

THE ISSUE OF TRUST IN MEDICAL CARE: BUILDING, MAINTAINING, AND LOSING IT

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I. Historical Retrospective

It is axiomatic that patients must trust their doctors, otherwise the treatment that would be given will not succeed. The purpose of this article is to explore the elements of trust as applied to the doctor-patient relationship, especially as it is viewed by African American and other minority patients and healthcare providers. It is necessary to go back in history and determine what the situation has been for African Americans, because this history has been unlike that of any other in this country.

When blacks first came to this country in 1619, one year before the landing of the Mayflower, they came in chains and in bondage, snatched from their native Africa and loaded aboard slave ships and transported here through the Middle Passage. Once here, they were subjected to the most atrocious living and working conditions imaginable, and when they became ill, they were treated with massive doses of cathartics and other medicinals more fit for treating horses, such as croton oil, which induced heavy diarrhea, and tartar emetic, which caused effusive vomiting. Thus cleansed and purged, the slave who was unfortunate enough to become ill was immediately returned to work in the fields, because the master did not want sickness to cause a loss of his revenue brought in by his slave's labor. A slave was a commodity, and commodities had to be maintained in top working condition in order to maximize income on the plantation. Needless to say, the slaves did not trust the master's medical ministrations, and they preferred to use their own treatments, which consisted of voodoo and hoodoo potions, practices and remedies brought over from Africa. Sometimes these were successful, but they often resulted in disastrous side-effects which might lead to more disability than they started with.

Over time, the slaves developed their own practitioners, called "slave doctors", who attained considerable fame in their localities. Some of these slave doctors went on to become quite successful and many

were credited with curing specific diseases and conditions such as snakebite and rabies. Some even bought or were granted their freedom. A very few went to medical schools, and the first black graduate of an American medical institution was David John Peck in 1847. After the Civil War ended, several black medical schools were started so that African Americans could treat their own. The first to open was Howard University School of Medicine in 1868, and by 1910 there were 11 such schools. However, after the Flexner Report on Medical Education in the United States and Canada was commissioned by the Federal Government, 9 of these institutions were closed on the grounds that they were not qualified to produce competent doctors, and by 1930 the number had been reduced to 2: Howard, and Meharry Medical School in Nashville, Tennessee. The Flexner Report stated that black medical schools should restrict their efforts to training “Negro sanitarians” rather than surgeons, because blacks were a source of infection and contagion which presented a threat to whites. As a result, the production of a sufficient number of black doctors to treat the health problems of a growing black population was perpetually crippled, thus adding to the slave health deficit, which Byrd and Clayton maintain has left African Americans in a continually negative health situation compared to whites. Accordingly, the number of black doctors in this country has never been above 5 % of the total number of American physicians.

To complicate the problem of inadequate health care delivery for blacks, many white doctors refused to care for these patients. Black babies were delivered at home by midwives rather than by physicians, who were not available, and in any case, hospitals would not admit black patients. With this type of background, it is no wonder that African Americans learned to mistrust the medical system, which they perceived as meaning them no good and possibly meaning them harm. Once they were able to be admitted to hospitals under the separate but equal system, they feared that they might never come home again, so an admission to the hospital was looked upon rather ominously, like a death sentence instead of a chance to restore health. Any trust in the medical system which was developed at that time was borne out of desperation as well as from a carryover from slavery of a feeling of obligation and loyalty to the white man. Black people had been conditioned to do as they were told, and they complied blindly to medical orders rather than doubting or questioning the system. This

kind of trust was not real; it was artificial and was based on fear, domination, and intimidation.

Another aspect of the early medical treatment of blacks which engendered mistrust for the system was the fear that blacks had of becoming unwilling and unwitting subjects of experimentation. They had good grounds for this fear. During slavery, many famous white doctors bolstered their careers by giving public exhibitions of experimental medical procedures. These demonstrations were often performed out in an open square, as was the habit of Dr. J. Marion Sims, who is considered the father of American gynecology. Dr. Sims would openly display surgical and gynecological conditions in slave women while he lectured to the audience about his technique in treating these conditions. This unsavory practice has resounded down through the generations to this very day, due to the fact that black patients have been made to feel disrespected by doctors. This pattern of disrespect for privacy, lack of dignity, abuse, scorn, and abuse was carried over to medical schools and was taught to students eager to learn from the masters of medicine about techniques to be refined and applied for the benefit of white patients. Blacks were used to demonstrate those techniques, and the demonstrations continued even after the black patients died, in the autopsy rooms and morgues. It is no small wonder, therefore, that African American patients declined to go into hospitals when they became ill, and it should not be surprising that the families of the deceased refused to allow post-mortem examinations—autopsies-- to be performed on their deceased relatives.

The Federal government became officially involved in the miscarriage of medical justice in two principal ways. First, it declared in a Supreme Court ruling, the Dred Scott decision, that a black man was not the equal of a white man and had no rights that whites were bound or obligated to respect. That opinion has had far-reaching consequences which have affected the doctor-patient relationship as well as having had an impact in other areas of life for blacks. The second event which is historically important was the Tuskegee Study, initiated in 1932, in which about 400 black men were surreptitiously mistreated for syphilis and were allowed to die from the ravages of this disease under the aegis of the United States Public Health Service. That study reinforced the fears of blacks about being experimented upon and is the worst example in the history of American medicine of the medical abuse of human rights. The Tuskegee Study continued until 1972, when it was stopped after criticism mounted about its intent and the abuses it had fostered.

With the presentation of the above facts about the medical history of African Americans it should be obvious that the issue of trust in the medical system on the part of black patients has to be considered to be in difficulty from the very beginning, because not only was there no trust, there was mostly mistrust. Over the years, many individuals and organizations have tried to dispel that presiding feeling, but they have had a mostly uphill battle, and the struggle continues to this day. One of the points of difficulty lies in the fact that the medical history of African Americans has been largely unwritten and therefore has been left for interpretation by others. Former President Richard Nixon, when asked about how he would be viewed by history in the wake of the Watergate scandal, stated, “the interpretation of history depends on who writes it”, and so blacks must write and promulgate their own history to make sure that there is no misinterpretation of the facts. In order to build trust into black patients, it is first necessary to eliminate the unhealthy but justified impression they have that the medical system in this country has victimized them rather than having benefited them. As one patient has stated, “it’s a bad situation when you have to protect yourself from the very system that should be protecting you”.

Most of what is known about the health history of minorities is based upon the African American experience. However, Hispanics, Native Americans, and Asians have also suffered from inadequate and inappropriate healthcare delivery which has resulted in health problems in these populations and has led to mistrust of the medical system. Many have had the same types of indignities imposed upon them that blacks did. The essential and overriding difference is that none of the other minorities had the yoke of slavery imposed upon them, a limitation so pervasive that its effects are being experienced to this very day in the “slave health deficit” that Byrd and Clayton speak of. The situation described here for blacks can be taken as a surrogate situation for all racial and ethnic minorities regarding the issue of trust.

II. Building Trust

What are the basic tenets of trust? They include dependability, reliability, respect for privacy, decency, belief in the abilities and good intentions of the providers of care, and a feeling that the patient will be treated with dignity and proper concern. The historical backdrop that has been presented above illustrates that, in the case of the black patients, these ingredients and necessary precursors of trust have been

painfully missing. In order to build trust, it is necessary that we must first correct this situation, which means that we have to begin by acknowledging its existence. Denial of the transgressions of history must be eliminated, starting with the proper education of practitioners and students of medicine.

In the case of medical practitioners, it is important for them to be re-educated about the cultural, ethnic, racial, and religious distinctions and differences that characterize minority patients. As a first step, these practitioners need to learn what cultural diversity is and how to develop cultural competence. For example, they must learn that there are differences in the way that illness and disease are perceived by different ethnic groups, and also in the way that diseases are expressed. A patient who is of Maya Indian origin who was born in Zinacantan in the highlands of Chiapas, Mexico might not understand illness in the orthodox Western context, and instead may think of disease as a foreign process or spirit invading the body. Another example is the Haitian patient who comes to the American physician with acute renal failure after being treated by her voodoo priest with kerosene-soaked sugar cubes for a cold; the patient believes that the medical problems she is experiencing are caused by evil spirits. In addition, representatives of certain ethnic groups may not respond to treatment in the same way that other groups may. Some drugs used to treat tuberculosis such as Isoniazide, for instance, may not work as well in black patients as in whites. Such differences might be caused by what are called genetic polymorphisms. And in the treatment of hypertension, certain medications which focus on blocking the neurohormonal axis such as angiotensin converting enzyme inhibitors and beta-blockers may not reduce blood pressure to goal levels as readily in African Americans as in Caucasians when those medicines are used as monotherapy. Some Chinese patients may have an exaggerated response to the beta-blocker propranolol, to which they may exhibit an unusual sensitivity. There are many other examples of differences which can affect clinical outcomes between different groups. The main thing is that doctors must realize that the patient must first be assessed according to the cultural, racial, ethnic, and other special characteristics that he or she brings to the clinical setting. It has to be understood that “one size does not fit all”, and that treatment has to be tailored for the individual.

Once the practitioner has been properly educated about the principles of cultural competence, he should then concentrate on learning the methods of approaching the patient. The most important

facet on which to concentrate is effective communication, both non-verbal and verbal.

Non-verbal communication refers to elements such as looking the patient in the eye, and expressing an attitude of welcome and genuine interest in the patient's problem. As Sir William Osler said, "it is more important to consider what sort of patient has a disease, rather than what sort of disease the patient has". Just the knowledge that the doctor is focusing on YOU can be a tremendous instrument for building trust. Another element of non-verbal communication is shaking hands with the patient. This can provide an initial point of physical contact between doctor and patient and serves as an "ice-breaker".

Verbal communication is important, too. This includes elements such as the way the doctor greets the patient. The greeting should always be cheerful, and the salutation should include addressing the patient by the last name, such as, "Good morning, Ms. Jones. I am Dr. Smith." This immediately shows respect for the patient and verbally indicates the fact that the doctor is interested in the patient. The doctor should not address the patient by his or her first name unless the doctor requests and receives permission to do so. Following the salutation, the doctor should ask the patient for a brief description as to why he or she is there, after which the doctor should explain what the patient should expect to happen such as the performance of a medical history and a physical examination. Knowing what is going to happen puts the patient at ease and makes him or her more comfortable with the physician. This is an excellent way to build trust.

There are many other examples of ways in which trust can be built. Once established, it must be maintained. We will now explore how this can be accomplished.

III. Maintaining Trust

The first point of contact for the patient with the doctor is the office. How the patient is initially received at the office is pivotal in the establishment of a smooth and congenial doctor-patient relationship, and of course this contact usually occurs before the two meet. When the patient walks in the door and goes up to the receptionist, that person must be cordial, well-dressed, and eager to help. The receptionist as well as the rest of the office staff should greet the patient and should think of themselves as an extension of the physician in all of their dealings with the patient. Their behavior should be professional but compassionate at all times, and courtesy must be a hallmark of their attitude. They should

become experts in interpersonal relations and must make each patient feel special. Needless to say, they must emphasize and demonstrate that the patient's medical affairs are strictly confidential (now mandated by law by the HIPAA regulations). These elements have to be repeated each time the patient visits as well as when the patient is contacted for results of laboratory tests, etc. between visits. Appropriate handling of these elements will serve to strengthen the trust which the patient has built up and will help immeasurably in maintaining it. The doctor must be responsible for how his office staff manages the patient, and he must be the person designated to initiate and oversee their function, along with the office manager or medical assistant.

The doctor himself, therefore, is the key to maintaining the trust that has been instilled in the patient. In addition to motivating his staff, he must maintain a code of cultural competence at all times in dealing with patients. This means always regarding the patient as the center of the medical universe rather than himself, and manifesting a humane approach to the treatment of the patient. This does not have to be time-consuming. It is more a matter of showing a positive attitude during brief encounters with the patient rather than spending lengthy periods discussing medical matters. It is also important to show respect for the patient's intelligence and point of view, as well as for his family's wishes. Above all, the doctor must be sure to explain to the patient how he plans to treat the illness, the likely consequences of that treatment, and the importance of being compliant with the medication which the physician has judiciously chosen.

Many times, trust which has been established breaks down. We will now analyze the reasons for this.

IV. Losing Trust

Although the patient may not express it verbally, he or she may lose trust in the doctor. It is difficult to determine in every instance why this occurs, but the symptoms and signs may be apparent. The best example of a loss of trust is when the patient stops coming to the doctor. This is an overt signal that something is wrong and needs to be followed up. Often it is caused by a breakdown of those principles mentioned above on building and maintaining trust. Perhaps the office staff did something which the patient felt was embarrassing or demeaning, and rather than facing the staff again, the patient decides not to return. Or perhaps it was something that the doctor did or did not do, such as not explaining to a young black male with hypertension that the powerful

anti-hypertensive medications which he is taking may cause him to experience sexual dysfunction. These are elements which can destroy the faith and trust that were painstakingly constructed, which leads to a situation potentially harmful to the patient from not taking his prescribed medications, and diminishes the doctor's status in the eyes of the patient.

Through efforts by his office staff, the doctor should strive to maintain contact with the patient between visits. Reminders should be mailed to the patient about upcoming appointments, and when the patient fails to show up for an appointment, the office should make contact and urge the patient to reschedule. Such an indication of interest on the part of the doctor will engender a sense of trust in the patient and will help to avoid the loss of trust.

V. Summary

Judging from the material that has been presented above, it is evident that matters of trust are extremely significant in establishing and maintaining a good doctor-patient relationship. In addition, if the principles underlying trust are followed, this should have a huge impact on healthcare disparities. In the end analysis, we can positively affect the outcomes of our medical interventions simply by treating all patients equally well. This will help to fulfill the tremendous promise which our healthcare system can and should provide, especially to those who are most in need.