How do they balance these obligations against *other* moral obligations (toward their coworkers, families, insurance companies, or society in general)? How do we identify potential conflicts of interest?

We'll consider these questions both in the context of providing medical care (when the goal is "to help the patient get better") and biological or medical research (when the goal is to "learn something to help future patients.").

SHOULD WE ALWAYS TELL THE (WHOLE) TRUTH?

In health care, **veracity** refers to "accurate, timely, objective, and comprehensive transmission of information, as well as to the way the professional fosters the patient's or subject's understanding." The obligation of veracity is entailed by three more general obligations: (1) to show respect for patients, (2) to keep promises and contracts, and (3) to cultivate and maintain relationships between patients and caregivers. Of course, the obligation of veracity is not *absolute*, and there are several problem cases worth considering¹:

- While it is almost always wrong to *lie*, it may (sometimes) be OK to intentionally *deceive* patients by the **nondisclosure** or **underdisclosure** of information. However, one needs to be very careful about doing this. For example, it *might* be OK to withhold a terminal diagnosis from a patient *if* she had previously told you that she did not want to be told this sort of information. However, it would be wrong to withhold the information merely because family members/medical staff thought it would make her "happier" not to know. Deception can easily undermine trust in the medical system, with bad consequences.
- For similar reasons, it is generally wrong to deceive **third-party payers** such as insurance companies or Medicare. If medical staff make a practice of doing this, the relationship between payers and providers will break down, which could have *very bad consequences* for patients.
- It is easier to justify **staged disclosure** (telling patients the information over time, rather than all at once) and the use of **cautious language** (leaving room for patient "interpretation" instead of straightforwardly delivering bad news) than other types of deception (such as outright lying). One reason for using staged disclosure or cautious language is to make sure that the patient is able to understand the importance of the information that the professional is trying to communicate, and is able to make coherent, reasonable decisions based on this information. B-C offer the example of a patient who steadfastly believes that *all* cancer is deadly that "he does not have cancer" even though he in fact has a treatable variety of cancer. In such a case, a physician might say "you have a treatable disease, called [something really long and complex]" and NOT tell the patient that he has cancer (at least initially). In the long run, of course, the goal would be to help the patient understand the nature of his condition (and of the sort of treatment that is being used).
- One especially challenging case involves the disclosure of **medical errors**. In these cases, a professional must balance the patient's needs for transparency, respect, accountability, continuity, and kindness. One should *not* consider these sorts of disclosures a "betrayal of one's colleagues."

HOW FAR DOES THE RIGHT TO PRIVACY EXTEND?

In a general sense, the **right to privacy** consists of "right" to control outside access (from the government, private institutions, or other individuals) to certain areas of one's private life (in the U.S., the courts have held that this right means that laws outlawing contraception are unconstitutional, as are certain laws restricting abortion). Some particular instances of this general right include²:

1. The right to **informational privacy** means that certain information should not be shared without permission. For example, patients' information should be shared only (as needed) with members of the treatment team, and not with medical staff in general (as sometimes happens). **Exceptions?** People infected with conditions such as HIV can benefit greatly from timely, correct treatment; this treatment will also lower their chance of infecting others. Given this fact, is it OK for hospitals to release the names of these patients to public health officials (who could contact the individuals to encourage them to seek proper treatment)?

¹ For a short, but nuanced, take on withholding information see Ronald M. Epstein, David N. Korones, and Timothy E. Quill, "Withholding Information from Patients — When Less Is More," *New England Journal of Medicine* 362, no. 5 (February 4, 2010): 380–81, <https://doi.org/10.1056/NEJMp0911835>.

² The SEP has two good articles on privacy: Judith DeCew, "Privacy," in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, Spring 2018, 2018, <https://plato.stanford.edu/archives/spr2018/entries/privacy/>; Anita Allen, "Privacy and Medicine," in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, Winter 2016, 2016, <https://plato.stanford.edu/archives/win2016/entries/privacy-medicine/>.

2. The right to **physical privacy** entails that the body and the space around it should not be interfered with unless there is express consent. For example, the (fairly common) practice of allowing medical students to give pelvic exams to patients under general anesthesia seems like it might be a violation of physical privacy. **Exceptions?** People who are unconscious and/or incompetent (on drugs or alcohol) are often given surgeries without consent.
3. The right to **decisional privacy** concerns a person's ability to choose a course of treatment or action without being rushed, coerced, or manipulated. A patient should be given time, information, and emotional support to make a decision that reflects his or her own interests. **Exceptions?** In cases where the person's competence is at issue, intervention may be desirable (for example, by making a patient talk with a counselor, or trying to get the family more involved).
4. The right to **proprietary privacy** holds that people's bodies are their own property, and that others (such as medical researchers) cannot use their body parts without consent. The treatment of Henrietta Lacks' cells violated this right. **Exceptions?** In most developed nations, there have been arguments over whether organ donation should be "opt in" (so, your organs won't be used unless you have signed a form saying it is OK) or "opt out" (your organs can be used unless you have signed a form stating that is NOT OK.)
5. The right to **relational/associational privacy** means that people are free to enter into (or get out of) relationships with other people (among other things, this means some control over which medical professionals they see). Medical professionals should not try and impede patients from having relationships (either with visiting family members or other medical professionals), *even if they don't think these relationships are the best ones to have.*

The right to privacy is closely linked to many important legal and moral rights (to free speech, property, etc.), and is closely associated with the principle of autonomy, which holds that we ought to respect and promote competent people's abilities to make their own choices what the "good" things in life are, and how they ought to pursue these things. If people were not confident in their right to *some* sorts of privacy, it is difficult to see how relationships like friendship or love could even exist (since these relationships require that we be able to *choose* who has access to certain parts of our lives). However, there are limitations to privacy rights. For example, public health officials regularly gather data (from clinics and hospitals) about the frequency of various diseases and conditions among various groups (by age, race, gender, etc.). While these data are often "anonymized" (so the patient's names are replaced by ID numbers), this is not always the case (e.g., if a person checks into an ER with a contagious disease such as antibiotic-resistant TB, the hospital will inform public health officials of the patient's name). The question, as always, is one of balance.

REVIEW QUESTIONS

1. When, if ever, is it ever justifiable for medical staff to deceive patients about their diagnosis, treatment, or prognosis? If so, when? Be sure to refer to B-C's ideas about veracity as well as of the four basic moral principles.
2. Do you agree or disagree with B-C's claim that "deception that does not involve lying is usually less difficult to justify than lying, in part because in many contexts in health care it does not threaten as deeply the relationship of trust"? Why or why not?
3. Describe a case where it might be OK to use **staged disclosure**.
4. Give examples of conduct (besides those given above) that would violate patients' right to (a) informational privacy, (b) physical privacy, (c) decisional privacy, (d) proprietary privacy, and (e) relational/associational privacy.

CASE STUDY: DISCLOSING INFORMATION ABOUT THE RISK OF INHERITED DISEASE³

"Mrs. Durham was diagnosed with an invasive epithelial ovarian cancer and, in conjunction with conversations about her treatment, was offered genetic testing for the BRCA1 and BRCA2 mutations. It was revealed that she carried a harmful BRCA1 mutation that is known to increase the lifetime risk of breast and ovarian cancer significantly. Once the results came back, her oncologist brought up the option of a prophylactic mastectomy and advised her to inform her living relatives of the results of the test.

Mrs. Durham's primary care physician, Dr. Bartlett, expected she would do so, too. At her first appointment after the diagnosis, Dr. Bartlett asked Mrs. Durham how she was holding up and how her sister, Mrs. Weir—her only living family member and also one of Dr. Bartlett's patients—had taken the news.

"Oh. Well, I haven't told her."

"Are you going to?" asked Dr. Bartlett.

Mrs. Durham responded, "You know we haven't spoken in quite some time, and I can't imagine making this the topic of our first conversation."

"Yes, I know...but I think this is important information that may affect her health."

Mrs. Durham sighed. "We're estranged, for one thing, and for another, I want to keep my cancer private. I don't want people knowing I'm sick and pitying me."

Dr. Bartlett felt pulled in two directions—his obligation to respect Mrs. Durham's wishes and protect her privacy conflicted with his obligation to promote Mrs. Weir's health. BRCA1 mutations are not "reportable" illnesses like HIV and tuberculosis, so he was not compelled by law to break Mrs. Durham's

³ Clint Parker, "Disclosing Information about the Risk of Inherited Disease," *AMA Journal of Ethics* 17, no. 9 (September 1, 2015): 819–25, <https://doi.org/10.1001/journalofethics.2015.17.9.ecas1-1509>.

confidentiality. Dr. Bartlett considered how he might be able to encourage Mrs. Durham's sister to be tested for the BRCA mutations while preserving Mrs. Durham's confidentiality." **What should Dr. Bartlett do?**