

IS THERE A RIGHT TO “THE TRUTH”? A RIGHT TO PRIVACY?

Brendan’s Big Book of Bioethics | Brendan Shea, PhD (Brendan.Shea@rctc.edu)

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2 TRUTH TELLING AND THE RIGHT TO PRIVACY

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?
3. Define confidentiality, and discuss the factors that might permit or require on to breach it.

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.").

2.1 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 outright laying). 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. So, consider 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

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>.

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.”

2.2 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)?
2. The right to **physical privacy** entails that the body and the space around it should not be interfered without the person’s 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** requires that patients be given the 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** (or **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

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/>.

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.

2.3 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**.

2.4 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 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?**

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>.

3 WHEN IS OK TO BREACH CONFIDENTIALITY?

What is confidentiality? According to Beuchamp and Childress (2020) **confidentiality** is present “when one person discloses information to another, whether through words or other means, and the person to whom this information is disclosed pledges, implicitly or explicitly, not to divulge this information to a third party without the confider’s permission.”

Why does confidentiality matter? One reason for respecting confidentiality concerns the *consequences* of not doing so. For example, suppose that therapists began turning their patients over to the police every time they suspected they may harm themselves, or that physicians immediately informed every past sexual partner of patients with HIV. This may (eventually) lead to a situation in which patients with these conditions do not seek help at all. A second reason for respecting confidentiality concerns the principle of autonomy—one ought to respect the rights of competent adults to “live their own lives.”

When can confidentiality be breached? B-C argued that this is a function of two things: (1) the *probability* that you could prevent harm by breaching confidentiality and (2) the *magnitude* of the harm that could be prevented. This leads to something like the following setup:

Prob. of Harm	Mag. of Harm	Examples?	Breach confidentiality?
High	Major	1. Highly infectious, deadly disease (pandemic influenza, drug-resistant TB, HIV patients with known risky behaviors) 2. Intent to murder someone	Usually yes (to authorities or third parties as allowed by law)
High	Minor	Infectious disease, treatable (gonorrhea, influenza)	Depends on policies
Low	Major	Predisposition toward violence (e.g., certain sorts of mental health disorders or drug use)	Depends on policies
Low	Minor	Behaviors that could possibly harm others (alcoholism, risky sexual behavior)	Usually not

3.1 WHAT IS THE NATURE AND PLACE OF FIDELITY AND FAITHFULNESS?

Medical professionals have obligations of **fidelity** (or “faithfulness”) toward their patients. In some cases, these can come in conflict both with self-interest and other moral obligations⁴. Some example cases:

- **Divided loyalties.** Health care professionals are often employed by the military or by private corporations, and many researchers are employed by academic institutions. These employers often have aims distinct from patient welfare, and professionals must consider carefully how to respect the moral rights of the patient. This can sometimes lead to moral dilemmas (e.g., the case of a military physician who must consider whether to discharge a patient with a head wound).
- **Nurses, patients, and physicians.** Nurses are often in closer contact with patients than are physicians, and are thus more likely to realize if a treatment is not working. This can lead to situations in which the nurses must balance their obligations to the patient vs. their obligations to “carry out the treatment as directed by the physician.” Studies have repeatedly shown that physicians *vastly* underestimate how frequent these sorts of ethical problems occur.

⁴ For a highly interesting story about the potential conflicts of interest in pharma-funded clinical trials (and the very bad results they can lead to), see Carl Elliott, “The Deadly Corruption of Clinical Trials. One Patient’s Tragic, and Telling, Story,” *Mother Jones* (blog), 2015, <https://www.motherjones.com/environment/2010/09/dan-markingson-drug-trial-astrazeneca/>. This case happened in Minnesota, and has had significant impacts on the University of Minnesota in the past decade (both on the medical and academic sides).

- **Conflicts of interest.** A **conflict of interest** exists when “an impartial observer would determine that a professional’s judgments, decisions, or actions are at risk of being unduly influenced by his or her personal interests, such as financial interests or friendship.” This can lead to cases of **overtreatment** (a physician orders a test or procedure because he stands to profit from it) or **undertreatment** (a physician declines to tell a patient about a costly treatment because she receives bonuses for “keeping clinic expenditures low”). Research has also shown that medical staff are often (probably unconsciously) influenced by things such as small gifts/meals from pharmaceutical and medical equipment companies.
- **Funding of research.** A significant portion of medical research is funded by companies that are interested in getting a certain outcome (e.g., getting a drug approved) and researchers sometimes have a financial stake in the outcome (e.g., they work for the company, or own stock). In general, researchers should NOT participate in studies involving human subjects if they have a financial stake in the outcome.
- **Actual, potential, apparent?** B-C argue that ALL appearances of partiality are to be avoided, and that there is little sense in trying to determine whether a *particular* researcher is capable of “being objective” in a certain situation. This is because (1) bias is often unconscious and unintentional, and (2) the only good way of preventing bias from occurring is through institutional policies, and not by considering the “character” of individual people.

3.2 REVIEW QUESTIONS

1. What TWO questions should be considered when deciding whether to breach confidentiality? Give examples where each sort of question is answered “Yes” or “No”, and explain how this should impact decisions to divulge information.
2. What is the duty of fidelity as it relates to medical professionals and their patients? Give two examples of ways that might be violated.

3.3 BIOETHICS AND THE LAW: TARASOFF V. CALIFORNIA BOARD OF REGENTS⁵

On October 27, 1969, Prosenjit Poddar killed Tatiana Tarasoff. Plaintiffs, Tatiana's parents, allege that two months earlier Poddar confided his intention to kill Tatiana to Dr. Lawrence Moore, a psychologist employed by the Cowell Memorial Hospital at the University of California at Berkeley. They allege that on Moore's request, the campus police briefly detained Poddar, but released him when he appeared rational. They further claim that Dr. Harvey Powelson, Moore's superior, then directed that no further action be taken to detain Poddar. No one warned plaintiffs of Tatiana's peril...

We shall explain that defendant therapists cannot escape liability merely because Tatiana herself was not their patient. (1) When a therapist determines, or pursuant to the standards of his profession should determine, that his patient presents a serious danger of violence to another, he incurs an obligation to use reasonable care to protect the intended victim against such danger. The discharge of this duty may require the therapist to take one or more of various steps, depending upon the nature of the case. Thus it may call for him to warn the intended victim or others likely to apprise the victim of the danger, to notify the police, or to take whatever other steps are reasonably necessary under the circumstances.

In the case at bar, plaintiffs admit that defendant therapists notified the police, but argue on appeal that the therapists failed to exercise reasonable care to protect Tatiana in that they did not confine Poddar and did not warn Tatiana or others likely to apprise her of the danger. Defendant therapists, however, are public employees. Consequently, to the extent that plaintiffs seek to predicate liability upon the therapists' failure to bring about Poddar's confinement, the therapists can claim immunity under Government Code section 856. No specific statutory provision, however, shields them from liability based upon failure to warn Tatiana or

⁵ Tarasoff v. Regents of University of California, 551 P. 2d 334 (Supreme Court No. S.F. 23042).

others likely to apprise her of the danger, and Government Code section 820.2 does not protect such failure as an exercise of discretion.

Plaintiffs, however, plead no relationship between Poddar and the police defendants which would impose upon them any duty to Tatiana, and plaintiffs suggest no other basis for such a duty. Plaintiffs have, therefore, failed to show that the trial court erred in sustaining the demurrer of the police defendants without leave to amend.

Plaintiffs therefore can amend their complaints to allege that, regardless of the therapists' unsuccessful attempt to confine Poddar, since they knew that Poddar was at large and dangerous, their failure to warn Tatiana or others likely to apprise her of the danger constituted a breach of the therapists' duty to exercise reasonable care to protect Tatiana.

Question: In this case, Tatiana Tarasoff was murdered by Prosenit Poddar. Prosenit had previously told his therapist about his plan, and the therapist had told the police (who arrested and released him). The court ruled that the therapists and police could NOT be sued for releasing Poddar. However, they could BE held accountable for failing to warn Tatiana. Do you agree? Why or not?

4 READING: THE TRUTH ABOUT TRUTH-TELLING IN AMERICAN MEDICINE: A BRIEF HISTORY (BY SISK ET AL.)⁶

ABSTRACT. Transparency has become an ethical cornerstone of American medicine. Today, patients have the right to know their health information, and physicians are obliged to provide it. It is expected that patients will be informed of their medical condition regardless of the severity or prognosis. This ethos of transparency is ingrained in modern trainees from the first day of medical school onward. However, for most of American history, the intentional withholding of information was the accepted norm in medical practice. It was not until 1979 that a majority of physicians reported disclosing cancer diagnoses to their patients. To appreciate the current state of the physician-patient relationship, it is important to understand how physician-patient communication has developed over time and the forces that led to these changes. In this article, we trace the ethics and associated practices of truth-telling during the past two centuries, and outline the many pressures that influenced physician behavior during that time period. We conclude that the history of disclosure is not yet finished, as physicians still struggle to find the best way to share difficult information without causing undue harm to their patients.

A History Of Disclosure In Medicine

4.1 PRE-20TH CENTURY COMMUNICATION

Disclosing bad news to patients has challenged physicians since the early days of American medicine. In the 19th century, physicians often made medical decisions on behalf of their patients, in what they perceived to be the patient's best interest. This paternalistic approach led most physicians to disclose only information that they believed would not harm the patient, as embodied in the 1847 Code of Ethics of the newly founded American Medical Association:

⁶ Bryan Sisk, Richard Frankel, and Eric Kodish, "The Truth about Truth-Telling in American Medicine: A Brief History," *The Permanente Journal - Kaiser Permanente*, 2016, <https://www.thepermanentejournal.org/issues/43-the-permanente-journal/original-research-and-contributions/6183-the-truth-about-truth-telling-in-american-medicine-a-brief-history.html>.

*A physician should not be forward to make gloomy prognostications, because they savour of empiricism. ... But he should not fail, on proper occasions, to give to the friends of the patient timely notice of danger, when it really occurs; and even to the patient himself, if absolutely necessary. ... For, the physician should be the minister of hope and comfort to the sick.*¹

On one level, paternalism in this period was rooted in benevolent concern for the patient's well-being. As further stated in the Code: "The life of a sick person can be shortened, not only by the acts but also by the words or the manner of a physician. It is, therefore, a sacred duty to guard himself carefully in this respect, and to avoid all things which have a tendency to discourage the patient and to depress his spirits."¹ This ethical standard followed directly from **Thomas Percival's** 1803 treatise on medical ethics: "For the physician should be the minister of hope and comfort to the sick that by such cordials to the drooping spirit he may smooth the bed of death, revive expiring life, and counteract the depressing influence of those maladies which rob the philosopher of fortitude, and the Christian consolation."² In his writings, Percival also discussed whether a "falsehood may lose the essence of lying, and become even praiseworthy, when the adherence to truth is incompatible with the practice of some other virtue of still higher obligation."²

At the same time, there were less benevolent incentives for physicians to occasionally refrain from honesty. American medicine in the mid-19th century was poorly organized and had limited authority in society. Physicians were the product of a fractured apprenticeship model with no oversight to ensure quality of training, which led to an increase in the number of physicians, many of them poorly trained, while professional competition also loomed from other medical sects, including Thomsonians, eclectics, and homeopaths.³ In short, the mid-19th century medical market was saturated with physicians.

For physicians to succeed, ensuring an ample number of patients was paramount, and honesty occasionally took a backseat. In his 1888 manual for success as a physician, DW Cathell intricately laid out methods by which physicians could create respectable images of themselves while also protecting their claim to patient populations.⁴ Neuhauser⁵ observed, "His book was so popular that it was in its 10th edition in 1892, last revised in 1922 and republished finally in 1932." In addition to meticulously describing the type of clothing to wear and the medical paraphernalia to display in the office, Cathell also encouraged physicians to withhold information to prevent patients from becoming medically self-sufficient. For example, he encouraged physicians to inscribe Latinate terms on medication vials to conceal their ingredients. He also believed that physicians should "avoid giving self-sufficient people therapeutic points that they can thereafter resort to. ... It is not your duty to cheat either yourself or the other physicians out of legitimate practice by supplying this person and that with a word-of-mouth pharmacopoeia for general use."⁴ For both benevolent and self-serving reasons, honesty was lower on the physician's list of priorities.

[Brendan's Question: What is your response to the idea expressed at the end here—basically, that physicians (and other medical staff) need to look out for their well-being of themselves and their profession, even if this means withholding information from patients?]

4.2 THE DAWN OF THE 20TH CENTURY

As the 20th century dawned, the physician's standing in society began to rise, in part because medical science was growing more sophisticated and physicians were becoming indispensable. "Every man, it became clear, could not be his own physician."³ This enhancement of status furthered a social divide between physicians and laymen, as evidenced by an 1898 excerpt from the *Philadelphia Medical Journal*:

Into many homes the doctor brings the only refinement and culture that its inmates ever come in contact with. They recognize it, just as do even dumb animals, and it must have an elevating effect, if only a temporary one. His quiet air of composure, and that reserved force which education and culture set up in a

man, appeal to poor fallen wretches as something worthy of admiration, even if they have not the strength remaining to care to strive toward it.⁶

The growing class divide and the perceived dangers of bad news perpetuated the paternalistic approach of benevolent deception. An article in 1898, more than 50 years after the initial American Medical Association Code of Ethics, repeated this same principle of nondisclosure nearly verbatim: “In regard to cancer, the consensus of opinion is that patients be kept in ignorance of the nature and probable outcome of the disease as long as possible, in this way obviating the severe mental depression which invariably accompanies such knowledge.”⁷ The cause for concern was unchanged: “It is not merely the danger of ‘fatal shock’ that should restrain a physician in many cases from disclosing the truth to his patient, but the almost certainty that such a disclosure will be the greatest obstacle to a cure.”⁸ In 1909, William Osler declared, “It is a hard matter ... to tell a patient that he is past all hope. As Sir Thomas Browne says: ‘It is the hardest stone you can throw at a man to tell him that he is at the end of his tether.’”⁹ The reasoning was simple. “With many hospital patients once we gain their confidence and inspire them with hope, the battle is won.”⁹

[Brendan’s Question: To what extent is “hope” important for patients? Can this justify lying to them?]

4.3 MID-20TH CENTURY AND BEYOND

Although there were some opponents of benevolent deception, physician surveys during the first half of the 20th century consistently demonstrated a belief in nondisclosure. As recently as 1961, 90% of physicians preferred not to disclose cancer diagnoses to patients.¹⁰ This was despite the results of a 1950 study showing that a vast majority of patients wanted to know the truth.¹¹ On the basis of his observations in a veterans’ hospital in 1966, Glaser¹² proposed several factors that influenced the physicians’ approaches to disclosure:

Few doctors get to know each terminal patient well enough to judge his desire for disclosure or his capacity to withstand the shock of disclosure Some doctors simply feel unable to handle themselves well enough during disclosure. ... Others do not tell because they did not want the patient to “lean” on them for emotional support, or because they simply wish to preserve peace on the ward by preventing a scene.¹²

During the 1960s, tremors of change began rumbling through American society. After the assassination of President John Kennedy, President Lyndon Johnson “sponsored the largest reform agenda since Roosevelt’s New Deal.”¹³ From 1963 through 1966, Johnson undertook a major reform agenda that touched on many aspects of society. With the expansion of Social Security to include Medicare and Medicaid, as well as the passage of the Food Stamp Act,¹⁴ Housing and Urban Development Act,¹⁵ Child Protection Act,¹⁶ and the Child Nutrition Act,¹⁷ the government assumed additional responsibility for the safety and well-being of its citizens.

The 1960s also marked the start of a great transformation in American social norms as underrepresented groups challenged the status quo. The Civil Rights Movement pushed for passage of the Civil Rights Bill¹⁸ and the Voting Rights Act.¹⁹ The feminist movement demanded more autonomous control of women’s reproductive health and a shift in society’s view of women.^{20,21} The 1960s also marked the beginning of a psychedelic culture of drug experimentation, the sexual revolution, and the countercultural “hippie” movement.²² It was not uncommon for people to wear buttons stating “Question Authority.” As society was redefining itself, “a new wave of individualism was breaking over the Western world—most marked and most advanced in the United States.”²³ Long-held social norms were being turned upside down in all segments of society, including the physician-patient relationship.

Owing in part to several well-publicized controversies, there was a new call for protection *from* the medical establishment. In 1963, it was revealed that researchers in New York had injected humans with live cancer

cells without consent.²⁴ In 1964, a surgeon transplanted chimpanzee kidneys into patients with renal failure without medical approval from the hospital.²⁵ By 1966, Henry Beecher published a special report highlighting and summarizing the widespread presence of “troubling practices” in clinical research.²⁶

Perhaps most notably, the ethical concerns of the **Tuskegee Syphilis Study** came to light in July 1972. This study, initiated in 1932, was a “long-term evaluation of the effect of untreated syphilis in the male Negro.”²⁷ Physicians informed participants that they were being treated for “bad blood” but not specifically syphilis. When the study began, treatments for syphilis were harsh and minimally effective. However, penicillin was established as an effective treatment and became readily available by the late 1940s.²⁸ Yet 20 years later, only 33% of participants had received curative therapy, and many had died of complications from syphilis.²⁷ This story quickly became front-page news in the *New York Times*²⁹ on July 25, 1972 with the headline “Syphilis Victims in US Study Went Untreated for 40 Years.” Other headlines in the following weeks included “A Shocking Medical Experiment,” “Humans as Guinea Pigs,” and “A Violation of Human Dignity.” The fallout from this exposé further exacerbated the adversarial relationship between medicine and society, especially in the African American community.

Twenty years earlier in 1951, an African American woman named **Henrietta Lacks** was diagnosed with cervical cancer in Baltimore, MD. When the physicians diagnosed her with cancer, they took a specimen from her cervix without her knowledge or consent. She died soon after, but her cells lived on as the HeLa cell line, using the first 2 letters of her first and last name. These cells had an enormous impact on public health and the advancement of science, but the family was not informed until the 1970s, 20 years after Ms Lacks’ death.³⁰ Though this was not as widely publicized as the Tuskegee scandal, it provides yet another example of troubling research practices at that time.

As controversies grew, new protections for patients and research subjects were established. In 1962, the Senate passed the Kefauver-Harris Drug Amendments,³¹ requiring for the first time that drug manufacturers “prove to FDA the effectiveness of their products before marketing them.”³² That same year, President Kennedy proclaimed a “Consumer Bill of Rights,” which included “the right to safety, the right to be informed, the right to choose, and the right to be heard.”³² In 1964, the World Medical Association published the Declaration of Helsinki, an international code of research ethics affirming that the physician’s first duty is to the research subject.³³ Simultaneously, informed consent law was growing in strength, mandating honest communication between physicians and patients under threat of legal liability. Also, Dame Cicely Saunders introduced the concept of hospice and palliative care to the US in the 1960s, further encouraging discussions between physician and patient about death. By 1973, the American Hospital Association created “**A Patient’s Bill of Rights**,” stating that “The patient has the right to and is encouraged to obtain from physicians and their direct caregivers relevant, current, and understandable information concerning diagnosis, treatment, and prognosis.”³⁴

[Brendan’s Question: Look up the “AHA Bill of Rights”, and look it over. Is there anything on there that surprises you? Is there anything you would add/remove?]

Responding to these pressures, physicians began calling for more transparency with patients. Nahum noted in 1963, “The responsible physician should have no hesitation in frankly but tactfully and at the correct time answering questions asked by the patient,” with the goal of being “truthful with the patient while at the same time avoiding a major emotional upset.” However, Nahum moderated this approach with a list of stipulations. “In patients judged to be unstable emotionally, the exact information should be withheld.” Additionally, “if he does not [ask for specific information], then the doctor’s legal and moral obligations have been discharged for such a person ... is aware of his trouble but does not wish to have it put into words.”³⁵ An article from 1974 pushed disclosure further, concluding that several factors could “justify me in modifying my primary approach and making the patient or his relatives, directly or indirectly, aware of the

diagnosis and perhaps even of the prognosis, grave as it may be.”³⁶ In 1969, Kubler-Ross³⁷ declared, “The question should not be ‘Should we tell...?’ but rather ‘How do I share this with my patient?’” The medical profession was transitioning from paternalism to a partnership-based medical ethics where patients participated in the decision-making process. In 1979, a landmark study using the same research questionnaire from 1961 showed that more than 90% of a new cohort of physicians preferred disclosing cancer diagnoses, a complete reversal from 18 years prior.³⁸

The progressive movement of the 1960s and 1970s pushed physicians toward more open and transparent communication with patients. This transition was reinforced by social pressure, legal mandates, and large numbers of young, progressive physicians entering the field. In the midst of these changes, Family Practice (now Family Medicine) developed as a new field, with an emphasis on the individual patient and his or her social environment. This trend toward transparency has continued over the ensuing decades, reinforced in part by developments in the field of bioethics. The 1979 “**Belmont Report**” established the fundamental ethical principles of research on human subjects, including respect for persons, beneficence, and justice.³⁹ These principles have served as the foundation for current research practices.

Advancements in research on physician-patient communication have also supported the trend toward disclosure. In 1987, Menahem⁴⁰ showed that communication in a partnership model was more effective than either a laissez-faire or physician-dominated model. In 1995, Girgis and Sanson-Fisher⁴¹ published consensus guidelines for giving bad news, which have provided a basis for discussion and improvement of communication in medicine.

Standards of care now include an explicit focus on disclosure and communication skills. In 2013, the Institute of Medicine published a monograph on delivering high-quality cancer care that focused an entire chapter on evidence for best practices in communicating with cancer patients.⁴² The National Cancer Institute produced an entire monograph on patient-centered communication in cancer care, devoting four of its six chapters to key communication skills including delivery of difficult news.⁴³ Most recently in 2014, the Institute of Medicine issued a new report that focused on end-of-life care in America, much of which centered on ways to improve the physician-patient dialogue about bad news.⁴⁴ Medical students and residents are now routinely trained in how to effectively communicate in challenging situations, and patients expect transparency in their interactions with physicians.

However, communication in medicine is still far from perfect. For example, a recent report from the Alzheimer’s Association in 2015 showed that less than half of patients with Alzheimer’s disease or their family members had knowledge of their loved one’s or their own diagnosis.⁴⁵ One physician noted in a media interview following the report, “It’s difficult to disclose a diagnosis of a fatal brain disease in just a few minutes.”⁴⁶ In parallel with these changes, the American Medical Association Code of Ethics has evolved substantially since 1847, with its current form stating “The patient has the right to receive information from physicians and to discuss the benefits, risks, and costs of appropriate treatment alternatives.”⁴⁷

Reinforcing these changes, the medical record has also evolved from a tool solely for physicians to a new means of communicating with patients. In 1973, Shenkin and Warner⁴⁸ proposed that “legislation be passed to require that a complete and unexpurgated copy of all medical records ... be issued routinely and automatically to patients as soon as the services provided are recorded.” This article furthered the belief that patients are owners of their medical information. In 1991, McLaren⁴⁹ proposed that medical records should not only be available, but also be understandable to patients. The **Health Insurance Portability and Accountability Act [HIPPA]**⁵⁰ was passed in 1996, creating new protections for patient confidentiality by restricting disclosure of medical information without the patient’s consent. This act reinforced the patient’s authority over his or her health information, while also mandating that physicians respect their patients’ confidentiality.

Communication in medicine has undergone dramatic changes during the past 170 years. Where once physicians withheld information for the benefit of the patient, it is now clearly recognized that patients have a right to know the truth. The medical profession has responded to both internal and external pressures and developed a standard of care based on honesty and patient-centered communication. However, many uncertainties remain. How much disclosure is enough? How much is too much? Can we cause harm by telling too much or in the wrong way? Is there ever a role for benevolent deception? Should physicians be the gatekeepers of medical information? How will the recent emphasis on shared medical records affect this relationship? Currently, several organizations are actively promoting sharing of medical data and notes with patients.⁵¹ Some current-day patients might have their test results available electronically before ever speaking with their physicians.

[Brendan's Question: What are your thoughts on some of the questions mentioned in this paragraph?]

Though we can certainly say that “patients ought to know,” it is difficult to know exactly *what* they ought to know, and how to best share this information. These are critical questions that are worthy of study. The truth about truth-telling is that it is an unfinished history that continues to evolve. Physicians and patients will undoubtedly need to partner to develop the next chapter in this story.

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4.4 REFERENCES

Available at <https://doi.org/10.7812/TPP/15-219>.

5 READING: MINORS' RIGHT TO KNOW AND THERAPEUTIC PRIVILEGE (BY CRISTIE M. COLE AND ERIC KODISH)

5.1 CASE

“Why do I feel so bad, doctor?”

Dr. Marion's heart broke as she looked at the adorable 9-year-old girl who asked the question. Jill had been diagnosed with acute lymphocytic leukemia almost 5 months earlier, and Dr. Marion had quickly grown attached to the young girl. When Dr. Marion first started caring for Jill, it appeared that she was responding to treatment quite well. But over the past several weeks, Jill was in the hospital more often—the combined result of frequent infection and the toxic agents needed to treat her leukemia.

Throughout Jill's treatment course, her parents had insisted she not be told about her diagnosis. A friend at school had died from cancer, and the loss had affected Jill profoundly. For months afterward, Jill had not wanted to go back to school and refused to sleep in her own room, preferring to be close to her parents. Not

long after Jill seemed to be recovering from the most intense effects of her schoolmate's death, she was diagnosed with leukemia. Her parents feared that telling her she had leukemia would compromise her emotional health and well-being. They asked Dr. Marion and others involved in Jill's care to refrain from disclosing her diagnosis to her.

Dr. Marion—and the rest of the medical staff—had thus far respected their wish, but felt strongly that Jill was mature enough to understand her condition and that she deserved to know what was going on, given that her leukemia might be life-limiting. Once, when her parents were not around, Jill asked what was wrong with her, and Dr. Marion offered an explanation that did not mention cancer but focused on side effects of medications. Now, Jill was asking again.

[Brendan's Question: Before reading the commentary, what would you do if you were Jill's doctor? If you were her parent? Why?]

5.2 COMMENTARY

Jill's parents are not alone. Families are generally concerned that knowledge of a life-threatening diagnosis will harm the patient's psychological and physiological well-being [1-5]. In the past, physicians routinely withheld medical information from a patient if they believed the information would harm the patient's overall health, justified by what is known as "therapeutic privilege" [1-3, 6, 7]. While not exclusive to pediatrics, the ethical dilemmas raised by nondisclosure requests are complicated further when made by a parent of a minor patient [8-11]. Dr. Marion and her team must grapple with reconciling their obligations to Jill with Jill's parents' authority to make decisions on behalf of their 9-year-old child [10].

5.3 PEDIATRIC DECISION MAKING: RECONCILING PARENTAL AUTHORITY, PHYSICIAN OBLIGATIONS, AND A CHILD'S DEVELOPING AUTONOMY

Informed consent is a cornerstone of patient-centered medical decision making. Rooted in respect for patient autonomy, it focuses on the process as much as on consent itself [8, 9, 12-15]. The goal is to elucidate the patient's values and preferences, given the decision and surrounding circumstances [8-11, 13]. Even for most adults lacking capacity, a surrogate strives to make decisions based on the adult patient's previously expressed preferences in accordance with the standard of substituted judgment [16].

In pediatrics, informed consent is at best an imperfect fit [8-10, 15]. Generally, a pediatric patient is not and never has been legally competent to make medical decisions. Until the child reaches 18, legal authority is vested in the patient's parents to determine what is in their child's best interest. Unlike decisions made by an adult's surrogate decision maker, such decisions cannot be based on the child's previously expressed values and beliefs, and so are based on the parents' values and beliefs [8, 9, 15, 16]. Instead of seeking informed consent, then, the American Academy of Pediatrics advises physicians to obtain "parental permission" and, when developmentally appropriate, *assent* (willingness to undergo the proposed treatment) from the young patient. Reframing informed consent as parental permission plus assent respects parental authority and recognizes its limitations. While substantial discretion is afforded to parents in child rearing, the interests of the child and the interests and obligations of the physician, state, and society at large act as limitations. Conflicts are rare, but, when they do arise, the interests and obligations of the stakeholders should be carefully weighed in light of the moral considerations and contextual factors [8-10].

In cases of nondisclosure requests from parents, the child's emerging autonomy and the physicians' obligation to provide appropriate treatment to the young patient must be balanced against parental authority [5, 10]. Of primary importance when thinking about medical decision making is the obligation to foster the child's capacity to make medical decisions [8, 9, 17]. This does not require treating the child as a fully

autonomous decision maker [8, 9]. Rather, as a young patient matures, his or her role in medical decision making should also evolve. The physician and parents have an obligation to enable the young patient's participation in accordance with the patient's cognitive and emotional capacity [8, 9, 17]. The process of assent embodies this obligation because it allows the child to take a more active role in decision making once he or she has sufficiently matured. Like informed consent, assent seeks to elucidate the child's willingness to undergo the proposed medical intervention in a developmentally appropriate manner [8, 9]. Out of respect for the person, a broader concept than respect for autonomy, assent (or dissent) should only be sought if the child's expressed preference will be seriously considered [1, 8, 9]. If it will not, then this should be clearly communicated to the child [8, 9].

While each child should be assessed based on his or her own capabilities, a 9-year-old such as Jill generally has sufficient capacity to assent to at least some medical interventions [8]. Regardless, some information about the medical condition and treatment should be provided in a developmentally appropriate manner for even the youngest patients [8, 9]. Disclosure fosters not only the patient's decision-making capacity but also trust in the clinician from an early age [5, 8-10, 18].

[Brendan's Question: What are the differences between "consent" and "assent"? How does the ability of children to assent (and eventually consent) change over time?]

5.4 THERAPEUTIC PRIVILEGE AND A MINOR'S RIGHT TO KNOW (OR NOT KNOW)

Patient autonomy was not always a defining value in medical ethics [2-4, 7]. As late as the 1970s, paternalism was the cornerstone of the physician-patient relationship and reflected a general belief that the physician's **fiduciary obligation** to act in the patient's best interest was of paramount importance [2-4, 7, 19]. The physician was the primary decision maker and not required to solicit or consider the patient's preferences [2-4, 7]. **Therapeutic privilege** embodies this fiduciary duty by protecting the patient from information the physician deems to be potentially harmful and that the patient does not have an overriding interest in [2-4, 7]. The American Medical Association itself endorsed the practice in its 1847 *Code of Medical Ethics*, stating that a physician has "a sacred duty...to avoid all things which have a tendency to discourage the patient and depress his spirits" [20].

In contemporary medical practice, paternalism has given way to patient autonomy and the corresponding values of bodily dignity and self-determination [3, 19]. Medical decision making is a partnership between the physician and the patient. The physician is obligated to disclose information that the patient needs to meaningfully participate in and make decisions regarding medical care [3, 7, 12]. While pediatric patients are not generally treated as fully autonomous decision makers, the young patient's developing autonomy warrants respect [1]. The same values upon which informed consent is founded also support a physician's obligation to engage children in medical decision making proportionate to their cognitive and emotional development [5, 8, 9, 17]. Consistent with this shift in philosophical priorities, the American Medical Association's *Code of Medical Ethics* now states that "it is a fundamental ethical requirement that a physician should at all times deal honestly and openly with patients. Patients have a right to know their past and present status and to be free of any mistaken beliefs concerning their *conditions*" [13].

Under some circumstances, respect for patient autonomy can paradoxically support withholding medical information. If a patient expresses a desire not to know all or some medical information, then the physician should respect that decision and withhold that information [21, 22]. This is distinguished from therapeutic privilege because the physician is acting in accordance with the patient's preferences rather than on his or her own judgment [21]. The patient's religious or cultural beliefs may indicate preferences, but they should not be attributed to the patient without corroborating them with him or her [22-25]. The physician should offer the

truth, speaking in general terms about categories of information to avoid mistakenly revealing information while also soliciting the patient's preferences [21].

Exercising therapeutic privilege also risks undermining trust in the physician-patient relationship. One risk of nondisclosure is the patient's discovering the withheld information from another source [2, 5, 10]. A family member or another clinical team member could mistakenly reveal the withheld information. The patient could also find the information on his or her own, whether through medical records, the Internet, or accidentally hearing a voicemail. If a patient discovers that the physician intentionally withheld information, trust is compromised, which could prove detrimental to the patient's care [2, 3, 10, 26].

[Brendan's Question: Can you give an example of a case where withholding information because of "therapeutic privilege" might be appropriate? What the risks of doing this?]

5.5 CLINICAL REALITIES OF NONDISCLOSURE: PROBLEMS AND UNINTENDED HARMS

Yet, some parents and even physicians are tempted to withhold a life-threatening diagnosis from pediatric patients [26-28]. Not disclosing a diagnosis, though, is fraught with its own obstacles and harms [1, 5, 10]. More often than not, the child is aware of the hushed whispers and discussions among grown-ups and can ascertain that a secret exists that is not to be discussed [29-31]. The child may know to some degree what that secret is, whether he or she knows the specific disease, the severity of the illness, or that he or she is dying from the disease [5, 29-32]. In the context of the terminally ill child, this is often called "mutual pretense"—all parties including the child know the child is dying but act as if he or she were not [31, 32].

Research shows that withholding information may result in the child's imagining a worse scenario or at least a much different scenario [5, 27]. Without understanding why he or she feels bad, the child may begin to ascertain his or her own explanation for secrecy, including that the illness or treatment is a form of punishment [5]. Research shows that children not aware of their diagnosis do not experience any less distress and anxiety than those who are told about their life-threatening illness [6, 29], and in some cases may actually experience *more* [6, 33]. Openness, by contrast, appears to contribute to good long-term adjustment [27, 33]. Practically speaking, not understanding a diagnosis may also prevent compliance with treatment recommendations, particularly in older children [26, 33].

Nondisclosure also raises the question of how to respond to inquiries from patients about their condition, just as Jill asked Dr. Marion. Several strategies may be used to evade questions, including providing contingent answers, narrow answers, non-answers, or questions [28]. These strategies, however, do not directly resolve the underlying moral dilemma, i.e., reconciling parental authority in pediatric decision making with the physician's obligation to be honest with the young patient.

5.6 CONCLUSION

The desire to protect Jill from knowledge of her own mortality is understandable, particularly given her experience with the death of her friend. This experience, her age, her developmental status, and the impact this information may have on her health should all be factors influencing how and even when the diagnosis is disclosed. These factors do not however justify withholding the diagnosis from Jill indefinitely. Ultimately, Jill's developing autonomy and Dr. Marion's obligations to Jill outweigh Jill's parents' desire to protect her from the knowledge of her life-threatening illness. In discussions with Jill's parents, Dr. Marion should be careful not to appear to be seeking parental permission for diagnostic disclosure. Rather, she should clearly communicate that the diagnosis will be disclosed within a finite period of time [11]. Allowing Jill's parents some control in choreographing how the disclosure takes place may help facilitate acceptance of disclosure

and demonstrates respect for Jill's relationship with her parents. Dr. Marion could offer three options: (1) Jill's parents tell Jill alone; (2) Dr. Marion tells Jill alone; or (3) Dr. Marion and Jill's parents tell Jill together. Explaining that diagnostic disclosure is a process and that prognosis may be treated separately may also help Jill's parents accept diagnostic disclosure.

Lying to Jill is not an option. If Jill asks a direct question, then Dr. Marion has an obligation to answer it honestly and in a developmentally appropriate manner. She should clearly convey this obligation to Jill's parents. Even absent Jill's questions, Dr. Marion at the very least has an obligation to offer 9-year-old Jill the truth and assess whether Jill wants to know about her diagnosis and if so, how much she wants to know.

[Brendan's Question: What is your response to this commentary? Do you agree? Disagree? Why?]

5.7 REFERENCES

Available at <https://journalofethics.ama-assn.org/article/minors-right-know-and-therapeutic-privilege/2013-08>

6 READING: WHEN SHOULD A THERAPIST DECIDE TO BREAK CONFIDENTIALITY? (BY PAMELA GARBER)⁷

I was shaken and transfixed in the aftermath of the shootings at the Marjory Stoneman Douglas High School in Parkland, Florida. Like most of those in the United States, prevention was on my mind. According to partial psychiatric records obtained by the *Miami Herald*, the shooter, Nikolas Cruz, confided 'gory fantasies' and dreams to a school therapist in 2014. The revelation set me to wondering: what *else* had Cruz revealed to all the therapists who, most likely, had interacted with him in the months or years before the attack? Because the danger of Cruz existed before his actual use of a gun in the attack, so did the opportunity for prevention. Where exactly and at what interval in the assembly line of caretakers and third-party involvement did this opportunity lie? Had I been working with him, what would I have done?

It is understandable that people might believe a mental health professional can provide certainty about the future actions of another person. By analogy, we reasonably believe that our brakes won't fail us because our trusted mechanic did the needed repairs. We go for annual medical exams and make decisions based on test results and guidance from our doctor. But confidence that a school psychologist or private practice therapist can accurately assess – and then prevent – the lethal acts of someone they have known only professionally is a set-up for all involved.

It is a set-up for the therapist, whose preventative actions will cause them to be labelled 'heavy handed'; after all, until an act occurs, how can you really prove it would have? It is a set-up for the patient, who might now no longer turn to that therapist for help. If the therapist is wrong, a patient who never would have hurt anyone might enter an advanced level of care via family supervision or law enforcement. And it is a set-up for society, who might be propelled to greater risk when the person in danger is set adrift.

To see what I mean, let's look at the internal structure of therapy itself. To kick things off, a therapist encourages free expression by fully engaging. This involves an internal commitment to experientially understanding what the patient is saying, recognising not only what he or she feels about their message, but also seeing why they chose their message and the meaning of it all for them. For therapists, the quality of

⁷ Pamela Garber, "Can Therapists Break Confidentiality to Prevent Violence? | Aeon Ideas," Aeon, June 9, 2018, <https://aeon.co/ideas/can-therapists-break-confidentiality-to-prevent-violence>.

listening, and then becoming a participant in the conversation, is key. This is beyond crucial when the material shared reveals your patient is enraged and at the maximum threshold.

These are the disclosures that need professional empathy and clinical decision-making, requiring that the therapist act as inside participant and outside observer at once. When this kind of rage unfurls, a therapist must decide whether or not to escalate care by getting others, such as family in good standing or law enforcement, involved. Sometimes a patient might verbally purge heinous or grisly fantasies of revenge. Other times, the patient might reveal rigid rage towards someone they feel wronged by, all while verbally denying anger but causing worry and concern. There is such a thing as passive homicidal ideation, when a person truly *feels* like hurting another, maybe even *feels* like killing a person or people, but never would. As a therapist working with a patient, how can you assess the situation and draw the line? The therapist's job is to yield on the side of empathy – especially when a patient who has been harmed or abused is now managing wounds. For this patient, delving into the muck of feeling about the past is mandatory. They did not elect to feel these feelings and think these thoughts.

[Brendan's Question: What do you think about the claim that the “therapist's job is to yield on the side of empathy?]

At best, a therapist giving an overly cautious notification ruins the therapeutic relationship and creates a situation where someone who might be a high risk is now averse to therapy or giving their own healing a true chance. At worst, a therapist gives information to potential targets, and the act still takes place without interception.

Despite empathy for the patient, a therapist has a moral obligation to break confidentiality if they assess real risk and, in some jurisdictions, a legal obligation to contact law enforcement. In the United States, this legal obligation began in 1976, with the ruling in *Tarasoff v The Regents of the University of California*. In this case, a male college student told his therapist that he was going to kill his ex-girlfriend for ending their relationship. The therapist wrote a letter to campus police but did not inform the intended victim herself. The patient left therapy and later murdered his ex-girlfriend. Initially this led to a ruling that a therapist had a duty to warn an at-risk person; in 1976, the bar was changed from a duty to warn to a duty to protect. In the state of New York, legislation enacted in 2013 created a mandatory duty for mental health professionals to make a report when they believe that a patient might pose a danger to themselves. The law also allows law enforcement to remove firearms owned by a patient deemed dangerous.

No matter the jurisdiction, the therapist is in a double-bind. On the one hand, she is creating an environment for the patient to vent. On the other hand, she is not completely sure that the patient won't act on those feelings and thoughts. Studies validate this point of view. In a paper published in *The BMJ* in 2012, a team in the United Kingdom studied a series of risk-assessment tools available to psychiatrists and psychologists. They found the instruments poorly to mildly useful in predicting violence, but quite precise in identifying those at low risk – something professional therapists don't need a test for at all. Australian researchers, meanwhile, reported in a meta-analysis in *PLOS ONE* that suicide prediction was so poor that the proportion of suicides among high-risk patients was lower than that found in lower-risk patients.

In short, it is impossible for any person, even a skilled therapist, to predict violent behaviour with complete accuracy. No matter how trained the psychology professional or how advanced the testing instrument, research shows an inability to predict the future acts of another.

[Brendan's Question: Why do you think that it is so difficult to predict when/whether a patient will attempt to harm themselves or others?]

When the patient escalates to a point that is getting close to active risk of harm to self or others, I attempt to persuade the patient to have, where relations are good, a family member or a friend participate in a portion of a session. This often offers the patient some consistent validation, which can help to reduce the level of emotions. I emphasise that the patient could at some point be an asset to that same friend or loved-one at another time. This can provide a resource for support and bolster the patient's self-image simultaneously.

Therapists on the front lines are not psychics, but the more they know a patient, the more they can steer an outcome towards good. Rapport, connection and commitment between therapist and patient won't override feelings of rage or desperation, but they can serve as incentive to motivate a different choice. Sometimes a therapist must report a patient, but once that happens, the chance for any meaningful psychological intervention might be lost for good.

7 CASE STUDY: DECEPTION IN DEMENTIA CARE

From National High School Ethics Bowl National Cases 2018-2019

Case Authors and Editors: Chris Blake-Turner, Izzy Brassfield, Dominique Déry, Matthew Hernandez, Intercollegiate Ethics Bowl, Joanna Lawson, Pavel Nitchovski, Macy Salzberger, Steve Swartz, Lauren Townsend, Jacky Wang, Rob Willison, Brian Wong, and Lili Zay

Amara works in a dementia care home, where the patients are in various degrees of physical and cognitive decline. Some of them find it difficult to perform routine tasks, such as getting dressed and eating. Many have trouble remembering basic information, like what day of the week it is. They sometimes struggle to identify their closest family members.

Barry is a resident of the care home with severe memory problems. Almost every day, he asks Amara where his wife is, forgetting that she died many years ago. When Amara first started working with Barry she would tell him the truth. But learning that his wife had died was extremely upsetting for Barry, and Amara eventually began to wonder whether it might be kinder to spare him the pain of bereavement every day. So now when Barry asks, Amara tells him that his wife is out at work, or has gone to take their granddaughter to a soccer game. This doesn't distress Barry, who soon forgets about his question.

Lying to patients with dementia is extremely widespread. As one author recently put it, "a recent survey found that close to a hundred per cent of care staff admitted to lying to patients, as did seventy per cent of doctors".¹ Proponents of the practice argue that lying to patients keeps them calm and prevents suffering. It also makes things easier for staff, who might otherwise have to deal with distressed patients that can sometimes become violent.

But some think that lying to patients with dementia is inappropriate. They argue that telling patients the truth is the right thing to do even if it is disturbing or harmful for them. Wouldn't you want to know about a loved one's death, no matter how painful it might be? Lying in dementia care can also cause breakdowns in trust between patients and their caregivers. If different people give them contradictory information, the patients won't know who to trust anymore.

Those who defend lying in dementia care argue that the diminished mental capacity of dementia patients justifies treating them in ways that it would not be permissible to treat competent adults. An analogy is drawn to childhood: just as it can be acceptable to lie to young children, who lack the capacity to decide for themselves what is best for them, so it can be acceptable to lie to those with dementia whose capacities are impaired.

7.1 STUDY QUESTIONS:

1. Why is honesty generally morally important in healthcare settings? To what extent are these moral issues applicable or inapplicable in a dementia care setting?
2. Are there circumstances in which we are morally required to lie to dementia patients?
3. Is it morally permissible for Amara not to tell Barry that his wife is dead? Why or why not?

8 CONTEMPORARY “CODES OF ETHICS” FOR MEDICAL PROFESSIONALS

This section contains some sample “codes of ethics” from major medical associations.

8.1 AMERICAN MEDICAL ASSOCIATION (AMA) PRINCIPLES OF MEDICAL ETHICS

<https://www.ama-assn.org/about/publications-newsletters/ama-principles-medical-ethics>

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 that define the essentials of honorable behavior for the physician.

Principles of Medical Ethics

1. A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights.
2. 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.
3. 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.
4. 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.
5. 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.
6. 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.
7. A physician shall recognize a responsibility to participate in activities contributing to the improvement of the community and the betterment of public health.
8. A physician shall, while caring for a patient, regard responsibility to the patient as paramount.
9. A physician shall support access to medical care for all people.

8.2 AMERICAN NURSES ASSOCIATION CODE OF ETHICS FOR NURSES

<https://www.nursingworld.org/practice-policy/nursing-excellence/ethics/code-of-ethics-for-nurses/>

Provision 1	The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person.
Provision 2	The nurse's primary commitment is to the patient, whether an individual, family, group, community, or population.
Provision 3	The nurse promotes, advocates for, and protects the rights, health, and safety of the patient.
Provision 4	The nurse has authority, accountability and responsibility for nursing practice; makes decisions; and takes action consistent with the obligation to provide optimal patient care.
Provision 5	The nurse owes the same duties to self as to others, including the responsibility to promote health and safety, preserve wholeness of character and integrity, maintain competence, and continue personal and professional growth.
Provision 6	The nurse, through individual and collective effort, establishes, maintains, and improves the ethical environment of the work setting and conditions of employment that are conducive to safe, quality health care.
Provision 7	The nurse, in all roles and settings, advances the profession through research and scholarly inquiry, professional standards development, and the generation of both nursing and health policy.
Provision 8	The nurse collaborates with other health professionals and the public to protect human rights, promote health diplomacy, and reduce health disparities.
Provision 9	The profession of nursing, collectively through its professional organizations, must articulate nursing values, maintain the integrity of the profession, and integrate principles of social justice into nursing and health policy

9 CASE STUDY: REPORTING CREEPINESS

From Cases for the 26th APPE Intercollegiate Ethics Bowl® National Championship.

Law enforcement agencies of all sorts promulgate the “See something, say something” mantra, in an attempt to get the average citizen to become hypervigilant in watching for illegal activities. In a similar vein, many colleges and universities focus on training incoming students to report “problematic” behaviors in order to anticipate harassment and related conduct issues. In an effort to support and provide resources to students who may be harmed by the words and actions of others, many campuses have developed bystander programming that encourages students to report any and all instances of potentially harmful behavior, especially behavior that could fall under Title IX legislation.

While the ideal would be for all students to feel safe and respected on campus, awareness campaigns that encourage the reporting of all unusual behaviors sometimes harm an already marginalized group of students. On some campuses, for instance, student affairs administrators have been surprised that the awareness campaigns have resulted in many reports in which students with disabilities were the main subject. Perhaps this result shouldn't be surprising. As one student conduct administrator explained, students who identify as having certain types of disabilities are not as adept at reading social, verbal, or physical cues as students who do not so identify. Students with communication or social challenges, for instance, have sometimes found their behavior reported by their peers as “stalkerish” or “creepy.” Students sometimes reported classmates with disabilities for making them feel uncomfortable by excessively staring, following them after class to try to talk, or persisting in contact even though the reporting student thought they had made their discomfort clear. When asked whether they told the other student to leave them alone or to stop staring at them, the aggrieved student often reported having been uncomfortable about saying anything or having been scared of the other student. In such cases, the student affairs administrators receiving these reports had to determine

how to handle the seemingly competing interests of the scared and uncomfortable students as well as those who faced social and communication challenges.

Although many disabilities are visible or identifiable, many others are mostly invisible. Persons whose disabilities are mostly invisible may have some control over who knows about their disability, whereas those with identifiable disabilities, like those requiring a wheelchair, for example, do not have the same level of privacy.

Persons with both identifiable and invisible disabilities frequently meet with negative affective responses from others. According to research on the aesthetics of disability, many people who do not identify as having disabilities will express “discomfort” when confronted by someone with a disability. It could be argued that this “discomfort” may seem similar to the feelings expressed by survivors of sexual misconduct when in the presence of someone who acts in a way they find triggering, like staring or following or just seeming to be “creepy.”

9.1 QUESTIONS:

1. Why do you think colleges/universities have encouraged early reporting? What problems are these intended to address?
2. How have these programs harmed students with disabilities?
3. How should colleges respond to these problems?
4. As an individual, what do you think students *should* do if they find a classmate “creepy”? On the one hand, it’s important to be wary of potential trouble. On the other hand, it’s important not to stigmatize or punish people just for being different.