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**Abstract:** "To be used in some type of experiment and then be forgotten. Why are you interested in me now?" This is one of many sentiments felt by African Americans. In one of many surveys conducted by researchers, African Americans feared they would be used as guinea pigs for medical research. This survey also found that blacks were more likely than whites not to trust that their doctors would fully explain the significance of their participation in clinical research or other studies. Many scientists believe that bad feelings make it difficult for them to recruit minorities as participants in biomedical research studies in different areas. There continues to be an underlying element of mistrust between the poor populations and minority populations that may be subjects of research and the research establishment. The perception of mistrust from the African American community is in large caused by their previous experiences with the health care system. However, the mistrust is not only in perception, but has many other reasons. Mistrust of the health care system by African Americans is a major problem that has to be addressed and corrected. This paper is a historical perspective of the African Americans relating to their distrust of research and the traditional health care system.

**Key Words:** African Americans, Health Care System, Distrust

# AFRICAN AMERICANS AND THEIR DISTRUST OF THE HEALTH CARE SYSTEM: HEALTHCARE FOR DIVERSE POPULATIONS

The now infamous Tuskegee Syphilis study is perhaps the most widely known study exclusive to African American males. It was conducted by the United States Public Health Service from 1932 to 1972, in which researchers withheld treatment from about 400 black men in Macon County, Alabama in order to study how the disease progressed (Adams, 2003). The study continued without treatment, even after penicillin became the standard cure. This study has become to many, a classic and historical case of blatant governmental racism against African Americans and is one major reason why so many

African Americans' distrust the health care system. According to James Jones, professor of history at the University of Houston, in his book entitled "Bad-Blood", he identifies that for many African Americans, the Tuskegee study became a symbol of their mistreatment by the medical establishment. He further states, "This study was a metaphor of deceit, conspiracy, malpractice, and neglect, if not outright genocide" (White, 2000). Although written with bias, Jones is not far off from the truth of how African Americans view the government and the traditional health care system overall. Entering the 21st century, African Americans continue to distrust research participation. They distrust that their physician would fully explain research participation more than their White counterparts, regardless of social class (Corbie-Smith, Thomas, & St. George, 2002).

The United States of America is often called the great melting pot because of its diverse population. As the diversity of this great nation continues to grow, so does the continuing problem of distrust of the traditional health care system. The more negative attitudes expressed by African Americans towards the nations health and social institutions are partially

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grounded in the circumstances and experiences that failed to eliminate historical racial disparities (Blendon, et al., 1995; Randall, 1996).

However, as a subculture of the American society, African Americans have experienced something that others have not: the unique combination of racism, slavery and segregation. It has caused African Americans to develop not only different behavioral patterns, values, and beliefs but also different definitions, standards, and differences in value systems and perspectives (Randall, 1996). Distrust of the health care system by African Americans runs from the feelings of ill gains for participation in clinical trials to being used only as guinea pigs. In addition, there are feelings by African Americans of whether the physician, intentional or not, do treat minority patients differently than White patients (Lake, Snell, Perry, & Associates 2004). In a study by Blendon et al. (1995) 42% of African Americans are more likely to state that the health care system in this country needs to be rebuilt. African Americans need to be able to learn how to best advocate for themselves within that system. In addition, they, along with other minority groups need more minorities of their own cultural groups visible and practicing in the health care system and their communities.

#### **HISTORICAL PERSPECTIVE**

The history of African Americans and the traditional health care system can be traced back to the times of slavery. Many members of the African American community have their roots in the continent of Africa, with many being descendants from people that were brought here as slaves from Africa, specifically the West coast. Ironically, the first African American immigrants that arrived in North America did not come as slaves between 1619 and 1860; however, later more than 4 million African people were transported here as slaves (Bullough & Bullough, 1972). Regardless, many of today's African Americans are voluntary immigrants from other countries. Although African Americans live in all regions of the country, the majority have roots in the Deep South. They are represented in every socioeconomic group, but a great majority live in poverty and they also remain disproportionately poor.

As slaves, African Americans were not offered the opportunity to see physicians or nurses, so they relied on many of the folklore remedies that they brought with them from Africa for times of illness (Leininger & McFarland, 2002). Further, their African remedies were often mixed with European folklore, from which the slave owners created additional remedies for the slaves to combat injury and illness. As times changed, and the African Americans migrated North from the South for better for job opportunities. They were introduced to the biomedical system in which African Americans became acculturated to the dominant American ways of health (Leininger & McFarland, 2002). However, this did not sway them from continuing to use their traditional folk remedies and many are still in use today.

Although many of the hurdles to gaining health care access for African Americans have been knocked down or blocked, and many barriers persist. Many of the disparities that exist for African Americans also exist for other minorities, but for African Americans it is more widely documented. Regardless of the improvement made for African Americans to gain access, there is documented proof that they still receive decreased access and treatment to care when compared to their White counterparts.

According to Blendon and others (1995), this disparity is reflected in the continuing disparities in income level, education, treatment decisions, socio-cultural factors and failures by the medical profession. In the article entitled "Black-white disparities in health care," it has been a long standing policy of the United States and the American Medical Association that equal access to basic medical care is provided to all Americans. "Although African Americans require more health care services, access to these services is limited. Part of this is due to distrust of the medical community and in part due to racial biases and discrimination. Research continues to show disparities to the actual access of treatment. In spite of the progress that has been achieved in the African American community within the last 25-30 years, racial prejudice has not been entirely eliminated in this country.

African Americans constituted approximately 12.9% of the population of the United States in 2000 (Dalaku, 2001). Despite overwhelming hardships and enforced separation, the African American people managed in most circumstances to maintain both a family and community presence, dispelling many myths regarding the Black/ African American family. With all the inhumane treatment they endured, the Black family has grown and survived. It is the historical problems of the African American community that need to be appreciated by modern day health care providers.

In today's modern society, many African American people feel that the actual act of receiving health care is very often a degrading and humiliating experience. Often times African Americans are viewed as beneath White Americans by White health care providers (Spector, 2004, p. 245). Some problems can be attributed to intentional insults by health care providers, to include communication or poor quality of care. Also, Unintentional insults by the providers may include some form of gestures or comments that may be demeaning; i.e., the actual tone of the voice used when speaking to a client. Some health care providers may have fears or problems relating to African American clients and the client may sense this uneasiness contributing to their distrust. Reports based on surveys of African Americans have suggested that bias, prejudice, and stereotyping on the part of the health care provider may contribute to differences in care leading to feelings of mistrust (Smedley, Stith, & Nelson, 2003). The root causes of the mistrust of the health care system by African Americans are without a doubt multifactorial. There is no

simple, single explanation that can be cited. Within the United States, the governments' obligation to assure equity in health care arises mainly from Title VI of the Civil Rights Act of 1964, which prohibited discrimination in any program receiving federal financial assistance on the basis of race, color, or national origin (Geiger & Borchelt, 2004). In addition, the Healthy People 2010 initiative has made the reduction of racial disparities a central national health priority (Lavizzo-Mourey & Knickman, 2003).

### **SHORTAGE OF MINORITY CARE PROVIDERS**

According to the American Nurses Association's position statement on discrimination and racism in health care (1998), the under-representation of minorities in the health care system is but one indicator that we have failed to recognize and develop fully the human resources of our diverse population. This under-representation of minorities in health affects the total structure of the health care system. With so few minority health care professionals, the control of the health care system lies almost exclusively in the hands of White Americans (Randall, 1996) or in other words, the dominant culture. Because of the inadequate representation of minority health care providers, issues that are most prevalent to the minority population, are usually not known and are not given a priority platform by those in authoritative positions. Often, friction is displayed amongst minority groups and health care officials, thereby creating an atmosphere of powerlessness and alienation. African American patients looking for African American doctors are many times disappointed because of their shortage. The number of African Americans both enrolled in health programs and those in selected health practices are extremely low (Spector, 2004).

### **PATIENT-PHYSICIAN RELATIONSHIP**

The mistrust in the health care system by African Americans has had a direct impact on the relationship of physicians and clients. It is the duration of the physician-patient relationship that is directly correlated with trust. Trust in turn is identified as a fundamental element of the physician-patient interaction. It is a key element in a therapeutic alliance (Peterson, 2002). Patients that see physicians of their own race, rate the care that they receive higher than when they see a physician from another race or ethnic group. Studies have found that ethnic differences between physicians and patients are often barriers to partnership and effective communication. Additional studies have pointed out those patients and physicians that belong to the same race or ethnic groups are more likely to share cultural beliefs, values and experiences in society, which in turn makes them more comfortable with each other. This relationship also shows a higher prevalence of participation by the patient in regards to their own health care needs (Mechanic, 1998; Mechanic & Schlesinger, 1996).

### **CULTURAL COMPETENCE**

Perhaps one of the most dynamic factors relating to mistrust of the health care system by African Americans is the lack of cultural competence by health care providers. It is this lack of cultural sensitivity and cultural competence on the part of the physician and other health care workers that breeds mistrust of the health care system by this minority group. The cultural differences and the inadequacies of many health providers to be culturally competent in regards to dealing with minority populations can be staggering. Many health care providers, unless they are of the same ethnic background, know very little about how to interact with the African American client population. Many times there is a misunderstanding of both the verbal and non-verbal behavior of this minority group. It has been estimated that by the end of this century, 50% of all Americans will be African-American, Hispanic American, Asian American or Native American (Randall, 1996). Not only are there differences between White Americans and minority groups, physicians need to be aware of the cultural differences within groups.

### **ACCESS TO CARE**

Millions of Americans are under-insured; a disproportionate number of these under-insured people are minorities. The lack of access directly correlates with the quality of health care received by African Americans and other minorities. African Americans are more likely to require health care services, but are least likely to receive appropriate care. Lack of quality care and access to this care, in turn imparts a mistrust of the system. Recent studies have shown that when minorities receive access to the health care system, and even have the comparable ability to pay for the service, they are still less likely than whites to receive the appropriate therapies (Tomaselli, 2003). A critical concern to African American clients is that many of them access medical care through large public hospitals. Mistrust of the health care system also manifests itself in the fact that those who receive care in public clinics or hospitals are the "material" on whom students practice and on whom medical research is done (Spector, 2004, p. 246).

### **RECOMMENDATIONS FOR IMPROVEMENT**

#### **Recruitment of Minority Health Care Providers**

It is imperative that more minorities are encouraged to enter the health care system. Efforts need to be manifested to recruit and retain more African Americans in health occupations and professions because they are more likely the one' to serve the minority and medically underserved populations. Health care that is individualized to the health practices and specific needs of each person and/or population group is vital to maintain and improve the health of all Americans (ANA position statement). Care must be taken to improve the physician-patient relationship. By establishing a trusting relationship with their physician, minorities are more likely to take an active, participatory role in their

own health care. This translates into a decrease of suspicion and mistrust of the health care system and higher participation of minorities in care, health care surveys, research studies and clinical trials.

### **Cultural Competence Education**

Improving cross cultural communication and competence training in health care settings may lead to more patient involvement in care, adherence recommended treatment, higher quality of care, and better health outcomes (Cooper-Patrick, et al., 1999). The development and implementation of these culturally competent training programs need to be geared toward medical students, doctors and nurses. In an article of the *Wall Street Journal* (2004), it was reported that Aetna insurance company is one company that is sponsoring seminars on cultural competencies. These seminars are to help both physicians employed by the company, and those in their network to become more aware of the issues that may affect the care that their minority patients may be receiving. This is one example of how Corporate America is getting involved in this issue of health care and cultural sensitivity. In addition, providers may have fears or problems relating to African American patients or African American people in general and unknown to them, the patient may sense this difficulty. The need for cultural competence plays such a large part into how the provider and patient relate to each other. Evidence suggests that bias, prejudice, and stereotyping on the part of the health care provider may contribute to differences in care (Smedley, Stith, & Nelson, 2002)

### **Improving Access to Health Care**

Finally, it is the accessibility to health care that is so vital to establishing and maintaining quality health care for African Americans and other minority groups. Although universal coverage in the form of Medicaid for the poor, who are often times the minority groups, and Medicare for the elderly, makes it somewhat easier to seek and obtain effective health care services. The system has to be restructured to cover many concerns and services needed by these same minority groups. An infrastructure has to be developed to address the overwhelming needs and concerns of those who quite readily use their services most often; the poor, the underrepresented, and the minority. Appropriateness of research on African American groups needs to be evaluated. Research on minority groups should be based on their needs. New research studies such as genome research, in vitro fertilization and artificial insemination are not considered priorities for many of the underserved and minority patients who need and want basic health care, i.e. immunizations for their children, yearly mammograms, antibiotics for sickness, etc. Even if they wanted to pursue some of these options, many African Americans and other minority groups could not afford new technological medical procedures.

### **IMPLICATIONS FOR CHANGE**

It is the combination of both historical and modern day experiences that has created this mistrust of the health care system by not only African Americans, but by many minority groups as well. Gamble (1997) asserts that the history of the medical experimentation African Americans endured during slavery laid the foundation of distrust. Slaves were used in school dissection experiments and as autopsy specimens. As previously discussed, the most prestigious experience that has heralded this mistrust is the Tuskegee Syphilis Study of untreated syphilis in African American men. This study was conducted by the US Public Health Service from 1932 until 1972 and was the longest non-therapeutic study in medical history (Freimuth et al., 2001; White, 2000). The Bell Curve Study also reported the negativity of the conclusions found by the researchers which basically states that the intelligence of African Americans is inferior when compared to other groups. Although their conclusions drew much controversy, the authors insisted that their conclusions were based on sound, scientific fact (Herrnstein & Murray, 1994). There is also the discovery that during the 1920s and 1930's many state mental institutions conducted involuntary sterilization programs on their patients (Durso, 1997).

The legacy of mistrust by African Americans has a long-standing history and will not be shed over night. It is pertinent that more is done to correct the problem of mistrust of the health care system by African Americans. African Americans must be encouraged to pursue careers in the sciences to explain research to their communities and get minorities involved. The shortage of African American physicians and other health care providers partly explains why many blacks distrust the medical establishment.

The community has to be educated about promotion and prevention related to health and health care issues. Because of the continuing distrust of the health care system, African Americans will continue to experience increased disease complications, increased health costs, and poor health care management and outcomes. Those of us in health care must overcome the low social trust that has been salient to the legacy of Tuskegee and other studies. A larger voice has to be heard on Capital Hill to get these changes passed through Congress. The institution of health care must be re-directed so that more awareness by health care groups and the community can help mobilize and change these complex problems. Trust in the system has to be established and a concerted effort on the part of government, businesses, health care providers and the general community will play key roles into getting this accomplished. Reducing and abolishing race and culture based inequity in medical care is a moral obligation that has to be upheld at all cost.

### **CONCLUSION**

The re-establishment of trust in the health care system will not be an easy task. Just as there are many

reasons for the mistrust, there is no one answer that will solve all of the mistrust issues. We must enhance and make the attempt to gain a better foothold and common ground on which to regain African Americans trust in medical institutions and the health care system.

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