



(REVIEW ARTICLE)



Trust decay in the American healthcare delivery system

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GSC Biological and Pharmaceutical Sciences, 2022, 20(02), 072–079

Publication history: Received on 01 July 2022; revised on 03 August 2022; accepted on 05 August 2022

Article DOI: <https://doi.org/10.30574/gscbps.2022.20.2.0318>

Abstract

This treatise examines the four main principles of biomedical ethics, i.e., beneficence, nonmaleficence, autonomy, and justice, and their impact on the healthcare system and providers legally permitted to prescribe or recommend medicines in the United States. It defines the four principles of biomedical ethics and describes how failure to achieve them has contributed to trust decay in the United States healthcare delivery system over the last several decades, that is to say, medical mistrust. An illustrative case of conflicts will be presented that provides insight into whether protocols practiced by the healthcare delivery system to treat intractable pain conform to the principles of biomedical ethics. The increasing distrust in the American healthcare delivery system of two disparate minority populations will be examined. An illustrative case study of a disabled patient's experiences with the standardized healthcare delivery system provides insight into healthcare delivery system administratively mandated policies that may violate the principles of biomedical ethics resulting in established medical protocols that require disabled intractable pain patients to succumb to an addiction disorder.

Keywords: Ethics; Trust; Healthcare; Protocol; Biomedical ethics; Medical mistrust

1. Introduction

Heart attacks and cancer are the two leading causes of death of Americans, killing 45% of Americans who die each year. 161,000 Americans die in accidents, and over one-quarter million die each year due to the failure of the American healthcare delivery system. This makes the failure of the healthcare system the third leading cause of death in America [1]. Medical mistrust has been attributed to the very real historical and ongoing healthcare injustices experienced by socially and economically marginalized groups, resulting in a myriad of negative consequences associated with medical mistrust, including lower healthcare utilization. Studies conducted over decades suggest medical mistrust as a phenomenon has been generated by a system that creates, cultivates, generates, sustains, and reinforces racism, classism, homophobia, transphobia, and stigmatization [2, 3, 4].

The following disquisition examines the four main principles of medical bioethics; beneficence, nonmaleficence, autonomy, and justice, and their impact on the healthcare providers legally permitted to prescribe or recommend medicines in the United States. These four principles will be defined and explained. It will then examine how failures of the healthcare system to achieve these principles have contributed to trust decay in the United States healthcare delivery system over the last several decades, in other words, medical mistrust. An illustrative case study of a patient's conflicts with the standardized healthcare delivery system will provide insight into whether the medicines allowable by the healthcare system to treat intractable pain conform to the principles of biomedical ethics. The increasing distrust in the American healthcare delivery system of two disparate minority populations will be examined. The first is the population of practicing physicians, and the second is disabled individuals, a patient population that has been traditionally ignored. Over the last several decades, the medical cannabis industry has generated enough economic

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influence and political strength that the conventional healthcare delivery system has come to consider it a threat, but studies of the trust perceptions of this rapidly expanding patient population of the American healthcare delivery system are nonexistent. A case study of a medical cannabis patient provided an illustrative example of the structural barriers imposed on patients who utilize the medicinal properties of botanic cannabinoids by the United States healthcare delivery system and resulting in its failure to adhere to the principles of biomedical ethics, while medical cannabis patients are typically ignored and stigmatized.

1.1. The Principles of Biomedical Ethics

The four principles of biomedical ethics are beneficence, nonmaleficence, autonomy, and justice. Each is defined and examined below.

1.1.1. Beneficence

Beneficence refers to the physician's obligation to act for the patient's benefit and provides moral rules designed to protect and defend the right of others, prevent harm, and eliminate situations that will cause harm. The principle requires avoiding harm, benefiting patients, and promoting their welfare [5].

1.1.2. Nonmaleficence

The nonmaleficence principle of medical ethics purports to ensure patients' safety and prevent harm and is foremost for healthcare providers [6]. Nonmaleficence refers to a prescribing physician's ethical and legal obligation not to harm a patient through acts of commission or omission. For the provider of medicines, the commitment involves several ethical responsibilities; not to kill, not to cause pain or suffering, not incapacitating, not offending, and not depriving others of the goods of life [7]. Theoretically, the practical application of nonmaleficence is the physician is responsible for determining whether the benefits of interventions and treatments outweigh the possible hazards and choosing the best course of action for the patient.

1.1.3. Autonomy

The theoretical foundation for autonomy is that people have intrinsic and unconditional value, and therefore, the right to make rational decisions regarding their healthcare. Acknowledging an individual's autonomy obligates physicians to divulge medical information and treatment options for patients to exercise self-determination and supports informed consent, truth-telling, and confidentiality [8].

1.1.4. Justice

Justice is construed as fair, equitable, and appropriate treatment of people. It entails the distribution of healthcare fairly and equitably [9].

The four ethical principles are designed to work together as fundamental tenets for all healthcare system components. There is no hierarchy of principles, where one supersedes the others, and every component of the healthcare system is mandated to comply with the aggregate intent of these ethical principles.

2. Material and methods

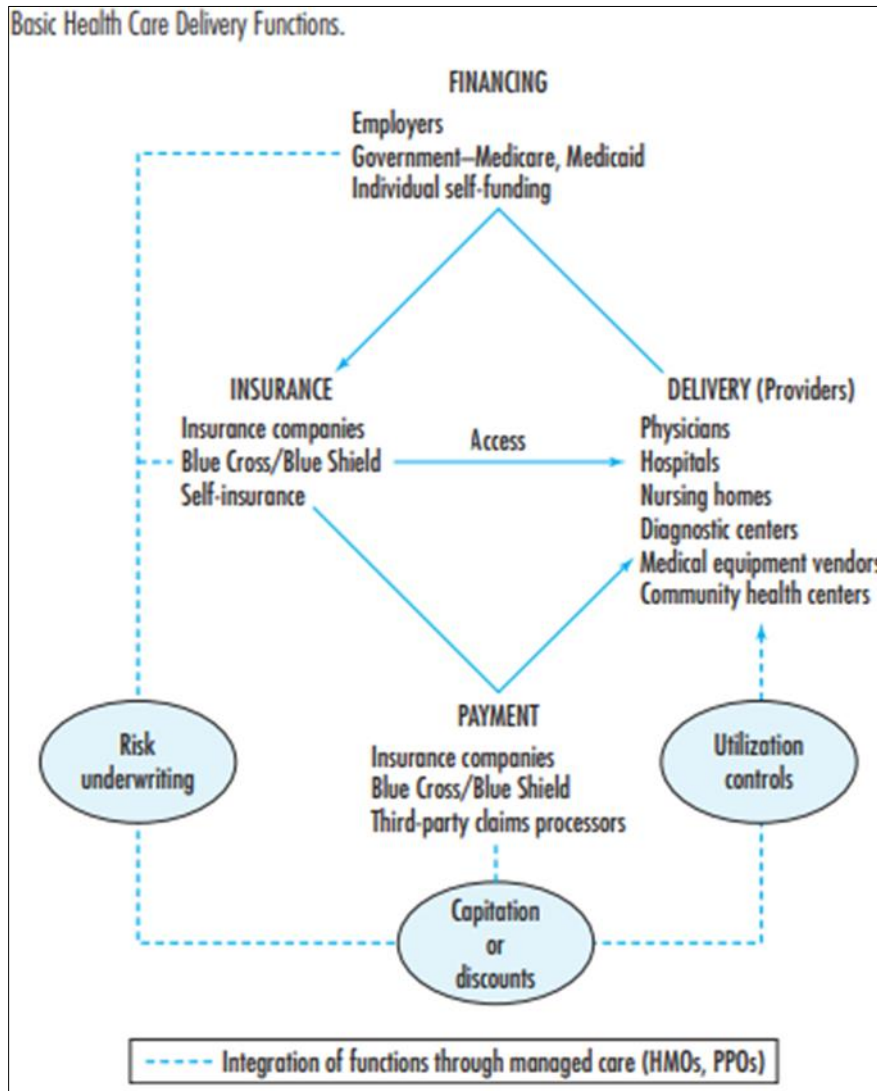
2.1. The Derangement of Healthcare Delivery in America

The healthcare system in the United States is unlike any in the world. Unlike other developed countries, where all citizens are entitled to receive healthcare services through national health insurance programs arranged by the government and financed through general taxes, not all Americans are entitled to healthcare. The United States healthcare delivery system is an irrational and unintegrated network of components designed to work together incoherently [10]. In its truest sense, despite the moniker, the United States healthcare delivery system is not a system at all and does not, in reality, exist, even with total employment in various health delivery settings reaching over 16.4 million in 2010 [10].

2.2. A Broad Description of the Healthcare Delivery System

The complexity of health care delivery in the United States is illustrated in Figure 1. It is a medley of bankrolling, indemnification, distribution, and recompense mechanisms that remain loosely coordinated. This rudimentarily efficient machinery—financing, insurance, payment, and providers—represents an amalgamation of government and

private sectors. Government-run programs finance and insure healthcare for specific groups of individuals that conform to each program’s prearranged conditions for entitlement. Government programs also distribute specific healthcare services directly to particular recipients, including veterans, military personnel, American Indians, Alaska Natives, and some uninsured. Still, the bankrolling, insurance, payment, and delivery functions are principally under the auspices of for-profit organizations. The system components fit together loosely, and all have conspired together to condition individuals to believe the system conforms to the four principles of biomedical ethics.



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Figure 1 Basic Healthcare Delivery Functions

This conditioning of trust is accomplished by claims of Health Insurance Portability and Accountability Act (HIPAA) compliance and labeling medications as ‘FDA approved.’ These phrases are bandied about the healthcare system as a way of ensuring confidence that the healthcare delivery system is conforming to the principles of biomedical ethics. Challenges posed by Covid-19 have required federal agencies such as the FDA to move with greater speed than ever before to provide guidance perhaps selectively on which treatment regimens should be used, enhancing the perception that political pressures rather than data-driven procedures are influencing the FDA’s decision-making processes, eroding the trust the FDA has established and retained over the past century [11].

HIPAA compliance is another issue. 29,298,012 large healthcare data breaches were reported in 2020, more than in any year since the HITECH Act mandated the U.S. Department of Health and Human Services Office for Civil Rights publish healthcare data breach data on its website. This was 25% more than 2019, which was also a record-breaking year [12].

2.3. The Origin of Biomedical Ethical Principles

The principles of biomedical ethics were adopted in the 1980s after public exposure of horrific biomedical experiments conducted by the healthcare system, most conspicuously, the Tuskegee Syphilis Study. Officially titled The Tuskegee Study of Untreated Syphilis in the Negro Male, the 40-year experiment was funded by the Public Health Service and tracked 600 rural black men in Alabama with syphilis throughout their lives, researchers refusing to tell them of their debilitating disease and actively denying many individuals' treatment. The incredibly unethical study was terminated in 1972, instigating the development of what became modern biomedical ethics. *Principles of Biomedical Ethics* [13] was first published in 1985, delineating the ethical principles, and it rapidly became a must-read for academics, medical students, and researchers.

Suspicion of the healthcare system has emerged as an area of economic concern among the four bureaucracies that provide essential healthcare delivery functions. Only 23% of the American public express quite a lot or a great deal of confidence in the healthcare system [14], and the US medical establishment has a long legacy of discriminating and exploiting black Americans. The exploitation has become such an ingrained American tradition that Michael Che, one of the stars of Saturday Night Live, recently quipped, "I've got mixed feelings about the vaccine. On the one hand, I'm Black, so naturally, I don't trust it. But on the other hand, I'm on a white TV show, so I might actually get the real one."

Scientists researching the phenomenon of trust decay in the American Healthcare Delivery system rarely use the word distrust, instead favoring the word 'mistrust' which is defined in the literature as the 'absence of trust' [15, 16]. Most of the research on medical mistrust pertains to interpersonal trust relationships between healthcare providers and patients, although some studies examine physician and patient mistrust toward the healthcare delivery system, hospitals, health insurers, and the pharmaceutical industry in general [17, 18].

While the healthcare system as an entity expresses befuddlement about the origins of medical mistrust, doctors, researchers, and other healthcare actors conclude that the US healthcare system does not *deserve* trust. According to a survey conducted by the nonpartisan research group NORC at the University of Chicago commissioned by the ABIM Foundation, 30% of physicians do not trust the healthcare system they are aligned to, and even fewer generally trust healthcare system industry executives [19].

3. Results

3.1. An Illustrative Case of the Development of Medical Mistrust by a Disabled Individual

There are many disabled patient ethical encounters with the healthcare system, and some, especially those involving end-of-life decisions, are convoluted. This illustrative case provides insight into the four aspects of biomedical ethics throughout a four-decade timespan. It concerns a disabled patient diagnosed with Charcot-Marie-Tooth disease, a type of peripheral neuropathy that affects the transmission of information between the central nervous system and the rest of the body. Pain symptoms often begin between age 5 and 25, and the condition is slowly progressive. With this particular patient, neuropathic pain started around the age of eighteen; coincidentally, at the time the healthcare system adopted the principles of biomedical ethics.

Opioids have been regarded for millennia as the most effective drugs for treating neuropathic pain [20]. The patient was initially prescribed codeine and developed a tolerance to that opiate within the first ten years of the treatment regimen. As was established protocol defined by the healthcare system, his physician switched the opiate to hydrocodone. Hydrocodone worked effectively for several years until the patient developed tolerance and was switched to Oxycodone. Tolerance to Oxycodone took place within six months and Oxycontin was prescribed. By the time tolerance to this drug developed, the patient was 51, and the physicians recommended surgery to place a Fentanyl pump to administer the opiate directly into the spinal cord. Fortunately, the patient had contracted MRSA from prior surgery, and the pain management specialist was unwilling to perform that operation. The patient was then prescribed his final opioid – 500 milligrams of morphine three times daily. That dose caused the patient to suffer a stroke, which resulted in him losing the ability to walk and use his left arm.

At this time, his doctors informed him he had developed tolerance to every opiate invented. The protocol now was to place him into hospice as he had less than six months left to live. They assured him he would go out comfortably because they would increase the intravenous morphine until he stopped breathing. The doctors had followed established healthcare system protocol by addicting this disabled patient to opiates for his entire adult life.

The patient rebelled against the healthcare system and informed the physicians that he was not interested in dying and would explore alternative medicines. Against his doctor's orders, he terminated his relationship with the healthcare system and began researching nutraceutical alternatives contained in chemovars of *Cannabis sativa*. To the dismay of his physicians, the nutraceuticals treated the neuropathic pain and the withdrawal issues associated with being an opiate addict for more than four decades.

At this point, the patient had defied medical protocols, and it is when his journey through the healthcare delivery system became problematic. He was not yet officially a medical cannabis patient but was illegally medicating with an illicit substance that the American healthcare system viewed as containing the most dangerous molecules humans can ingest.

His next step was to become certified to medicate legally with cannabis in the state where he resided. The pharmaceutical industry had purchased the three healthcare organizations in his state, and each informed their physicians that they were forbidden to recommend medicinal cannabis to their patients. Unaware of this development, the patient went doctor shopping, searching for a physician willing to recommend medicinal cannabis. He met with seven physicians; each visit covered by his insurance. Seven reasons were given as to why they were unwilling to recommend the supplement.

- "I'm in favor of medical cannabis, and I am glad this is coming, but I don't have time to learn anything new."
- "I will not certify anyone for medical cannabis until every last bit of evidence comes in. I don't care how long it takes."
- "I've never recommended medical cannabis before, and I am not going to start now."
- "I'm not willing to recommend drugs that are psychoactive and cause brain damage."
- "I'm not willing to recommend medical cannabis for you. What I am willing to do is surgically insert a tube into your spine so I can pump pain-relieving narcotics directly into your spinal cord."
- "Ingesting cannabis results in brain damage equivalent to being on Bikini Island during a nuclear blast. As a doctor, I will not be a party to that."
- "Even if you proved to me this medicine would save a patient's life; I still wouldn't give it to them."

The patient finally located the only doctor in the State that provided recommendations for medical cannabis. He had to travel six hours to get to the doctor's office. The physician provided the patient with information on how the state healthcare system had chosen to manage the medical cannabis issue. The State had followed the model of other states that had established medical cannabis programs. Each had designed different methods of claiming they are the most restrictive state regarding medicinal cannabis. The State the patient resided in had chosen to make the application process virtually indecipherable. The State of Minnesota required their physicians to return to school for another year before being permitted to recommend it to patients. The State of Nevada certified organizations with enough money to lobby politicians to grow the *Cannabis sativa* plant to produce medicinal molecules but mandated they not use the sun.

The state requirement for the patient was to establish a doctor/patient relationship with the recommending physician. This required three \$200.00 fifteen-minute visits with the physician. The first visit entailed a get-to-know-you session and signing forms so the doctor could obtain the medical records necessary to demonstrate that the patient had a condition qualifying him to medicate with botanic cannabinoid molecules legally. By the second visit, the doctor had received the medical records that proved the patient had a disease that qualified him to be a medical cannabis patient and wrote the recommendation. He explained that this was different than a prescription because no doctor can prescribe a Schedule One drug. On the third visit, the relationship was established, and the physician faxed the recommendation forms to the State. The patient submitted his fingerprints and waited to receive his medical cannabis card in the mail. Once he received it, he continued to medicate illegally because the dispensaries had not yet opened. A few days before the dispensaries opened, the patient received a letter from his insurance company stating they would not cover any part of his hospice bill because he failed to follow the established medical protocol presented to him by his physicians.

This illustrative case study may provide insight into how a disabled individual might develop mistrust of a medical system. It certainly speaks to constructs of beneficence, nonmaleficence, and autonomy, although their interpretation is subject to the reader's views regarding natural medicines. It might also be argued that each component of the healthcare system; financing, insurance, payment, and providers either bent or blatantly violated these principles of biomedical ethics.

3.2. The Principle of Justice for the Disabled Medical Cannabis Patient

Patients who use pharmaceutical medications have legal recourse through the Americans with Disabilities Act (ADA) if they are discriminated against for using their medicine. However, federal courts have repeatedly ruled that ADA protections do not apply to medical cannabis patients due to federal illegality. Prohibitions on discrimination do not apply if failing to penalize medical cannabis patients would cause an institution to lose a monetary or licensing-related benefit under federal law or regulations [21]. This ruling came into play when the patient attempted to reenter society by returning to school to pursue his Ph.D. When he was in school as an opiate addict, he utilized a federal program called Vocational Rehabilitation (VR). VR is a federally funded state program designed “to help people with disabilities find and maintain employment and enhance their independence.” If the patient had been an opiate addict, he would have been eligible to receive educational assistance to aid him in pursuing the degree. On November 18th, 2018, he was deemed ineligible for this educational assistance due to his participation in the undeniably illegal State Health Department sanctioned medical cannabis program. As a state program conforming to federal government oversight, the Department of Rehabilitation mandated that the patient withdraw from the state-sanctioned medical cannabis program to attain financial assistance for the educational services to which he was entitled. Due to the significant financial benefit these educational services entailed; the patient consulted multiple attorneys. It was made quite clear that the Department of Vocational Rehabilitation is a state program that falls under the funding auspices of a federal program. As such, they must comply with federal law. They are well within their rights in their demand that the patient complies with federal law also. The patient withdrew from the State’s medical cannabis program and returned to medicating illegally. While this illustrative case study provided a somewhat convoluted way of making a point, it might arguably be recommended that adjustments be made to discriminatory federal regulations that would mandate disabled medical cannabis patients withdraw from State Health Department sanctioned medical cannabis programs in favor of committing a felony that ensures their survival.

4. Discussion

Blendon and Benson [22] review data from more than 100 public opinion surveys conducted over fifty years demonstrating trust in the American healthcare system is progressively decaying. They report significant dissatisfaction with the health care delivery system in general and with private health insurance and managed care companies, and their data indicates overall support for a national health plan. Still, the data reveals most participants distrust the federal government to act ethically and do not favor a single-payer type of national health plan. The review also finds that confidence in the leaders of medicine has declined but that most Americans maintain trust in the honesty and ethical standards of their physicians. No data is available pertaining to the trust in the healthcare system of the exponentially expanding numbers of individuals who use botanic cannabinoids medicinally. This is an area where research is warranted, and the case study presented in this treatise provides insight into the experience and perceptions of a single patient in this traditionally stigmatized population. The blatant disregard of the principles of biomedical ethics inflicted on this patient may be justified because the American healthcare delivery system is administratively mandated to preserve policies to maintain compliance with the Controlled Substances Act which required the healthcare system to addict intractable pain patients to opioids.

5. Conclusion

This review article examined how failures of the healthcare system to achieve the principles of biomedical ethics have contributed to trust decay in the United States healthcare delivery system over the last several decades. Throughout this time, the medicinal use of botanic cannabinoids has increased exponentially, but studies of the trust perceptions of the American healthcare delivery system of this rapidly expanding patient population remain nonexistent. A case study of a medical cannabis patient is provided as an illustrative example of the United States healthcare delivery system’s failure to provide adequate healthcare and adhere to the principles of biomedical ethics. It is hoped this research reveals specific barriers imposed on medical cannabis patients and serves to inform policymakers, clinicians, and patient advocates and initiate efforts to eliminate these institutionally imposed barriers.

Compliance with ethical standards

Acknowledgments

An acknowledgment is made to the pharmaceutical industry, the Department of Justice, the Americans with Disabilities Act, the American healthcare delivery system, the health insurance industry, the criminal justice system, the Department of Vocational Rehabilitation, and the paradigm of medicine that punishes physicians economically if they think for themselves or adhere to the principles of biomedical ethics.

Disclosure of conflict of interest

The author has no conflict of interest to disclose.

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