

The Truth about Truth-Telling in American Medicine: A Brief History

Bryan Sisk, MD; Richard Frankel, PhD; Eric Kodish, MD; J Harry Isaacson, MD

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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

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:

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 Latin 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.

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*:

Bryan Sisk, MD, is a Pediatrics Resident at the St Louis Children's Hospital in MO. E-mail: sisk_b@kids.wustl.edu. Richard Frankel, PhD, is a Professor of Medicine and Geriatrics at the Indiana University School of Medicine Education Institute in Indianapolis. E-mail: rfrankel@iu.edu. Eric Kodish, MD, is the Director of the Center for Ethics, Humanities and Spiritual Care at the Cleveland Clinic in OH. E-mail: kodishe@ccf.org. J Harry Isaacson, MD, is the Director of Clinical Education at the Cleveland Clinic Lerner College of Medicine and an Internist in the Department of General Internal Medicine at the Cleveland Clinic in OH. E-mail: isaacsj@ccf.org

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

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

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, Gargis 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 Act⁵⁰ 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.

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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