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A Legacy of Mistrust: African-Americans, the Medical Profession, and AIDS

by

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The fight against the AIDS epidemic has entered a new era with the advent of AZT (Zidovudine), the protease inhibitors (Crixivan, Invirase, Norvir, etc.), and the AIDS cocktail (a combination of AZT and a protease inhibitor). The success of these drugs has given new hope to those infected with the AIDS virus. While the mortality rate has begun to decrease overall, especially among the white, non-Hispanic population, as a result of these new, more effective drug therapies, the rate of decline among the African-American community has been much less significant. The Centers for Disease Control (CDC) reports that while AIDS is the third leading cause of death for American women aged 25 to 44, it is the leading cause of death for African-American women in the same age group. The infection rate of AIDS is following the same pattern. Between 1985 and 1995 there has been a steady decrease among the white, non-Hispanic population, but there has been an increase in AIDS cases in the minority population, especially among African-Americans. In February, 1997, the CDC released data showing that in 1996, for the first time, blacks had a higher proportion of newly diagnosed AIDS cases (41%) than whites (38%) nationwide. Black women are almost 15 times more likely than white women to test positive for Human Immunodeficiency Virus (HIV). The reasons for these trends in the African-American population are complex, ranging from socioeconomic factors to a lack of educational programs. However, culture also plays a major role in that there is a "legacy of mistrust" within the African-American community toward the medical profession and public health authorities. This mistrust encompasses both the area of health care delivery and medical research.

Many today attribute this mistrust to the events surrounding the Tuskegee Syphilis Study, which was sponsored by the United States Public Health Service from 1932 to 1972.[1] However, after careful research and analysis, it appears that this study is but a marker for a more serious problem, regarding racist attitudes and stereotypes, that has existed for centuries in the medical profession. Historian Allan Brandt argues that the medical professionals and researchers who directed and devised the Tuskegee Syphilis Study accepted the mainstream assumptions regarding blacks. "There can be little doubt that the Tuskegee researchers regarded their subjects as less than human. As a result, the ethical canons of experimenting on human subjects were completely disregarded."[2] The major impact of the Tuskegee story was that it authenticated a historically based pattern of medical mistreatment that has been well-known to the African-American community through their oral folklore tradition. This pattern shows that African-Americans were viewed as inherently inferior by the medical profession and public health agencies. This has led to the lingering suspicion that medical professionals are not out to help black people, but to use them as guinea pigs.[3] The influence of racism in the medical profession and a general disregard toward those who are poor and vulnerable by the federal government has contributed to the "legacy of mistrust" in the African-American community and has had far-reaching consequences.[4]

One consequence of this legacy is the widespread skepticism on the part of African-Americans concerning mainstream medical treatments and research studies regarding AIDS. Rumors about AIDS in the African-American community are rampant. Many believe that AIDS was deliberately created in a government laboratory in order to reduce the African-American population. Equal numbers look upon AZT and the AIDS cocktail as just another experiment designed to harm the most vulnerable, especially those in the African-American community. As a result, participation by African-Americans in clinical AIDS trials has been disproportionately small in comparison to the number of African-Americans who have been infected with HIV. A major concern of medical researchers regarding this lack of participation is that recent studies have shown that there is a strong possibility that African-Americans may respond differently to drugs being tested to fight AIDS.[5] Fear of treatment and lack of participation in drug trials has interfered with efforts to prevent the spread of AIDS and to treat effectively those with the AIDS virus.[6] Unless immediate measures are taken to overcome the suspicion and mistrust of African-Americans toward the medical establishment, the end result will not only be the continued spread of the AIDS epidemic, but also a steady increase in the mortality rate in the African-American community.

The purpose of this article is threefold: first, to trace the development of the "legacy of mistrust" that exists between the African-American community and the medical profession; second, to show the impact this historically based legacy is having on the prevention and treatment of AIDS within the African-American community; third, to offer some practical suggestions on ways to overcome this "legacy of mistrust" so that the African-American community and the medical establishment can work together more effectively to combat the spread of AIDS.

Historical Context for the Legacy of Mistrust

The oral folklore tradition is deeply rooted in the African-American heritage. For generations, a wide variety of negative stories have circulated within this community about the medical profession and public health programs. In 1972, when the tragedy of the Tuskegee Syphilis Study was revealed publicly, news spread rapidly throughout the African-American community. The truth was bad enough, but the problem was compounded as this information spread by word of mouth, and exaggerations and rumors intertwined with the truth. Today, in the African-American community, the Tuskegee story is a major part of childhood folklore passed down by family members for the purpose of preparing present and future generations to deal with the harsh realities of life. By contrast, in the white community, very few have heard of the Tuskegee Syphilis Study, and even fewer have been affected by it.

Those who study folklore make a distinction between rumor and legend. A rumor is "a specific proposition for belief, passed along from person to person, usually by word of mouth, without secure standards of evidence being present.[7] A legend "is a narrative account set in the recent past and containing traditional motifs that is told as true."[8] Since certain accounts incorporate modern motifs as well as traditional ones, most folklorists and social scientists now use the designation "contemporary legend" to describe "unsubstantiated narratives with traditional themes and modern motifs that circulate orally (and sometimes in print) in multiple versions and that are told as if they are true or at least plausible."[9] Drawing a clear distinction between rumor and contemporary legend is not always possible.[10] This paper will attempt to make this distinction and demonstrate the ways in which rumors and contemporary legends have impacted on the oral folklore tradition of the African-American community.

To accomplish this, Patricia Turner identifies two distinct and recurrent "motifs of danger" which have influenced the African-American community in its distrust of the medical profession and public health programs. The first is the conspiracy motif. The conspiracy motif suggests that there is an organized plot against African-Americans by the "powers that be" which threatens individual black bodies, and is then translated into animosity toward the whole race. Turner traces the history of this conspiracy theory from the European involvement in the slave trade of black Africans to the contemporary powers that be, which includes the Federal Bureau of Investigation (FBI), the Central Intelligence Agency (CIA), the Food and Drug Administration (FDA), the CDC, various branches of the armed services, commercial interests, and the medical and health establishments.[11] This motif dominates the historical period from the time of slavery in the United States to the late nineteenth century, but also has appeared in subtle ways during this century. The second "motif of danger" is the contamination motif, which dominates the twentieth century. This motif examines both medical and public health efforts and at times coincides with the themes of genocide and conspiracy. Turner uses contamination to refer to "any item in which the physical well-being of individual black bodies is being manipulated for racist reasons."[12] Examining these two motifs within an historical context will illustrate the reasons that suspicion and distrust of the medical profession and public health programs is not only reasonable for African-Americans, but also the basis for the resistance or refusal of African-Americans to participate in new clinical drug trials for AIDS and other AIDS treatments.

Throughout the centuries, medicine has never been considered a value-free discipline. It has reflected and reinforced the beliefs, values, and power dynamics of the society at large. As such, it has been influenced by issues of race and racism.[13] This is evidenced by the use of medical theories to justify slavery. Medically, it was believed that black people possessed peculiar physiological and anatomical features that justified their enslavement. These medical theories not only influenced societal attitudes that black people were inferior and inhuman, but justified the use of blacks for medical experimentation and dissection.[14] This is not to say that poor whites were not abused in the United States, but the point is that blacks were used more often and with greater disregard because of their race.

In the antebellum South, black bodies were used by medical schools for teaching purposes. As the ideas of the French school of hospital medicine reached the United States, the need for human specimens in medical schools became recognized.[15] In order to learn anatomy, to recognize and diagnose diseases, and to treat conditions requiring surgery, medical students needed to try out their ideas and new techniques. In addition, they had to perform autopsies to confirm their diagnoses and to understand the effects of disease on the human body.[16] The fierce competition among southern medical schools to recruit students, in the thirty years preceding the Civil War, placed additional pressure on each medical school to have an abundant supply of clinical materials.[17] This need for human specimens, both living and dead, was first met by placing various advertisements in local newspapers. The following ad appeared in *The Charleston Mercury* between 1837 and 1839 giving notice of the establishment of a special clinic for the treatment of blacks:

> Surgery of the Medical College of South Carolina, Queen St. -- The faculty inform their professional brethren, and the public that they have established a Surgery, at the Old College, Queen street, *For The Treatment Of Negroes,* which will continue in operation during the session of the College, say from first November, to the fifteenth of March ensuing. The object of the faculty, in opening this Surgery, is to collect as many interesting cases, as possible, for the benefit and instruction of their pupils - at the same time they indulge the hope, that it may not only prove an accommodation, but also a matter of economy to the public. They would respectfully

> call the attention of planters living in the vicinity of the city, to this subject; particularly such as may have servants laboring under Surgical diseases. Such persons of color as may not be able to pay for Medical advice, will be attended to gratis, at stated hours, as often as may be necessary. The Faculty takes this opportunity of soliciting the co-operation of such of their professional brethren, as are favorable to their objects.[18]

The result of these advertisements led both blacks and poor whites to fear mistreatment in southern hospitals. Either unnecessary experiments would be performed on them or they would be allowed to die so autopsies could be conducted. Evidence proves this fear was not imagined but real.

In the post-reconstruction period, the absence of anatomical laws providing for the legal acquisition of human bodies, led the American medical profession to resort to illegal means of procuring cadavers. Bodies were illegally obtained by exhumation from graveyards, by purchase or theft of cadavers before internment, and by murder. Of the three methods, grave robbing was the most popular.[19] During this period, the term "night doctor" became well known, especially in the black community. "The term 'night doctor' (derived from the fact that victims were sought only at night) applies to both students of medicine, who supposedly stole cadavers from which to learn about body processes, and professional thieves, who sold stolen bodies - living and dead - to physicians for medical research."[20] The appearance of "night doctors" coincides with the post-Reconstruction period when blacks were migrating to industrial centers. This migration lasted from about 1880 to the end of the First World War.[21] Folklorist Gladys-Marie Fry contends that, "many blacks are convinced that Southern landowners fostered a fear of 'night doctors' in the post-Reconstruction period in order to discourage the migration of blacks from rural farming areas to Northern and Southern urban centers."[22] Fostering a fear of night doctors to discourage black migration appears to be historically well-founded. However, there is also evidence proving that night doctors did play a major role in the procurement of black bodies for medical purposes.

The oral folklore tradition of African-Americans concerning night doctors is widespread and testifies to the influence they had on blacks living in the United States at that time. Stories of the "night doctors" are still told within the African-American community and it appears from historical research that many may be true. During this period of time, it is estimated that about 5,000 cadavers were dissected each year in the United States and that at least a majority were procured illegally.[23] Historian David Humphrey found that "in 1893, a decade after Maryland passed an anatomy act, legal channels supplied only 49 cadavers for the 1,200 students at Baltimore's seven medical schools. State laws faltered also because the illicit traffic in cadavers was a far-flung, interstate business. Southern body snatchers, for instance, regularly shipped the bodies of Southern blacks to Northern medical schools. For several years during the 1880's and 1890's a professor of anatomy at one New England medical college received a shipment of twelve Southern blacks each academic session, while the bodies of blacks filched in Tennessee furnished the entire supply of anatomical material for another northern medical school in 1911."[24] By the 1920's, passage of anatomy acts eliminated body snatching in most parts of the United States, but it did not substantially alter the social origins of the supply of cadavers for medical schools.[25]

The oral folklore tradition of night doctors and the unethical practice of medical schools in obtaining cadavers for autopsies and bodies for experimentation not only fostered a fear of the medical profession among African-Americans that has been handed down through the centuries, but also reinforced societal attitudes toward racism. From 1619 until the early 1900's, it appears that the "powers that be" in the United States were involved in a form of conspiracy against African-Americans, both individually and corporately, African-Americans were degraded, threatened, and physically and emotionally abused by many in the medical profession. As a result, many African-Americans today, aware of what occurred in previous times through oral folklore, have an innate mistrust of the medical profession. With the advent of the twentieth century, the influence of racism on the attitudes and values of medical professionals did not end, but became more subtle. The motif of conspiracy was replaced, for the most part, by the motif of contamination.

In the late nineteenth and early twentieth centuries many of the medical and public health journals focused on the problem of syphilis among African-Americans.[26] Racist assumptions and stereotypes still existed within the medical profession. Blacks were viewed as inferior and this continued to justify using black bodies in ways that white bodies would never be used. The predominately white medical establishment maintained that, "intrinsic racial characteristics such as excessive sexual desire, immorality, and overindulgence caused black people to have high rates of syphilis...Physicians also pointed to alleged anatomical differences - large penises and small brains - to explain disease rates."[27] These racist assumptions became the basis for the initiation of the Tuskegee Study of Untreated Syphilis in the Negro Male.

In 1932 the United States Public Health Service initiated a study on African-American men with syphilis in Macon County, Alabama, to determine the natural course of untreated, latent syphilis in black males. The study comprised 399 syphilitic men as well as 201 uninfected men who served as the control group. These subjects were recruited from churches and clinics throughout Macon County and were led to believe they would receive free meals, "special free treatment" for what was called "bad blood", and burial insurance. In reality, they were enrolled in this study without their informed consent. These men were deceived in that the infected were never told that they had syphilis, which was known to cause mental illness and death. In fact, the infected were never treated for the disease. To determine the natural course of syphilis, the researchers withheld the standard treatment of mercury and arsenic compounds from the subjects. In 1947 when penicillin was determined to be an effective treatment for syphilis, this too was withheld. The treatment these men actively received came in the form of placebos.

The Tuskegee Syphilis Study was not a covert medical research study. It was widely known in medical circles. As late as 1969, a committee at the federally operated CDC examined the study and agreed to allow it to continue. Not until 1972, when the first accounts of this study appeared in the press, did the Department of Health, Education, and Welfare (HEW) terminate the experiment. At that time, seventy-four of the test subjects were still alive; at least twenty-eight, but perhaps more than one hundred, had died directly from advanced syphilitic lesions.[28] For many in the African-American community this study is just another example of how the medical profession and the federal government used various forms of contamination as genocide.

Stories about the motif of contamination, as a form of genocide, continued to spread in the African-American community throughout the twentieth century. There are many in the African-American community who believe that condom distribution was part of a government plan to reduce the number of black births.[29] This belief became more credible when Norplant came on the market.[30] Following the legalization of Norplant as a contraceptive device, stories began to circulate that African-American women in the inner city who were on welfare were being forced to use this contraceptive device. These stories intensified when various editorial writers and public policy makers began to suggest that "welfare mothers" be required to have the device implanted as a condition for further benefits.[31] Additional regulations on fertility such as the sterilization statutes in many states in the 1970's also supported this notion of genocide in the African-American Community. One of the most interesting findings has to do with how the race of a patient has a direct correlation to the availability of certain medical procedures. Various medical studies have shown that certain procedures, such as renal transplants, hip or knee replacements, and gastrointestinal endoscopy, are less likely to be performed on blacks. However, blacks are more likely to undergo other procedures such as hysterectomies, bilateral orchiectomies, and the amputation of lower limbs.[32] Is this a subtle form of sterilization? This information, coming from reputable medical journals, has only increased African-American cynicism toward the medical profession.

Genetic screening and public immunization programs have also raised suspicions in the African-American community. The sickle cell anemia screening programs of the 1970's created misinformation, confusion and fear. Inadequate planning and preparation on the part of the medical profession and public health officials, and a failure to educate the American people on the difference between being a carrier versus having the disease, resulted in unnecessary stigma and discrimination. The result of this confusion and misinformation was that great suspicion arose in the African-American community that this was another form of genocide.[33] Public immunization campaigns have also raised various concerns around the issue of contamination as a form of genocide. The most common basis for concern has been the fear that certain drugs may be experimental and thus potentially toxic. Inoculations have been suspected of being vehicles for the introduction of experimental substances or infectious agents into the African-American communities. Even today, health fairs and "immunization days", sponsored by community-based clinics, raise concerns among African-American parents. This fear of immunization, as a possible form of genocide, has been advanced by the circulation of various books found in the African-American community. One such book, *Vaccines are Dangerous: A Warning to the Black Community*, published in 1991, decries the practice of vaccination as an obvious violation of hygiene, "purposely injecting loathsome filth from a diseased animal directly into the crystal-clear bloodstreams of our precious children."[34] As a result of such material, diagnostic tuberculosis (TB) skin testing has often been refused, because it involves injecting tuberculin material directly under the skin. The fear is that testing positive may suggest that the patient was given TB, rather than that the current or historical presence of TB in the body is being detected.[35] This widespread misinformation has greatly contributed to the "legacy of mistrust" in the African-American community.

Finally, the contamination motif has been associated with the AIDS epidemic. There are many who believe that AIDS was conceived as a deliberate plot to exterminate African-Americans.[36] In a 1990 survey conducted by the Southern Christian Leadership Conference, 35% of the 1, 056 black church members who responded believed that AIDS was a form of genocide.[37] A consistent rumor found in the African-American community is that the AIDS virus was created in the CIA laboratory. As a result, the contamination motif commonly emerges in one of two ways: The AIDS virus is characterized as either (1) the aftermath of a biological warfare experiment that was tried out on Africans and Haitians or (2) the intentional use of biological warfare intended to diminish the African or Haitian population.[38]

The most convincing argument that AIDS was created for genocidal purposes is the long incubation period for the disease. Turner writes, "If one were going to design a disease for genocidal purposes, it would certainly be convenient if it were capable of residing dormant in the body for a while. Ultimately it would kill its host, but in the meantime he or she will be unknowingly spreading it, with the conspirators escaping detection."[39] Where many in the white community see this as paranoia and hypersensitivity, many in the African-American community see it as just another example of the influence of racism in the medical profession. Even though safeguards and reforms in research standards have been established as a result of the Tuskegee Syphilis Study, the legacy of Tuskegee lives on. This has been reinforced "as many white Americans expressed attitudes about AIDS victims that were remarkably similar to the beliefs most white Americans shared about syphilitic blacks earlier in the century."[40] The end result has been devastating in regard to the fight against AIDS in the African-American community.

As AIDS continues to spread among African-Americans and the hope for a cure remains illusive, the conspiracy and contamination motifs that have been part of African-American folklore will also continue to circulate.[41] This will only interfere with efforts to prevent and treat the AIDS virus in the African-American community. Glenn Brown encountered this in his work as the outreach coordinator of Philadelphia FIGHT, a nonprofit organization that conducts research on AIDS and potential treatments. Brown states, "I've come in contact with tons of people who are not interested in treatment at all and boast of the fact that they have never taken any of the 'cocktail' drugs or AZT. There is so much mistrust. A lot of people don't even know exactly what Tuskegee was, but it has become mythological. They know it was against black people, and it was bad."[42] In an attempt to quantify the attitudes of blacks and whites regarding avoidance of medical treatment because of distrust, a recent national survey was commissioned by Dr. Stephen Thomas, director of the Institute of Minority Health Research at Emory University. In this survey 1,000 people were polled at random in two groups - 500 in black households and 500 in general population households, of which 84% were white. Thomas reports that, "of the group of black respondents, 36% believed they were very likely to be used as guinea pigs without their consent."[43] This apprehension has significantly contributed to the low enrollment rate among African-Americans in clinical AIDS trials. This concern has been heightened recently by numerous medical studies showing variability in physiologic functions relevant to the drug efficacy between persons of different racial backgrounds.[44]

The results of a study released by the Durham Veterans Affairs Medical Center, "call for an end to the assumption that drugs will work the same in all populations. Race and sex need to be prospectively studied, targeting a sufficient number of patients for adequate power."[45] This now confirms that African-American participation in AIDS drug trials has become a necessity. However, to complicate this issue, there is new data showing that African-Americans have been purposefully under-represented in clinical trials, even when the conditions under investigation (Such as hypertension) disproportionately affect them.[46] Put simply by one physician, "we're battling centuries of mistrust based on historical actions of the very institutions involved."[47] Subtle racist attitudes and stereotypes, such as noncompliance, have been given as reasons why African-Americans have been excluded from some medical research projects. Other reasons are that "in the past most clinical researchers have used white men as a standard or norm from which to extrapolate data to the rest of the population. Young white men were presumed to be a homogeneous population that had fewer confounding factors.[48] Medical research has shown that these reasons no longer hold true.

Today, even though federal guidelines call for the inclusion of minority groups and women in research studies, participation by these groups is limited because of the events of the past, especially the shadow cast by Tuskegee.[49] Drastic changes are needed both in the attitudes and practices of medical professionals and researchers and in the attitudes that exist in the African-American community if the fight against AIDS is to succeed. The fundamental question is how do we bring about these changes?

Practical Solutions

The positive impact of President Clinton's apology to the survivors of the Tuskegee Syphilis Study on May 16, 1997 cannot be understated. But it also should not be overstated. By admitting that the United States government "orchestrated a study so clearly racist," the President brought the issue of racism in this nation out of the darkness and into the light.[50] Building upon this initiative, the President has established a Presidential Advisory Board on Race and is even considering extending a national apology to African-Americans for slavery. The problem is that while apologizing may be cathartic for the national soul, there is still much that must be done on the practical level to overcome the legacy of Tuskegee. Dr. Bill Jenkins, who in 1969, while a statistician with the National Center for Health Statistics in Washington, D.C., was one of several people who tried uunsuccessfully to end the Tuskegee Syphilis Study, believes the apology of President

Clinton should not be an end but a beginning. "There's a tendency to believe that African-Americans are reluctant to participate in research because of this one study and I think that belittles the concerns of African-Americans. They are concerned about public health research because they're alienated from American society in any number of ways and this study is the bellwether. It's much bigger than just this study and we're going to have to do a lot more work than just apologize for this."[51] To address this concern of racial polarization, immediate practical changes must occur both within the medical profession and from within the African-American community.

The medical profession must admit that racial disparity in the American health care system has substantially influenced the health status, access to health care, and scope and quality of health care for African-Americans.[52] Then, they must send a clear signal to the African-American community that they are committed to overcoming this disparity by eliminating racial intolerance and inequality in the health care system. Corporately, this can accomplished by making the routine and ongoing examination of racial disparities in the use of services and in the choices of diagnostic and therapeutic alternatives part of the quality assurance protocols of every hospital, every health maintenance organization, and every other system of care.[53] This will help eliminate racial disparity institutionally. Individually, health care professionals and medical researchers need to be made aware of how social attitudes and values affect professional behavior. This can be done by making racial and ethnic sensitivity part of every health care professional's training. In a 1994 survey of United States medical schools, only 13 of 78 responding institutions offered cultural sensitivity courses designed to improve understanding of diverse ethnic groups, and all but one of those courses was elective.[54] Patricia Turner suggests that folklore materials be considered in conjunction with more traditional sources.[55] Unless medical and research professionals are conscious of racial and ethnic differences and are made aware of how certain races and ethnic groups perceive the medical profession and themselves, race may continue to influence medical decision-making in ways that these professionals do not even recognize.

The prevailing attitudes of medical and research professionals concerning race, sex, and economic status need to be examined and reevaluated. A close examination of the Tuskegee Syphilis Study "reveals the persistence of beliefs within the medical profession about the nature of blacks, sex, and disease - beliefs that had tragic repercussions long after their alleged 'scientific' bases were known to be incorrect."[56] It is true that much has changed in the medical profession since 1972, but societal values and attitudes that affect medical and research professionals have been more resistant to change. Medical and research professionals cannot dismiss the "legacy of mistrust" that exists within the African-American community. This mistrust must be confronted directly. This can be accomplished by listening to community fears and suspicions, confronting these concerns directly, and by admitting past mistakes. In addition, they must explain the purposes, procedures, and goals of various medical treatments and research studies in ways that are understandable to all. This should include more information about individuals' roles in experimental treatments and research and how this will benefit them and society in general.[57] However, the establishment of trust with the African-American community cannot be accomplished without actively soliciting cooperation from the leaders in the African-American community. Long-term cooperation between these two groups is essential in overcoming this "legacy of mistrust". Failure to cooperate will result in dire consequences regarding the AIDS epidemic, especially in the African-American community.

The African-American community also has a responsibility to address this "legacy of mistrust" before it is too late. The AIDS mortality rate has decreased 28% for whites and only 10% for blacks, according to statistics released by the CDC in 1996. The major reason for this gap is that many in the African-American community refuse to take the AIDS cocktail and other drug-related therapies. Many medical professionals believe that those statistics do not reflect the impact of the protease inhibitors on the fight against the AIDS virus. When the impact of the protease inhibitors is known, the gap between black and white mortality rates will grow even wider. Until community leaders address the many rumors and myths surrounding AIDS, the spread of AIDS will continue and more deaths will result. This is not to say that what has happened in the past should be ignored or forgotten. The African-American community cannot close its eyes to what the Tuskegee Syphilis Study exposed. Instead, it should be used as a tool to begin an honest dialogue with the community about AIDS and other related health issues.

Kevin Pleasant, community education coordinator with Philadelphia FIGHT, believes that the African-American community must see Tuskegee "for what it was, deal with it, and then move beyond it before it is too late."[58] This can be accomplished by the initiation of public fora and education programs, where community leaders and medical professionals work together to dispel the myths surrounding AIDS.[59] Such a coordinated effort to show the positive effects of the AIDS cocktail and other drug therapies would do much to dispel unsubstantiated rumors. Having AIDS patients, of all races, come forward and speak openly about the successes and limitations of the various drug therapies would be a major step in overcoming fears and suspicions. Mistrust will only be eliminated by open and honest discussions. For this to happen, there needs to be strong and forceful leadership from within the African-American community. Qualities of initiative, creativity, integrity and openness are a necessity. Unfortunately, the leadership within the African-American community appears to be segmented due to internal strife. Differences must be put aside for the good of the whole. Only strong leadership, a willingness to cooperate, and honest dialogue will foster community trust. The problem is that time is of the essence. The latest clinical results concerning the success of the AIDS cocktail have been very promising. New drug therapies for AIDS are being developed and approved rapidly. Hope has begun to replace a sense of despair for those suffering from AIDS. Yet many within the African-American community still resist the latest medical advances. Now is the time to put aside differences, to address racial attitudes and stereotypes directly, and to establish a dialogue based on trust between the medical establishment and the African-American community. Now is also the time for individuals within the African-American community to overcome personal cynicism and bias and take responsibility for their own health and well-being, because AIDS is a matter of life and death.

As of June, 1996, more than 540,000 Americans were diagnosed with AIDS and more than 330,000 had died.[60] However, the CDC estimates there are from 600,000 to 900,000 people in the United States infected with AIDS. Deaths attributed to AIDS in the United States have dropped by 19%. Overall this is very encouraging; however, the rate is far less in the African-American community due to the suspicion surrounding these newer drug therapies. As this article has shown, many attribute this mistrust to the Tuskegee Syphilis Study, which revealed "more about the pathology of racism than it did about the pathology of syphilis; more about the nature of scientific inquiry than the nature of the disease process."[61] However, after placing the Tuskegee Syphilis Study within its historical context, one can see that the roots of racism, within the medical establishment and within the United States as a whole, are deep-seated and far-reaching. The problem is that this "legacy of mistrust" is having a detrimental effect on stopping the spread of AIDS and is placing a heavy burden on the health care system in the United States. Dr. Victoria Sharp, of St. Luke's Roosevelt Hospital in Manhattan, believes that "the new drug therapies are allowing many more AIDS patients to stay out of the hospital and saving insurers $190 million a year.[62] Unless something is done quickly to address this mistrust, many more lives will be lost unnecessarily and a more severe burden will be placed on our health delivery system. This is an issue which now affects all Americans, because it is directly affecting our limited medical resources. Leadership, integrity, and sincerity are the only cures for the disease of mistrust. If racism, inequality, and prejudice can be addressed honestly, then fear, suspicion, and mistrust can be eliminated. President Clinton took the first step by apologizing to the victims of Tuskegee. The next step must be taken by the medical profession and the leaders of the African-American community together. This next step may seem like an insignificant one to many. But within the African-American community, it is a leap that has the potential for saving thousands of lives.

References

1. The Tuskegee Syphilis Study will be discussed in more depth later in this paper. For a more detailed analysis of the Tuskegee Syphilis Study, see James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment - A Tragedy of Race and Medicine* (New York: The Free Press, 1981).

2. Allan Brandt, "Racism and Research: The Case of the Tuskegee Syphilis Study", *Hastings Center Report* 8 (December 1978): 23, 27.

3. Angie Cannon, "Officials Hope Apology for Tuskegee Study is a Healing Step", *The Philadelphia Inquirer,* 16 May 1997, A-1.

4. Other examples of the general disregard of the federal government toward those who are poor and vulnerable have come to light recently. First, from 1963 to 1971, at Oregon State Prison and at Washington State Prison, prisoners' testicles were irradiated to learn what doses made them sterile. Second, from 1946 to 1956, mentally handicapped children at the Walter E. Fernald State School in Waltham, Massachusetts were told that they were joining the "science club" and were given radioactive material in their cereals. Third, from 1945 to 1947, 820 pregnant women were given small doses of radioactive iron at Vanderbilt University. Finally, during the 1960's and 1970's, subjects at the University of Cincinnati and three other universities were exposed to radiation over their entire bodies to measure the effects. For a more detailed analysis see Matthew L. Wald, "Rule Adopted to Prohibit Secret Tests on Humans", *The New York Times*, 29 March 1997, A-1, 4; see also Ruth Faden, "The Advisory Committee on Human Radiation Experiments: Reflections on a Presidential Commission", *Hastings Center Report* 26 (September-October 1996): 5-10.

5. Patricia A. King, "The Dangers of Difference", *Hastings Center Report* 22(November-December 1992): 36; see also Wafaa El-Sadr and Linnea Capps, "The Challenge of Minority Recruitment in Clinical Trials for AIDS", *Journal of the American Medical Association* 267 (1992): 954-957.

6. There are some within the African-American community who believe that this "legacy of mistrust" is also why many African-Americans are less willing to donate blood and blood products, are less likely to donate organs, and have a fear of their children being vaccinated.

7. Gordon W. Allport & Leo Postman, *The Psychology of Rumor* (New York: Henry Holt, 1947), ix.

8. Patricia A. turner, *I Heard It Through the Grapevine: Rumor in African-American Culture*, (Berkeley, CA: University of California Press, 1993), 4.

9. Ibid., 5.

10. Allport and Postman make a case that legends are often little more than solidified rumors. See Allport and Postman, 167.

11. Ibid., xv and 108.

12. Ibid., 138.

13. Vanessa Gamble, "A Legacy of Distrust: African-Americans and Medical Research", *American Journal of Preventative Medicine* 9 (1993): 35.

14. Ibid. Physicians during the time of slavery theorized that Africans had thicker skins, which allowed them to tolerate better the rays of the sun. They also observed, in this case accurately, that black people seemed to be less susceptible than white people to some diseases, such as yellow fever and malaria. In 1839 abolitionist Theodore Dwight Weld asserted, " 'Public opinion' would tolerate surgical experiments, operations, processes, performed upon [slaves], which it would execrate if performed upon their masters or other whites." Two antebellum experiments carried out in Georgia and Alabama confirm Weld's charge. In the first test, physician Dr. Thomas Hamilton conducted a series of brutal experiments on a slave to test remedies for heatstroke. The subject was loaned to Hamilton as repayment for the owner's debt. The subject was forced to strip and sit on a stool on a platform placed in a pit that had been heated to a high temperature. Only his head was above ground. Over a period of two or three weeks, the man was placed in the pit five or six times and given different medications to determine which enabled him best to withstand the heat. Each ordeal ended when the subject fainted and had to be revived. The whole purpose of the experiment was to make it possible for masters to force slaves to work still longer hours on the hottest of days. In the second experiment, Dr. J. Marion Sims, the so-called father of modern gynecology, used three Alabama slave women to develop an operation to repair vesicovaginal fistulas. Between 1845 and 1849, the three slave women on whom Sims operated each underwent up to thirty painful operations. The physician himself described the agony associated with some of the experiments. Sims finally did perfect his technique and ultimately repaired the fistulas. Only after his experimentation with the slave women proved successful did the physician attempt the procedure on white women volunteers. The slave women were forced to submit because the state considered them property and denied them the legal right to refuse to participate. For a more detailed analysis, see Ibid., 35-36. See also, T.D. Weld, *American Slavery As It Is: Testimony of a Thousand Witnesses* (New York, 1939); F.N. Boone, *Dr. Thomas Hamilton: Two Views of a Gentleman of the Old South* (Phylon, 1967); and J.M. Sims, *The Story of My Life* (New York: Appleton, 1889).

15. For a more detailed analysis of the influence of the Paris school on American medicine, see Edwin Ackerknecht, *Medicine at the Paris Hospital, 1794-1848* (Baltimore, MD, 1967); Richard Shryock, *The Development of Modern Medicine: An Interpretation of the Social and Scientific Factors Involved* (New York, 1947); Michel Foucault, *The Birth of the Clinic: An Archeology of Medical Perception* (New York, 1973); and Gerald Grob, *Edward Garvis and the Medical World of Nineteenth-Century America* (Knoxville, TN, 1978).

16. Todd Savitt, "The Use of Blacks for Medical Experimentation and Demonstration in the Old South", *The Journal of Southern History* 48 (1982): 332-333.

17. Ibid., 333.

18. Gladys-Marie Fry, *Night Riders in Black Folk History*)Athens, GA: University of Georgia Press, 1991), 174-175. Emphasis in the original. Another advertisement appearing in *The Charleston Mercury* gives supporting evidence that Charleston many have been a busy center for traffic in slave bodies. In this advertisement, Dr. T. Stillman, in the interest of improved medical techniques, decided to operate his own infirmary stocked with slaves having interesting and unusual diseases. The advertisement states: "To Planters and Others - Wanted fifty negroes. Any person having sick negroes, considered incurable by their respective physicians, and wishing to dispose of them, Dr. S. will pay cash for negroes affected with scrofula or king's evil, confirmed hypocondriasm, apoplexy, diseases of the liver, kidneys, spleen, stomach and intestines, bladder and its appendages, diarrhea, dysentery, etc. The highest price will be paid on application as above." Ibid.

19. Ibid., 176. See also Allan Guttmacher, "Bootlegging Bodies", *Society of Medical History of Chicago* 4 (January 1935): 353-402.

20. Ibid., 171. According to Fry, "night doctors" were also known to blacks as "student doctors" (referring specifically to apprentice physicians), "Ku Klux doctors", "night witches", and "night riders". The apparel of these "night doctors" ranged from white robes or suits, black robes or suits, to plain clothes. The kinds of victims sought fit into two distinct categories. First, the "night doctors" preyed on the helpless because they offered less resistance to capture. These included the aged, infirmed, drunk, and physically disabled. The second category consisted of those who had special medical problems, such as those who were deformed, excessively fat, or of some unusual height. There were also two methods of ensnarement. First, operating in pairs, the "night doctors" would capture people walking alone late at night. Or, they would lure people into especially designed street traps, from which no one emerged alive. The oral folklore tradition among the African-Americans contends that people who were captured by the "night doctors" were taken directly to hospitals, laboratories, or medical schools where their bodies were used for experimentation or dissection. Ibid., 188-199.

21. For a more detailed analysis of the black migration to industrial centers, see "The Negro Migration of 1916-1918", *Journal of Negro History* 6 (January 1921): 383-498.

22. Fry, 171. Fry confirms this belief in a conversation with an informant named Fred Jackson on March 26, 1964. Mr. Jackson states: "The people that owned the farm in those days, why actually they would dress like that [as night doctors] to keep the fellows that worked in the farm and lived there, you know, and they would practically live there all of their life. And to keep them from leaving, they would dress like that to frighten them, to keep them from going away, leaving the farm going to the city." Ibid.

23. David C. Humphrey, "Dissection and Discrimination: The Social Origins of Cadavers in America, 1760-1915", *Bulletin of the New York Academy of Medicine* 44 (1970): 822. Humphrey also cites T.S. Sozinsky, "Grave-robbing and Dissection", *Penn Monthly* 10 (1879): 216.

24. Ibid., 823-824. See also F.C. Waite, "Grave Robbing in New England", *Bulletin of the Medical Library Association* 33 (1945): 283-284; L.F. Edwards, "Dr. Frederick C. Waite's Correspondence With Reference to Grave Robbing, Part II", *Ohio State Medical Journal* 54 (1958): 602.

25. Humphrey, 824. Humphrey further states: "A 1913 survey of 55 medical schools revealed that a 'large majority' relied on almshouses as the 'sole or main' source for their cadavers, while several schools depended chiefly on hospitals treating victims of tuberculosis, a disease that ravaged blacks and poor whites and killed more than 150,000 people annually at the turn of the century." Ibid. see also, Bureau of Census, "Tuberculosis in the United States", (Washington, D.C.: Government Printing Office, 1908): 18-19, 60.

26. Gamble, 36.

27. Ibid., Gamble supports her position with two examples. First, Dr. Thomas W. Murrell noted in 1910, "Morality among these people is almost a joke and only assumed as a matter of convenience or when there is a lack of desire and opportunity for indulgence, and venereal diseases are well-nigh universal." Second, Dr. H.H. Hazen echoes this sentiment: "The negro springs from a southern race, and as such his sexual appetite is strong; all of his environments stimulate this appetite, and as a general rule his emotional type of religion certainly does not decrease it." Ibid. See also, T.W. Murrell, "Syphilis and the American Negro", *Journal of the American Medical Association* 54 (1910): 847 and H.H. Hazen, "Syphilis in the American Negro", *Journal of the American Medical Association* 63 (1914): 463.

28. In August, 1972, HEW appointed an investigatory panel which issued a report the following year. The panel found the study to have been "ethically unjustified" and argued that penicillin should have been provided. See Brandt, 21; and Ad Hoc Advisory Panel, Department of Health, Education, and Welfare. "Final report of the Tuskegee Syphilis Study", (Washington, D.C.: Government Printing Office, 1973). For a more detailed analysis of the Tuskegee Syphilis Study, see Jones, *Bad Blood: The Tuskegee Syphilis Experiment - A Tragedy of Race and Medicine;* Arthur Caplan, "When Evil Intrudes", *Hastings Center Report* 22 (November-December 1992): 29-32; Harold Edgar, "Outside the Community", *Hastings Center Report* 22 (November-December 1992): 32-35; Patricia A. King, "The Dangers of Difference", *Hastings Center Report* 22 (November-December 1992): 35-38; and James H. Jones, "The Tuskegee Legacy: AIDS and the Black Community", *Hastings Center Report* 22 (November-December 1992): 38-40.

29. For a more detailed analysis of the impact of birth control on the African-American community, see R. G. Weisbord, "Birth Control and the Black American: A Matter of Genocide?", *Demography* 10 (1973): 571-590.

30. Norplant is the trade name for a birth control product consisting of six thin capsules that, upon being implanted in a woman's arm, release an ovulation-inhibiting hormone. Turner, 221.

31. Ibid., 222. See also, "One Well-Read Editorial", *Newsweek*, 31 December 1990, 65-66; and "Poverty and Norplant", *Philadelphia Inquirer,* 12 December 1990, A-18.

32. For a more detailed analysis of the effects of race on medical care see, H. Jack Geiger, M.D., "Race and Health Care - An American Dilemma", *The New England Journal of Medicine* 335 (1996): 815-816; and M.E. Gornick, P.W. Eggers, T.W. Reilly, et al., "Effects of Race and Income on Mortality and Use of Services Among Medicare Beneficiaries", *New England Journal of Medicine* 335 (1996): 791-799.

33. For a more detailed analysis, see D.Y. Wilkenson, "For Whose Benefit? Politics and Sickle Cell", *The Black Scholar* 5 (1974): 26-31; King, 37.

34. Bonnie O'Connor, "Foundations of African-American Mistrust of the Medical Establishment", (unpublished manuscript), Allegheny University Medical School, Philadelphia, PA, 10. See also, Curtis Cost, *Vaccines are Dangerous: A Warning to the Black Community* (Brooklyn, New York; A&B Books, 1991), 5.

35. O'Connor, 11.

36. A national survey, conducted by the Roper Starch Worldwide polling company, found that out of 500 blacks, 18% said they believed AIDS was a man-made virus; 9% in the general population agreed. When asked more specifically whether HIV and AIDS were part of a plot to kill blacks, 9% of the all-black group said it was definitely true; compared to 1% in the general group. See Lynda Richardson, "An Old Experiment's Legacy: Distrust of AIDS Treatment", *The New York Times* 21 April 1997, A-9.

37. Gamble, 37. See also, S.B. Thomas and S.C. Quinn, "The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk education Programs in the Black Community", *American Journal of Public Health* 81 (1991): 1499. In addition, a *New York Times*/WCBS news poll conducted in 1990 found that 10% of all black Americans thought the AIDS virus was "deliberately created in a laboratory in order to infect black people," and 20% believed it could be true. *The New York Times,* 12 May 1992.

38. Turner, 158.

39. Ibid., 160-161.

40. Jones, "The Tuskegee Legacy," 38.

41. It should be noted that the legacy of the Tuskegee Study and the conspiracy and contamination motifs have had an impact on other areas affecting the African-American community. Various needle exchange programs have been seen as a way to foment drug use among African-Americans. For a more detailed analysis, see D.L. Kirp and R. Bayer, "Needles and Race", *Atlantic* 38 (July 1993): 38-42. The conspiracy and contamination motifs have also been supported by the illegal drug trade. Rumors abound in the African-American community that illegal drugs, especially crack, are part of a systematic genocidal conspiracy to eliminate African-Americans. See Turner, 181-201.

42. Canon, A-1.

43. Dr. Stephen B. Thomas, interview by Peter A. Clark, S.J., 23 July 1997, phone interview, Director of the Institute of Minority Health Research at Emory University's Rollins School of Public Health, Atlanta, GA. It should be noted that the margin of sampling error was plus or minus 4%. See also, Richardson, A-9. For further statistics regarding why African-Americans are less interested in participating in health promotion and research because of the Tuskegee Syphilis Study, see Bernard Green, et al., "Participation in Health Education, Health Promotion, and Health Research by African-Americans: Effects of the Tuskegee Syphilis Experiment", *Journal of Health Education* 28 (July-August 1997): 196-201.

44. For a more detailed analysis of ethnic differences in drug testing, see Paul Cotton, "Examples Abound of Gaps in Medical Knowledge Because of Groups Excluded From Scientific Study", *Journal of the American Medical Association* 263 (1990): 1051; Mark D. Smith, "Zidovudine: Does It Work for Everyone?" *JAMA* 266 (1991): 2751; and W. Kalow, H.W. Goedde, and D.P. Agarwal, eds., *Ethnic Differences in Reactions to Drugs and Xenobiotics* (New York, NY: Alan Liss, Inc., 1986).

45. Paul Cotton, "Race Joins Host of Unanswered Questions on Early HIV Therapy", *Journal of the American Medical Association* 265 (1991): 1065. There is also increasing recognition of evidence of heightened resistance or vulnerability to disease along racial lines. See James E. Bowman and Robert Murray, Jr., *Genetic Variation and Disorders in People of African Origin* (Baltimore, MD: Johns Hopkins University Press, 1981); and Warren Leary, "Uneasy Doctors Add Race-Consciousness to Diagnostic Tools", *The New York Times,* 15 September 1990.

46. For a more detailed analysis, see C.K. Svensson, "Representation of American Blacks in Clinical Trials of New Drugs", *Journal of the American Medical Association* 261 (1989): 263-265.

47. Cotton, "Is There Still Too Much Extrapolation From Data on Middle-Aged White Men?", *Journal of the American Medical Association* 63 (1990): 1050.

48. Gamble, 37.

49. It should be noted that a recent HBO special about the Tuskegee Syphilis Study entitled "Miss Evers' Boys" has increased awareness about the Tuskegee story and has deepened the distrust the African-American community has for the medical establishment.

50. Alison Mitchell, "Survivors of Tuskegee Study Get Apology From Clinton", *The New York Tim*es 17 May 1997, B-10.

51. Carol K. Yoon, "Families Emerge as Silent Victims of Tuskegee Syphilis Experiment", *The New York Times*, 12 May 1997, B-8.

52. V. Navarro, "Race or Class Versus Race and Class: Mortality Differentials in the United States", *Lancet* 336 (1990): 1238-1240. Recent studies have shown that African-Americans have been treated poorly when treated for a problem, having to wait longer for treatments, spend less time with the doctor, and are not treated as aggressively as their white counterparts. See, D.R. Williams, R. Lavizzo-Mourey, & R.C. Warren, "The Concept of Race and Health Status in America", *Public Health Reports* 109 (1994): 26-41. It is interesting to note that a 1995 report by the Board of Trustees of the American Medical Association found that a search of the literature on racial and ethnic disparities in health care, covering only the 10-year period 1984 to 1994 and restricted to articles, commentaries, and letters in the *New England Journal of Medicine* and the *Journal of the American Medical Association* filled 66 single-spaced pages. See, Board of Trustees Report 50-I-95 (Chicago, IL: American Medical Association, November 1995).

53. Geiger, 816.

54. Ibid., see also, C.K. Lum and S. G. Korenman, "Cultural-Sensitivity Training in U.S. Medical Schools, " *Academic Medicine* 69 (1994): 239-241.

55. Turner, 219.

56. Brandt, 27.

57. Green, et al, 200.

58. Kevin Pleasant, interview by Peter A. Clark, S.J., 24 June 1997, phone interview, Philadelphia FIGHT, Philadelphia, PA.

59. An example of this would be the $25 million given annually by the New York Health Department to minority community organizations to help dispel the suspicions and fears the minority community has toward the medical establishment.

60. Jon Fuller, "AIDS Prevention: A Challenge to the Catholic Moral Tradition", *America* 175 (December 28, 1996): 14.

61. Brandt, 27.

62. Lawrence Altman, "AIDS Drop 19% in U.S., Continuing a Heartening Trend", *The New York Times*, 7 July 1997, A-14.