Overcoming the Legacy of Mistrust: African Americans' Mistrust of Medical Profession

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Abstract: Recent studies show that racism still exists in the American medical profession, the fact of which legitimizes the historically long-legacy of mistrust towards medical profession and health authorities among African Americans. Thus, it was suspected that the participation of black patients in end-of-life care has always been significantly low stemmed primarily from their mistrust of the medical profession. On the other hand, much research finds that there are other reasons than the mistrust which makes African Americans feel reluctant to the end-of-life care, such as cultural-religious difference and genuine misunderstanding of the services. If so, two crucial questions are raised. One is how pervasive or significant the mistrust is, compared to the other factors, when they opt out of the end-of-life care. The other is if there is a remedy or solution to the seemingly broken relationship. While no studies available answer these questions, we have conducted an experiment to explore them. The research was performed at two Philadelphia hospitals of Mercy Health System, and the result shows that Black patients' mistrust is not too great to overcome and that education can remove the epistemic obstacles as well as overcome the mistrust.

Keywords: Racism, institutional whiteness, end of life care, legacy of mistrust, hospice care.

I.   INTRODUCTION

This paper is about the problem of the "institutional whiteness" of American medical profession and public health authorities as experienced by African Americans, the black community's corresponding mistrust towards them, and how to overcome the vexing problem. Due to the history of American medical institution's systemic and systematic racism, African Americans' view of hospitals and public health agencies as discriminatory organizations has become shaped. As medical societies and schools were being created in the antebellum era, the poor socio-economic status of the black community made black bodies available for autopsy education, sometimes to be acquired by kidnapping or not providing medical care for sick black patients. Also, based on a prevailing scientific assumption of the time up until the late 20th century that a black body is racially inferior to a white body in the sense that black race is physiologically proximate to non-human animals, the public health agencies and medical societies performed a variety of medical experiments on African Americans. The well-known Tuskegee Syphilis Study (1932-1972) is a good example. The study was

conducted to see how Syphilis in the black body would get progressively worsened when untreated, grounded in the belief that the black body may not need treatment to overcome the disease.

Now, where are we? It is no doubt that the U.S. society has been moving towards social justice which includes racial equality. The annual reports of the National Urban League (NUL), the largest U.S. nonpartisan civil rights organization that advocates racial justice on behalf of African Americans, indicate that most American Americans feel that our society is advancing in racial justice year by year and got drastically better than 30 years ago. But quite a few studies also suggest that the majority black people still hold mistrust towards the American medical profession, where physicians are still predominantly white. Meanwhile, according to a 2017 report, "[n]inety-two percent of African-Americans surveyed said discrimination against black Americans exists today. Half of those thought discrimination that is based on an individual's prejudice is a larger problem compared to the 25 percent that feels institutional discrimination is more problematic."[1] On the other hand, a 2016 study conducted by Astha Singhal, Assistant Professor of Health Policy & Health Services Research at Boston University, and her team, reports that black patients, compared to their white counterparts, are much less likely to be treated for physical pain.[2] The reason for that is because today's (white) doctors, in general, still hold the age-old bias that blacks have "thick skin" consciously or unconsciously. The black body is biologically different and in many ways stronger than the white body due to their subhuman or animal-like quality, so the black patients do not need as much pain medications as the white body needs.[3]

If all this is true, it might be fair to say that, although a great progress has been made in procedural justice towards all races in health care, the institutional whiteness of medical institution is still there and subsequently the nefarious racial biases against black race are not entirely eradicated, the fact of which legitimizes the raison d'être of African Americans' mistrust of the medical profession as a justifiable ethical state of mind in today's U.S. society.

On the other hand, many researchers in recent years have attempted to figure out the nature of the current black patients' mistrust of their doctors. To locate the site where the mistrust can vividly be displayed, they have rightly narrowed the context to end-of-life care, which doctors and patients can address and discuss only when the two trust each other. With the development of medical technology over the past years, people's life expectancy has increased, and the end-of-life care services have grown exponentially. According to 2012 data, an approximately 44.6 percent of all deaths in the U.S. were under the care of a hospice program.[4] However, a great number of African American patients do not or perhaps are not willing to receive hospice care though they are eligible. As the researchers dug reasons for their underutilization of the service, they have come to identify several issues worthy of further scholarly discussion. According to Ramona Rhodes, Associate Professor of Medicine at University of Texas Southwestern, and her team whose research we believe best captures the problem in a succinct manner, many African Americans do not wish to use end-of-life care because of their inherent mistrust towards medical profession, cultural differences, conflicts with spirituality and religious preferences, and lack of knowledge about hospice care. And all the other similar research data available point to the identical or similar list.

If true, two crucial questions are raised. One is how pervasive or significant the black patients and families' mistrust is, compared to the other elements, when they decide not to use end-of-life care. The other is whether there can be a remedy or solution to the seemingly broken relationship. No studies so far seem to address these questions in a way of conducting a research to answer them. Therefore, we have taken up the task. 142 patients were selected at two Philadelphia hospitals of Mercy Health System: Mercy Philadelphia and Mercy Fitzgerald where predominantly white doctors are treating predominantly African American patients. The patient pool was comprised of 56% African American, 40% Caucasian, and 4 % other races. We ran what is called "Hospice Awareness Test." The patients were given questionnaires to test their understanding of hospice care, post and prior to being educated on the topic. Also, the question was asked if the patients were willing to accept hospice care before and after the education. The education here was a brief brochure presentation about what hospice care is or is not. The results show that 45 patients out of 61 who had not considered hospice care during the first survey changed their mind to opt for the service and that the

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[1] Karen Bates, "92 Percent of African-Americans Say black Americans Face Discrimination Today," *NPR News* October 24, 2017, accessed Jan. 9, 2018, https://www.npr.org/2017/10/24/559889541/92-percent-of-african-americans-say-black-americans-face-discrimination-today

[2] Astha Singhal, Yu-Yu Tien, and Renee Y. Hsia, "Racial-Ethnic Disparities in Opioid Prescriptions at Emergency Department Visits for Conditions Commonly Associated with Prescription Drug Abuse, *PLO One*, August 8, 2016, accessed Jan. 5, 2018, https://doi.org/10.1371/journal.pone.0159224.

[3] Kelly M. Hoffman, Sophie Trawalter, Jordan R. Axt, and M. Norman Oliver, "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences between blacks and whites," *Proceedings of the National Academy of Sciences U.S.A* 113 no. 16: 4298.

[4] "Hospice Facts & Figures" National Hospice and Palliative Care Organization, November 27, 2012, accessed Jan. 9, 2018, https://www.nhpco.org/press-room/press-releases/hospice-facts-figures.

difference in response between black and white patient groups was insignificant. In other words, education via a short brochure presentation had a great impact on patients regardless their race as they changed their mind to hospice care.

The research has limitations the most apparent one of which is the sample size. The sample is not large enough for us to take the outcome to arrive at a conclusion which may be universalizable. Thus, we do not assert that the same result will obtain in a large-scale research. Nevertheless, the sample we have selected here, though it addresses a small sector of the target-population, is of critical importance. Mercy Philadelphia and Mercy Fitzgerald are representative of the hospitals where white or Asian doctors treat black patients in America's typical "urban ghetto," the West Philadelphia area, consisting of the vast majority of the poor black population. Hence, we assert that it is highly probable that the research result is indicative of how African Americans view their (white) doctors on a national scale. Accordingly, we argue that, though institutional racism still may exist, African Americans' mistrust of the white profession has largely subsided enough to be considered not a defining issue in health care and that education help restore the historically scarred, patient-doctor relationship in a way of removing the cultural-religious and epistemic obstacles as well as overcome the legacy of mistrust.

The paper will have the following structure: 1. A brief history of American medical institution's systematic and systemic racism will be recounted and how the mistrust towards medical profession and public health authorities among the African American community was shaped and transmitted across generations as a legacy through oral folklore will be explored. One of the authors of this research, Bioethicist Peter A. Clark, wrote "A Legacy of Mistrust: African-Americans, Medical Profession, and AIDS" published in *the Linacre Quarterly* (1998) as he debunked the U.S. medical institution's racist practices in the past. Clark's work will be largely recapitulated in this section. 2. We will make an analysis of the current socio-ethical status of American society in terms of racial equality whereby the following premise is made: despite the die-hard presence of racism of medical profession and institution, the African American community's mistrust, fortunately, has been so lessened that a positive change to overcome the mistrust can be enabled. On the other hand, we stress the non-mistrust factors which have negative impacts on the relationship between black patients and white doctors, that is, cultural-religious difference and genuine misunderstanding. 3. Surveys conducted at two Mercy Philadelphia hospitals are expounded in detail to show that education has an efficacy in removing the cultural-religious and epistemic obstacles as well as overcoming the inherent mistrust.

Before proceeding, however, we ask the readers to take heed of our usage of the terms, distrust and mistrust. In common parlance, "distrust" is generally referred to as a state of mind where there is lack of or without trust based on experience or reliable information while "mistrust" is same as distrust but without the experience or reliable information. Thus, distrust can be an evidence-based regard while mistrust is not. However, when it comes to the present mistrust or distrust of medical professionals in the African American community, the conceptual demarcation line between the two terms is notoriously unclear because, although the skeptical penchant was originally shaped in the form of distrust based on the factual grounds, the inherited mindset of an individual African American gets shaped typically by the oral folklore through word of mouth among family and friends whose character is largely non-factual. Therefore, we will be using the terms interchangeably while mistrust is primarily used to include both meanings throughout the paper.

II.   A LEGACY OF MISTRUST: A HISTORICAL SURVEY

Many today attribute the present mistrust of African Americans towards medical profession, particularly white doctors, to the events surrounding the Tuskegee Syphilis Study, which was sponsored by the United States Public Health Service from 1932 to 1972.[1] However, the Tuskegee Study, in fact, is a small indicator that points to a long history of racism and subhuman stereotypes that existed for centuries in the U.S. society, particularly American medical profession.

A. A Brief History

Beginning with the antebellum era, as the ideas of the French school of hospital medicine reached the United States, the need for human specimens in medical schools became recognized.[5] "black bodies," particularly in the South, were used in the medical schools

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[5]A detailed analysis of the influence of the Paris school on American medicine is found in the following works: Edwin Ackerknecht, *Medicine at the Paris Hospital,* 1794-1848 (Baltimore, MD, 1967); Richard Schryock, *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); Gerald Grob, *Edward Garvis and the Medical World of Ninteenth-Century America* (Knoxville, TN, 1978).

for teaching purposes. In order to learn anatomy, recognize and diagnose diseases, and to treat conditions requiring surgery, medical students needed to test their ideas and techniques. Moreover, the future doctors needed to learn how to perform autopsies to confirm their diagnoses and to understand the effects of disease on the human body.[6] 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 a plentiful supply of clinical materials. [7] This need for living and dead human specimens 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 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.[8]

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 that autopsies could be performed.

In the post-reconstruction periods, the rise of the term "night doctor" among blacks and poor whites is notable. The absence of anatomical laws regulating 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 illegal purchase or theft of cadavers before internment, and by murder. Of these three methods, grave robbing was the most popular.[9] During this period, "night doctor" became well known, especially in the black community. "The term 'night doctor' (derived from the fact that the 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."[10] It is estimated that about 5,000 cadavers were dissected each year in the U.S. then and that a majority were procured illegally.[11] 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

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

[7] Ibid., 333.

[8] Gladys-Marie Fry, *Night Riders in Block Folk History* (Athens, GA: University of Georgia Press. 1991), 174-175. Another advertisement appearing in The Charleston Mercury gives supporting evidence that Charleston may 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 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, con finned hypochondriac, 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.

[9] Ibid., 176.

[10] Ibid., 171.

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

anatomical material for another northern medical school in 1911."[12] By the 1920's, passage of anatomy acts eradicated body snatching in most parts of the United States, but it had no effect on the social origins of the supply of cadavers for medical schools.[13]

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.[14] Folklorist Gladys-Marie Fry contends that "many blacks are convinced that Southern landowners fostered a fear of 'night doctors' in the post-Reconstruction period to discourage the migration of blacks from rural farming areas to Northern and Southern urban centers." [15] Fostering a fear of night doctors to discourage black migration appears to be historically well-founded. However, evidence also persists proving that night doctors did play a major role in attaining black bodies for medical purposes.

In the 20th century, the Tuskegee Syphilis Study (1932 to 1972) was clearly a main historical event that deserves scrutiny and criticisms. The study was specifically conducted on African Americans because of the belief at the time that the disease progressed differently in blacks and whites and because the medical researchers and health officials were interested to know whether treatment was necessary. Meanwhile, as Historian Allan Brandt argues, there is no doubt that the medical professionals and researchers who directed and devised the Tuskegee Syphilis Study accepted the mainstream assumption that blacks were "less than human."[2]

In fact, in medicine, it is impossible not to have any assumptions because medicine as a systematic study and profession is supposed to reflect and reinforce the society's beliefs and values and its power dynamics at large. The assumption that the medical professionals and health officials involved in the Tuskegee Study were influenced by the racism prevalent then. During the time of slavery, many doctors believed that black people possessed irregular physiological and anatomical features based on which they justified the slavery system. In the late 19th and early 20th centuries, medical texts, then, were written comparing black people's anatomy to Caucasians. Examples of this include German Physician Dr. Frederick Tiedemann's "On the Brain of the Negro, Compared with That of the European and the Organ-Outang," English Biologist Dr. Richard Owen's "The Gorilla and the Negro," and more. These texts were accepted as legitimate medical standard of their times the result of which inferiority theories could be perpetuated. These medical theories not only influenced societal attitudes that black people were physiologically closer to animals but also justified the use of blacks for medical experimentation and dissection.[16] In terms of syphilis, it was believed 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." [17] These racist assumptions became the basis for the initiation of the Tuskegee Study of Untreated Syphilis in the Negro Male.

To briefly narrate the Tuskegee Study, 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. They were enrolled in this study without their informed consent. These men were deceived in the sense that the infected were never told that they had syphilis, which was known to cause mental illness and death. And 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.

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[12] Ibid., 823-824.

[13] 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 tum of the century." Ibid. See also "Tuberculosis in the United States," Bureau of Census (Washington, D.C.: Government Printing Office, 1908), 18-19, 60.

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

[15] H. Donald, "The Negro Migration of 1916-1918," *Journal of Negro History 6* (January 1921): 383- 498.

[16] Ibid. 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); J.M. Sims, *The Story of My Life* (New York: Appleton, 1889).

[17] 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): 403.

The Tuskegee Syphilis Study was not a secret. In fact, it was widely known in medical circles. As late as 1969, a committee at the federally operated CDC examined the study and agreed to permit its continuation. 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, 74 of the test subjects were still alive; at least 28 but perhaps more than one hundred, had died directly from advanced syphilitic lesions. This view about black people was deeply rooted in the mainline white American culture and continued well into the 20th century though the social status of African Americans has improved. Thus, it is not surprising that the Tuskegee Study had been conducted up until 1972.[18]

Another important 20th century's legal act which helped maintain discrimination against African Americans in health care in a subtle way was the 1946's Hill-Burton Act, which had existed until the U.S. Supreme Court struck it down in 1963. The Hill-Burton Act enjoined that medical professionals ought not to discriminate patients based on race, color, national origin, but allowed "separate but equal facilities" to exist in the same area, which had made the anti-discrimination clause virtually ineffective while helping *de facto* maintain the systemic, substandard medical treatment for the black people. Meanwhile, cases of the medical advances made at the expense of blacks, such as the human HeLa cell line, broke out. Cells from the African American patient, Henrietta Lacks, were obtained in 1951 without her permission, knowledge, or consent.[19] This pattern of disregard and abuse led many African Americans to believe that they were viewed as inherently inferior by the medical profession and public health agencies, the result of which helped form the lingering suspicion that medical professionals' motives were not to help African Americans but to use them as guinea pigs.[3]

B. Continuing the Legacy through Oral Folklores

When a mistrust is formed as a shared mindset among members of a community, it can be inherited across the generations through the community members' storytelling. The African American community has a long-standing tradition of storytelling which is called "oral folklore." Over time stories have been told warning generations of African-Americans about the impropriety and malicious nature of the medical profession and public health programs. When the tragedy of the Tuskegee Syphilis Study was revealed publicly in 1972, the news spread rapidly throughout the African American community. As the truth of the experiment spread through word of mouth, resulting in a perpetuated oral history severely damaging to the medical profession's credibility. Today, in the African American community, the Tuskegee story is a major part of childhood folklore passed down by family members as a "proof" of the inherent injustices that generations of African Americans can expect from American institutions, particularly medical institution.

It is interesting to investigate how the African American folklore was shaped in a way of leading contemporary black people to mistrust all medical professionals. According to oral traditional researchers, folklore involves rumor and legend. A rumor is defined as "a specific proposition for belief, passed along from person to person, usually by word of mouth, without secure standards of evidence being present."[20] A legend "is a narrative account set in the recent past and containing traditional motifs that are told as true." [21] In sum, a legend is a truth- or fact-bearer while a rumor is not, though the two are not always neatly distinguished because facts are often blurred with fiction.

It is believed that the folklore of the African American community are legends. Most folklorists and social scientists use the term "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."[22] The folklorist, Patricia Turner, identifies two distinct recurrent "motifs of danger" which have influenced the African American community in its distrust of the medical profession and public health programs: the conspiracy motif and the contamination 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 which, ultimately, promotes a general sentiment of mistrust. Turner traces the

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[18] This does not disregard the unjust experimentation on poor whites in the United States. Nonetheless, blacks were used more often and with greater disregard because of their race.

[19] See Barry K. Shuster, "In the Wake of Henrietta Lacks: Current U.S. Law and Policy on Control and Ownership of One's Body Tissues Used in Medical Research," *The Journal of Healthcare Ethics & Administration* 3, no. 2 (Fall/Winter 2017): 8-18, https://doi.org/10.22461/jhea.1.71614

[20] Gordon W. Alport & Leo Postman, *The Psychology of Rumor* (New York: Henry Holt, 1947), ix.

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

[22] Ibid., 5.

history of this conspiracy theory from the European involvement in the slave trade of black Africans to the contemporary powers in the U.S. which include 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.[23] This motif is prevalent in the historical period from the time of slavery in the U.S. to the late nineteenth century, and a good example for the conspiracy motif is found in the tale about the night doctors as introduced above. Stories of the "night doctors" are still told within the African-American community. 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 subtler. The motif of conspiracy was largely replaced by the motif of contamination, the second motif of danger. This motif examines both medical and public health efforts and at times coincides with the themes of genocide and conspiracy. Turner uses contamination by reference to "any item in which the physical well-being of individual black bodies is being manipulated for racist reasons."[24]

The motif of contamination spread in the African American community throughout the 20th century as a form of "genocide." 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.[25] This belief became more credible when Norplant was introduced to the market.[26] Following the legalization of Norplant as a contraceptive device, stories began to circulate that inner-city, African American women on welfare were being forced to use this contraceptive device. These stories intensified when various editorial writers and public policy makers suggested that "welfare mothers" be required to have the device implanted as a condition for further benefits.[27] Additional regulations on fertility such as the sterilization statutes in many states in the 1970s also supported this notion of genocide in the African American Community. Interestingly, research findings have revealed that a patient's race 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, which may be considered a subtle form of sterilization.[28] 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 in the 1970s 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 public 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 an increase in suspicion within the African American community that it was another form of genocide.[29] Also, 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. Vaccines and injections 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. Thus, diagnostic tuberculosis (TB) skin testing has often been

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[23] Ibid., xv and 108.

[24] Ibid., 138.

[25] Ad Hoc Advisory Panel, Department of Health, Education, and Welfare. "Final report on the Tuskegee Syphilis Study" (Washington, D.C.: Government Printing Office, 1973). For a more detailed analysis of the Tuskegee Syphilis Study, see 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.

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

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

[28] For a more detailed analysis of the effects of race on medical care, see H. Jack Geiger, "Race and Health Care - An American Dilemma," *The New England Journal of Medicine* 335 (1996): 815-816.

[29] For a more detailed analysis, see O.Y. Wilkenson, "For Whose Benefit? Politics and Sickle Cell," *The Black Scholar* 5 (1974): 26-31.

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.[30] 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.[31] 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.[32] 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.[33]

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."[34] While some in the white community see this as paranoia and hypersensitivity, many in the African American community view this as another example of racism's influence in the medical profession. Consequently, the fight against AIDS in the African American community suffered because of detrimental oral legacies against the medical profession.

As of 2015, HIV and AIDS rates are highest amongst African American, homosexual men.[35] Though African Americans comprised roughly 12% of the U.S. population, they make up for 45% of total HIV diagnoses.[36] As HIV and AIDS continue to spread amongst this demographic and the hope for a cure remains elusive, the conspiracy and contamination motifs that have been part of African American folklore for generations may continue to circulate.[37] The perpetuation of these motifs does not aid in efforts to prevent and treat HIV/AIDS in the African American community.

C. Today's African Americans: Cultural-Ethical Analysis.

A research states that after 1972 when much of the truth behind Tuskegee was revealed, mistrust among African Americans toward the medical profession spiked. Many of them stopped going to see doctors even though they get ill. As a result, African Americans' use of health care system fell and their mortality increased years later.[38] The study also reveals that the closer you lived to Macon County, Alabama, where the Tuskegee study took place, the greater the distrust towards white doctors.[39] How about, then, today's African Americans?

According to a 2016 report published by the National Urban League (formerly, the National League on Urban Conditions Among Negroes), the oldest and largest community-based nonpartisan civil rights organization which advocates against racial discrimination on behalf of African Americans in the U.S., African Americans are doing much better than they did when its first annual report,

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[30] O'Connor, II.

[31] Lynda Richardson, "An Old Experiment's Legacy: Distrust of AIDS Treatment," *The New York Times* 21 April 1997, A-9.

[32] 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.

[33] Turner, 158.

[34] Ibid., 160-161.

[35] For a complete subpopulation analysis, see: www.cdc.gov/hiv/statistics/overview/ataglance.html

[36] Center for Disease Control [CDC] Diagnoses of HIV infection in the United States and Dependent Areas, 2015. *HIV Surveillance Report* 2016: 27.

[37] 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.

[38] On the same token, the same concerns related to trust between doctor and African American patient was observed in a recent study, published by the National Bureau of Economic Research as a working paper (meaning it has not yet undergone full peer review), combined data on mistrust of doctors from the General Social Survey, health care utilization from the National Health Interview Survey and mortality data from the Centers for Disease Control and Prevention.

[39] Marcella Alsan and Marianne Wanamaker, "Tuskegee and the Health of Black Men," April 22, 2016, doi:10.3386/w22323.

"State of black America," came out in 1976.[40] Marc Morial, President of the National Urban League (NUL), says that things have clearly gotten better for African Americans since 1976. "Fewer blacks live in poverty — 29 percent in 1976 compared with 27 percent now. More blacks have graduated high school and college — 28 percent in 1976 and 33 percent today for high school, and 6 percent four decades ago versus 22 percent today for college. Life expectancy of African-Americans has increased from 68 in 1976 to 75 today."[41]

The NUL uses what is called an "equality index," a combined measure drawn from the collected data from federal agencies including the Census Bureau, the Bureau of Labor Statistics, the National Center for Education Statistics, and the Centers for Disease Control and Prevention. With "full equality with whites in economics, health, education, social justice and civic engagement set at 100 percent, [the NUL reports that] this [2016] year's equality index for blacks stands at 72.2 percent, compared with last year's 72 percent."[42] Also, what surprises many is that, despite President Trump's seemingly racially discriminatory policies, the equality index measured during the Year 2017 shows that the conditions for blacks have gotten better than the previous year: 72.3 percent in 2017 compared with 72.2 percent in 2016.[43] All this data may suggest that, to bluntly put, black patients' relationship with white doctors has gotten better. In turn, African Americans' suspicion towards the predominantly white, medical profession, has lessened.

Nevertheless, African Americans' inherent mistrust towards medical profession has not disappeared. Many black patients still do not believe that white doctors or institutions have their best interest at heart,[44] and a substantive number of studies and data provide factual grounds for the mistrust. Federal guidelines call for the inclusion of minority groups and women in research studies, participation by these groups, particularly African Americans, is very limited.[49] Also, hospice care, palliative care, and other end-of-life treatments have been drastically under-utilized by African American patients during the past decade.[45] In a review of over 166,000 patient records, African Americans were 70% more likely than non-Hispanic whites to revoke hospice to pursue aggressive care. Also, among African American cancer patients who are well informed about the nature of hospice care, the actual use of the service was found to be approximately one in five.[46]

A 2016 study conducted by Astha Singhal and her team shows that black patients with the same level of pain and everything else being the same, compared to their white counterparts, are much less likely to receive opioid prescriptions.[47] The team examined the records of pain-related emergency department visits from 2007 to 2011 for people aged 18 to 65. For their study, five conditions were reviewed and divided into two categories: definitive and non-definitive. The former category includes the conditions that were easily diagnosed like kidney stones and long-bone fractures while the latter refers to conditions that are not such as a toothache, abdominal pain, and back pain. The result shows that black patients had about half the odds of being prescribed opioids compared to white patients for non-definitive conditions.[48] After all, the study shows that the doctors may still hold the age-old bias that blacks have "thick skin," which makes them feel less pain. A similar study was conducted by Kelly Hoffman and her team in 2016. They conclude that "white laypeople and medical students and residents believe that the black body is biologically different – and in many cases, stronger – than the white body," the racial bias closely associated with one's "perceptions of others' pain, which in turn

[40] Jesse J. Holland, "How black America Has Changed in 40 Years," *PBS News Hour*, May 17, 2016, accessed Dec. 4, 2017, https://www.pbs.org/newshour/nation/report-black-america-doing-much-better-than-40-years-ago

[41] Ibid.

[42] Ibid.

[43] Valerie Wilson, "Overview of 2017 National Urban League Equality Index," The National Urban League, accessed Jan. 5, 2018, https://soba.iamempowered.com/2017-equality-index

[44] L. E. Boulware, "Race and Trust in the Health Care System," *Public Health Reports* 118, no. 4 (2003): 360,362. doi:10.1093/phr/118.4.358; Robert B. Baker, Harriet A. Washington, Ololade Olakanmi, Todd L. Savitt, Elizabeth A. Jacobs, Eddie Hoover, and Matthew K. Wynia, "African American Physicians and Organized Medicine, 1846-1968," *The Journal of American Medical Association* 300, no. 3 (2008): 306, 308. doi:10.1001/jama.300.3.306.

[45] Patrick J. Dillon and Ambar Basu, "African Americans and Hospice Care: A Culture-Centered Exploration of Enrollment Disparities," *Health Communication* 31, no. 11 (November 2016): 1385-1394, accessed July 16, 2017, http://www.tandfonline.com/doi/abs/10.1080/10410236. 2015.1072886?journalCode=hhth20; H. Noh and T. A. Schroepfer, "Terminally Ill African American Elders Access to and Use of Hospice Care." *American Journal of Hospice and Palliative Medicine* 32, no. 3 (2014): 286-97, doi:10.1177/1049909113518092.

[46] Camille P. Wicher and Mary Ann Meeker, "What Influences African American End-of-life Preferences?" *Journal of Health Care for the Poor and Underserved* 23, no. 1 (2012): 48, doi:10.1353/hpu.2012.0027

[47] Astha Singhal, Yu-Yu Tien, and Renee Y. Hsia, "Racial-Ethnic Disparities."

[48] Ibid.

predict accuracy in pain treatment recommendations."[49] All this fact, it seems, legitimizes the current suspicion of African Americans towards the medical profession.

Nevertheless, the unseemly statistics and facts so far should not lead to the wholesale appropriation of the contemporary American culture and identity as racist and to accusation of the entire white doctors as racists. As the NUL's data above shows, the majority blacks and other racial minority do feel that the society as a whole is getting better off in advancing social justice, including racial equality. In fact, an important reason for this positive change lies in the fact that the U.S. population is getting more diverse every year. It is estimated that non-Hispanic white population in the U.S. will become a minority in the next 30 to 35 years. In a decade or two, African Americans, Asians, Hispanics, and other minority groups together in some U.S. States will be the majority. For example, the white population in Nevada is already 49.9 percent in 2016, and eight other states "where whites now account for under 60 percent of the population will likely become white minority states in the next 10 to 15 years."[50] With "White America" becoming "Multi-Color America," it is very difficult for the society not to move towards racial equality.

Accordingly, an accurate diagnosis should be that the present grim statistics and facts are not to be considered a heinous systemic or systematic problem of the white institutions or profession but residues of the dark past. Thus, we believe that education as a remedy *should* work, and quite a few studies recently published in current literature indirectly testify our premise as true. For example, a 2016 research published in *the American Journal of Hospice and Palliative Medicine* seems to succinctly capture the reasons why African Americans underutilize end-of-life care. Ramona Rhodes and her team examine the African American community's perceptions about end-of-life care and identifies several barriers to the use of it. Other than the mistrust, they list cultural differences, conflicts with spirituality and religious preferences, and overall lack of knowledge about what hospice entails.[51] The following quotes, the study shows, were obtained from multiple interviews of caregivers and Christian ministers:

> When it comes to enrollment into hospice, said the minister, I think again, it goes back to the faith thing. That if I go on hospice does that mean I'm losing my faith in God, that I'm saying that God can't heal me, or God won't heal me because I've gone on hospice? I've given up, and so God is not going to act on my behalf for sure because I'm not trusting God enough to just heal me? Again, God is going to do what God's going to do.

> I think enrolling African American patients in hospice is difficult and the reason why is because I think patients equate hospice with death. And I also think that they feel that once we enroll them in hospice, we've given up, no one cares, and no one is going to check on them, focus on them, and we're just saying, "You know what? You've got this disease process that you may not last long with and we're just done" . . . It's important for patients to understand that we still care."[52]

Another 2016 study, published by Justine Sanders and his colleagues in *Journal of Palliative Medicine*, may be a rather extended version of the study by Rhodes and her team. What makes this research interesting is that it is a comprehensive review of the 38 previous papers which the team found as "moderate and low-quality quantitative studies" which focus on examining African American patients' perspective of end-of-life care. The authors, Sanders and his team, argue that the findings suggested by the 38 studies are often contradictory but that it can be concluded, based on the data collected, that, compared to their white counterparts, African Americans prefer more aggressive care, participate less in advanced care planning, and "are more likely to informally discuss end of life care than to formally document wishes."[53] And they provide the following categories with the corresponding interview narratives.[54] Other than the black patients' mistrust, they are:

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[49] Kelly M. Hoffman el, "Racial Bias in Pain Assessment."

[50] Evan Horowitz, "When Will Minorities be the Majority?" *Boston Globe*, Feb. 26, 2016, accessed Jan. 3, 2018, https://www.bostonglobe.com/news/politics/2016/02/26/when-will-minorities-majority/9v5m1Jj8hdGcXvpXtbQT5I/story.html

[51] Rhodes, R. L., B. Elwood, S. C. Lee, J. A. Tiro, E. A. Halm, and C. S. Skinner, "The Desires of Their Hearts: The Multidisciplinary Perspectives of African Americans on End-of-Life Care in the African American Community," *American Journal of Hospice and Palliative Medicine* 2016. doi:10.1177/1049909116631776. p.512

[52] Ibid.

[53] Justin J. Sanders, Maisha T. Robinson, and Susan D. Block, "Factors Impacting Advance Care Planning among African Americans: Results of a Systematic Integrated Review," *Journal of Palliative Medicine* 19, No. 2, 2016: 202 doi:10.1089/jpm.2015.0325.

[54] Note that the interview narratives they use to pair with the categories are more than the ones we introduce here. Also note that, compiling and categorizing the interview narratives, they use a "third-order theme" for the categorization and re-list the narratives in terms of "tertiary themes represented." We put the former.

1) Beliefs about illness, death, dying and suffering – "The Bible says, 'If you speak it, as it is so, then it will be.' I don't want to talk about death and dying."[55]

2) Family and community structure, support and burden – "Bring Daddy home . . . we'll move the bed into the dining room and we'll take care of him until he dies . . . we'll be here until it's over. I've seen black families do that a lot, even people in my own family,"[56] "It is an unwritten rule that my family will take care of me. I don't want to worry writing something down [referring to advance directives] . . . but I have let people verbally know my views. We don't write down a lot of stuff. That is the way African Americans communicate so much of their instructions and their history."[57]

3) Religion and spirituality – "The doctor doesn't really know when someone is going to die. Only the Lord knows. I put my faith in God, and until He says it's time for me to go on to Glory, I want the doctors to do all that they can do to keep me alive."[58]

4) Preference regarding Life-Sustaining Treatment – "If somebody's heart stops, I think the doctor is supposed to try to get it pumping again. Wouldn't they just do that for everybody? I don't understand why somebody wouldn't want the doctors to do everything they can to save their life."[59]

5) Health Literacy – "So I know nothing about either one. But, I sort of had to leave it up to the doctor to explain it to me."[60] "blacks need to know more about it. We just don't do it."[61] "You had to say end of life, talk about comfort, talk about signing over what kind of care you want. Did you want to resuscitate? He didn't know what that was. I told the doctor, speak plainly so he understands what you're talking about."[62]

6) Style of processing and enacting health decisions – "I talk to my family. I talk to my doctors and I ask them what they think is best for me, then I say, tell me the truth, don't give me false answers, I want to know. If there is anything wrong, whatever is wrong with me I want to know."[63] "My family knows my decision even if it is not on paper, and I would want them to carry it out."[64]

7) Communication with medical teams – "My doctor never asked me, so I never brought it up,"[65] "If you have somebody who comes in and is just like you – a normal person, speaking your language, having similar life experiences with good solid information – that would be helpful."[66]

8) Believes and attitudes – "I had had that [advanced care planning] in my mind a long time before I found that I had cancer. Lot of things I had made up in my mind before I found out I had cancer because having 11 children, I felt like it was about

[55] Braun UK, Beyth RJ, Ford ME, et al. "Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making," *Journal of General Internal Medicine* 2008; 23:267–274 quoted in Sanders et al, "Factors Impacting Advance Care Planning," 220.

[56] Daaleman TP et al, "An exploratory study of advance care planning in seriously ill African-American elders," *J Natl Med Assoc.* 100 (2008): 1457–1462 quoted in Sanders et al, "Factors Impacting Advance Care Planning."

[57] WH Shrank et al. "Focus group findings about the influence of culture on communication preferences in end-of-life care," *Journal of General Internal Medicine* 2005; 20:703–7 quoted in Sanders et al, "Factors Impacting Advance Care Planning"

[58] Braun UK et al, "Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making," *Journal of General Internal Medicine* 2008; 23:267–274 quoted in Sanders et al, "Factors Impacting Advance Care Planning."

[59] Ibid.

[60] Dupree CY, "The attitudes of black Americans toward advance directives," *J Transcult Nurs* 2000; 11:12–18 quoted in Sanders et al, "Factors Impacting Advance Care Planning."

[61] Ott BB, "Views of African American nursing home residents about living wills," *Geriatr Nurs* 2008;29:117–124 quoted in Sanders et al, "Factors Impacting Advance Care Planning."

[62] Waters CM, "Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making," *Qual Health Res* 2001;11: 385–398 quoted in Sanders et al, "Factors Impacting Advance Care Planning."

[63] Hauser JM et al "Minority populations and advance directives: insights from a focus group methodology," *Camb Q Healthc Ethics* 1997;6: 58–71 quoted in Sanders et al, "Factors Impacting Advance Care Planning."

[64] Ott BB, "Views of African American nursing home residents about living wills," *Geriatr Nurs* 2008;29:117–124 quoted in Sanders et al, "Factors Impacting Advance Care Planning."

[65] Nath SB et al "A place called LIFE: Exploring the advance care planning of African-American PACE enrollees," *Social Work Health Care* 2008; 47:277–292 quoted in Sanders et al, "Factors Impacting Advance Care Planning."

[66] Ramsey CP, "Young adult African American family members' perceptions, knowledge, attitudes, and utilization toward advance directives," *ABNF Journal* 2013; 24:51–59 quoted in Sanders et al, "Factors Impacting Advance Care Planning."

time for me to do something because they're not bad, they got different minds."[67] "My husband refuses to deal with anything that has to do with death. He doesn't want to talk about it. He doesn't want to hear it. But, if you say it is about health care and talk about the living will during the forum, people will come. It is not a real happy topic to talk about, and people just don't want to go there, period."[68]

Sanders and his team conclude that, there are the multiple factors, as shown above, which impact African Americans' reluctance of the use of end-of-life care and but that they know little from the data about how best to improve the current situation. In fact, their conclusion here represents that of all similar studies conducted in recent years. Also, no studies show how pervasive or significant the mistrust, compared to the other elements, proportionally consists of, to explain the African Americans' underutilization of the end-of-life care. In fact, it is practically impossible to measure it in a quantifiable manner.

On the other hand, from the studies by Sanders et al and Rhodes et al, it is suspected intuitively that the non-mistrust factors are a significant part of the total sum that explains black patients' underutilization of end-of-life care, for we all are basically the product of religion, culture, and knowledge. Moreover, it is psychologically natural that the racially motivated mistrust gets lessened when one's cultural-religious difference and epistemic misunderstanding are overcome, for it is common sense that the better we understand and communicate with each other, the more trust we have towards each other.

III.   EDUCATION AS A METHOD OF REMEDY

Drawing on the premises above, we have conducted an experiment so that their validity might be statistically evidenced. We have selected 142 patients from two Philadelphia hospitals of Mercy Health System: Mercy Philadelphia and Mercy Fitzgerald where predominantly white doctors are treating predominantly African American patients. The patient pool was comprised of 56% African American, 40% Caucasian, and 4 % other races. We ran what is called "Hospice Awareness Test." The patients were given questionnaires for us to test their understandings of hospice care, post and prior to being educated on it. Most importantly, the question was asked if the patients were willing to accept hospice care either before education and afterward.

As we all know, with medical technology continuing to develop, the chances of people living longer with chronic medical conditions have increased. As of 2012 in the U.S., about half of all adults, 117 million people, had one or more chronic health conditions, and 1 in 4 adults had two or more chronic conditions.[69] To meet the demand, healthcare delivery has become more sophisticated as well as complex, the fact of which has created confusing terminology and complex programs. Advance care planning, advance directives, medical futility protocol, palliative care, hospice care, home care, etc. are such examples. What exact meanings or services they refer to, how they should be requested or invoked in a hospital setting, what the patients and families should do to interact with health insurance agency for the services, and what service agents (hospital employees or independent contractors) in the hospital are involved in delivering the services, etc. confuse not only patients and families but also health providers including ICB doctors and nurses. Therefore, African Americans' confusion about all these services is nothing but natural. However, it is admitted that, coupled with the cultural-religious difference and the history of medical mistreatment, black patients and families have become deeply skeptical about these services.

We have chosen particularly hospice care for this survey because, among different end-of-life services, hospice care seems most misunderstood among patients and families as well as health providers. As shown in the interview narratives above, black patients and family typically interpret addressing hospice care as giving up fighting to get better on the patient part and as refusing to treat on the doctor's part. We wanted to see if this misunderstanding could be rectified via education using a simple brochure presentation on what hospice care was and was not and if the black patients after the education who had refused to use hospice care before the education would opt for the service.

On the other hand, we performed the same "Hospice Awareness Test" on physicians during the same research period. At Mercy Philadelphia and Mercy Fitzgerald, 118 physicians were randomly chosen. Among 118, 3.6% were African American, 40% Caucasian, and 57% from other races. And 63 % were male and 37% female. The similar questionnaire was given as the one for the patient to inquire how likely the physicians were to recommend hospice care as an option to their patients before and after the education. The

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[67] Bullock K, "Promoting advance directives among African Americans: A faith-based model," *J Palliat Med* 2006; 9: 183–195 quoted in Sanders et al, "Factors Impacting Advance Care Planning."

[68] Shrank WH et al, "Focus group findings about the influence of culture on communication preferences."

[69] "Chronic Disease Overview," Center for Disease Control, accessed Jan. 30, 2018, https://www.cdc.gov/chronicdisease/overview/index.htm

reasons for the physician test were, first, because we wanted to figure how well trained the physicians were about knowledge of hospice care based on the assumption that many doctors were also confused about the service (to decide whether the hospital administration would need the hospital-wide education on the doctors), and, second, because we would like to acquire a possible comparative vantage point to understand African American patients' reluctance of the end-of-life care. Suppose that the result would turn out that a substantive number of both black patients and white doctors, respectively, did not wish to opt for and to recommend hospice care before education but changed their mind to utilizing and recommending the service post-education. Then, it would be likely that the misunderstanding was the primary cause of their reluctance regardless of race (black or white) and status (patient or doctor). Accordingly, if the expected outcome were obtained on the physician test, then an added strength would be given to the claim that the African Americans' *racial* mistrust issue is not a primary cause for the underutilization of hospice care. For, from the perspective of organizational culture, when doctors, who are expected by their patients to provide accurate information, give misinformation or confusing information or no information to their patients, the patients are not only confused but also naturally mistrust their doctors. Of course, the worst-case scenario would be that different doctors provide different information for the patient. Nevertheless, the mistrust in question here would not be racially related but merely epistemic.

A. *"Palliative Care," "Hospice Care," and "Home Care"*

To begin, we want to make sure how hospice care differs from palliative care and home care to make the context of our survey more intelligible. First, "palliative care" is a general term that points to a treatment of discomfort and management of pain and symptoms regardless of age, sex, or stage of a disease. The WHO defines the key elements of palliative care as follows:

> Provide relief from pain and other distressing symptoms; Affirm life and regard dying as a normal process; Intend neither to hasten nor postpone death; Integrate the psychological and spiritual aspects of patient care; Offer a support system to help patients live as actively as possible until death; Offer a support system to help the family cope during the patient's illness and in their own bereavement; Use a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; Enhance quality of life, and may also positively influence the course of illness; Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications[70]

Palliative care is delivered by a team of professionals who work in a cooperative manner with the patient's primary clinicians. And the palliative care team can function as part of the interdisciplinary team usually consisting of the palliative team, the patient's doctor, nurses, a social worker, a pharmacist, a chaplain, and sometimes more.[71] The palliative care team can also work with terminally-ill patients and, in so doing, cooperate with a hospice care team or can provide hospice care depending on the structure of its service provider. In sum, palliative care is *never* exclusively offered to patients with end-stage but to all who need pain management.

"Hospice care" is under palliative care umbrella in a broad sense. However, in a local hospital setting, hospice care is referred to as a service that deals specifically with patients with a prognosis of fewer than six months. While "six-month terminal condition" is commonly used among hospice workers, the designation is phrased as "end-stage" among ordinary medical professionals. On the other hand, health care law in most U.S. states uses "end-stage" instead of "six-month terminal condition" to designate the terminal condition. Thus, the hospice organization can receive a patient who must (1) have a life-expectancy of 6 months or less and (2) forego aggressive, cure-focused care.[72] Typically, when the patient is diagnosed with a terminally-ill disease which has evolved to its latest stages and there is no aggressive treatment option that doctors can provide, thereby making the patient's life-expectancy 6 months or less, the patient might be sent home or stay in the hospital without aggressive care but with hospice care. To describe the content of the care, hospice:

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[70] Sriram Yennurajalingam and Eduardo Bruera, *Oxford American Handbook of Hospice and Palliative Medicine* (Oxford: Oxford University Press, 2011), 2.

[71] "Palliative Care Metrics," *National Palliative Care Registry*, accessed July 27, 2017, https://registry.capc.org/metrics-resources/registry-metrics-definition/.

[72] J.G. Cagle, D. J. Van Dussen, K. L. Culler, I. Carrion, S. Hong, J. Guralnik, and S. Zimmerman, "Knowledge About Hospice: Exploring Misconceptions, Attitudes, and Preferences for Care." *American Journal of Hospice and Palliative Medicine* 33, no. 1 (2014): 27. doi:10.1177/1049909114546885.

[m]anages the patient's pain and symptoms; assists the patient with the emotional and psychosocial and spiritual aspects of dying; provides needed drugs, medical supplies, and equipment; coaches the family on how to care for the patient; delivers special services like speech and physical therapy when needed; makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time; and provides bereavement care and counseling to surviving family and friends.[73]

In brief, palliative care is about pain and symptom management while hospice care is to support or sustain dignity in dying process. Meanwhile, hospice workers can be part of the interdisciplinary team that is the hospital staff, but hospice care is sometimes offered by an independent organization in contract with the hospital where the patient is admitted.

On the other hand, home care is the care designed to address the needs of those who want assistance in daily living. Those who are elderly and weak, as well as those recovering from surgery or disabled, can request for home care so that they can live in the comfort of their own homes. Of course, the home care recipients include those who are in end-stage or, in the hospice term, six-month terminal. But the home care aids are not medically trained professionals; they help with ADLs such as bathing, cooking, dressing, and homemaking.[74] But the "home health services" that the aids provide might include some basic level of medical care such as wound care for pressure sores or a surgical wound, patient and caregiver education, intravenous or nutrition therapy, injections, and monitoring serious illness and unstable health status.[75] Nevertheless, when the home care service is rendered to those with end-stage, the home care may include some of hospice care services.

B. Hospice Awareness Test

A sample of 142 patients was screened at Mercy Philadelphia and Mercy Fitzgerald. The pool was comprised of 56% African American, 40% Caucasian; 4 % identified themselves as other races. The average age was 57.6 and most of the population were women at 61% and 31% were male. The patient's stage of conditions varied as they were from different units in the hospitals, from ER triage, inpatient, outpatient, NH, PT, and the endoscope suit. Based on the criteria set by the group, 6 were excluded due to inadequate medical documentation leaving us with 136 who filled out both the pre-test (pertaining to the survey before the education) and the post-test (survey after education) for a small compensation. Patients were asked to provide us with their age, gender, and race before receiving the questionnaire. Two questions were asked if they were willing to accept hospice care before education and afterward. The rest was 16 presumptions and general statements that the patients had to agree or disagree to the questions as true or false answers, so as to test their understandings on hospice care post and prior to being educated on the topic.

As for the doctors, 118 physicians were screened. Among 118, 3.6% were African American, 40% Caucasian, and 57% from other races. And 63 % were male and 37% female. However, among 118, 35 were excluded because of not taking the post-test survey and/or not having answered three or more questions, except 3 excluded due to not specifying age. In the end, 83 were left in the pool. Among the 83, 61 filled both the post and pretest as demanded while 22 missing one or two questions, though all participants specified in the post-test that "they fully understood all the questions." The questionnaire for the doctors was built the same as the one for the patient. It was comprised of 18 total responses, 2 were yes or no questions to see how likely they were to recommend hospice care to their patients before and after the presentation. The other 19 were true or false questions to test the physicians' understanding of hospice care. The statements found in their questionnaire were more advanced as they are related to more specific aspects and due diligence of hospice care.

Now, the patient test proceeded as follows. The first question, Question 1, on the patient questionnaire was "Would you consider hospice?" and the last question to be answered after education/presentation was "Would you consider hospice after our presentation?" The physician questionnaire was given in the same manner; the first and last questions were "Do you discuss hospice or end of life goals with your patients?" and "After this presentation would you consider discussing hospice?" To discuss the patient survey first, all answers showed strong improvement post education. Below is the data on values of the Chi-squared distribution.

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[73] "Hospice Care," National Hospice and Palliative Care Organization, accessed July 27, 2017. https://www.nhpco.org/about/hospice-care.

[74] "Home Care Services: MedlinePlus." MedlinePlus Trusted Health Information for You, accessed July 29, 2017. https://medlineplus.gov/homecareservices.html.

[75] "What's home health care?" Medicare.gov, accessed July 29, 2017. https://www.medicare.gov/what-medicare-covers/home-health-care/home-health-care-what-is-it-what-to-expect.html.

Figure 1
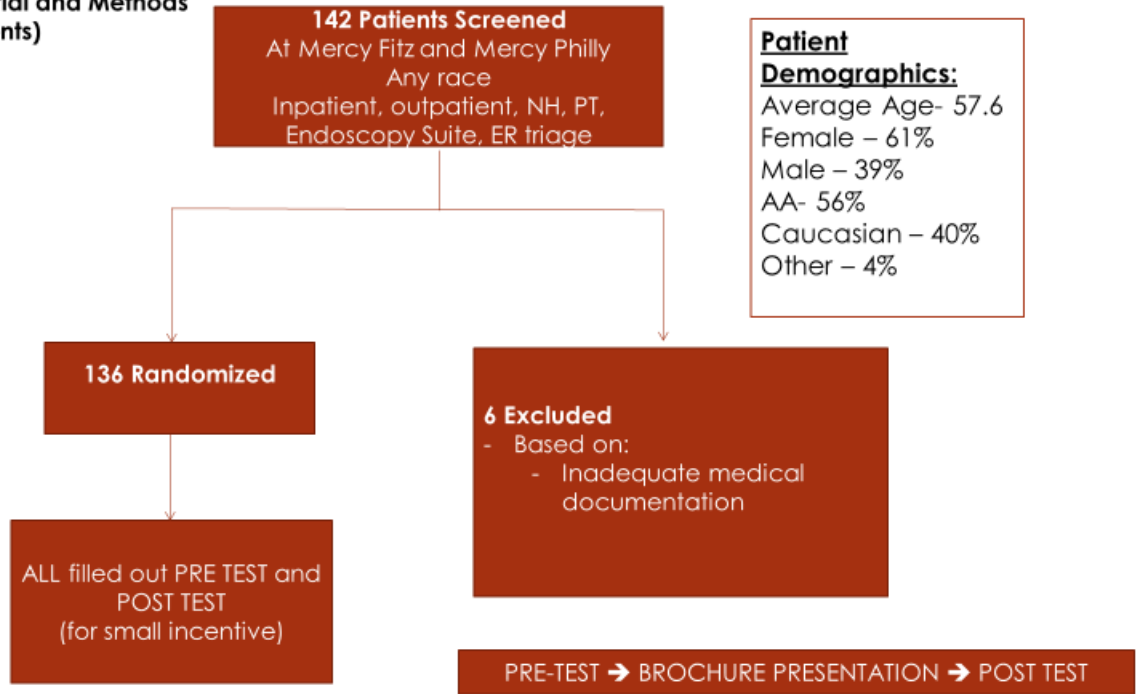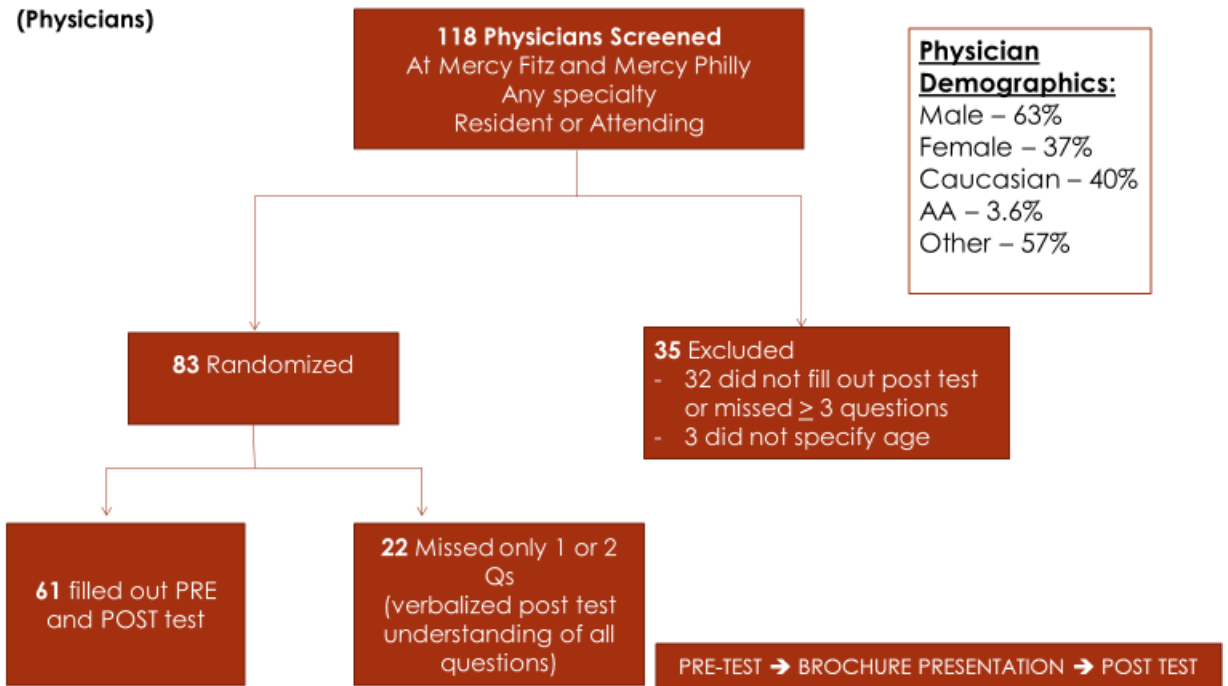
Material and Methods (Patients)

142 Patients Screened
At Mercy Fitz and Mercy Philly
Any race
Inpatient, outpatient, NH, PT,
Endoscopy Suite, ER triage

Patient Demographics:
Average Age- 57.6
Female – 61%
Male – 39%
AA- 56%
Caucasian – 40%
Other – 4%

136 Randomized

6 Excluded
- Based on:
  - Inadequate medical documentation

ALL filled out PRE TEST and POST TEST
(for small incentive)

PRE-TEST ➔ BROCHURE PRESENTATION ➔ POST TEST

Figure 2

Material and Methods (Physicians)

118 Physicians Screened
At Mercy Fitz and Mercy Philly
Any specialty
Resident or Attending

Physician Demographics:
Male – 63%
Female – 37%
Caucasian – 40%
AA – 3.6%
Other – 57%

83 Randomized

35 Excluded
- 32 did not fill out post test or missed ≥ 3 questions
- 3 did not specify age

61 filled out PRE and POST test

22 Missed only 1 or 2 Qs
(verbalized post test understanding of all questions)

PRE-TEST ➔ BROCHURE PRESENTATION ➔ POST TEST

Questions with Results – Patients

- 2) Hospice is where the terminally ill go for medical support. **TRUE** (chi –square= 0.69, p-value 0.40)

- 3) Only patients with terminal cancer go into hospice. **FALSE** (chi –square= 46, p-value 1.2 e-11)

- 4) Hospice patients must come from a hospital. **FALSE** (chi –square= 42.09, p-value 8.7 e-11)

- 5) A physician referral is required to enroll in hospice. **TRUE** (chi –square= 22.69, p-value 1.9 e-06)

- 6) Candidates can voluntarily opt for hospice. **TRUE** (chi –square= 8.27, p-value 0.004)

- 7) Hospice can be provided in a home setting. **TRUE** (chi –square= 16.81, p-value 4.1 e-05)

- 8) There are no doctors in hospice. **FALSE** (chi –square= 7.79, p-value 0.005)

- 9) Primary care physicians cannot provide care to their patients enter hospice. **FALSE** (chi –square= 22.47, p-value 2.1 e-06)

- 10) Hospice is only for senior citizens (above the age of 65). **FALSE** (chi –square= 8.27, p-value 0.004)

- 11) Hospice can only be discussed at the end of life. **FALSE** (chi –square= 40.14, p-value 2.37 e-10)

- 12) Mechanically ventilated patients can enter hospice. **TRUE** (chi-square 47.15, p-value 6.59 e-12)

- 13) Most hospice expenses are paid out of the pocket. **FALSE** (chi –square= 22.24, p-value 2.4 e-06)

- 14) Hospice provides care to family members involved. **TRUE** (chi –square= 29.30, p-value 6.21 e-08)

- 15) Hospice provides medications, medical necessities, and devices (i.e.: beds, commodes). **TRUE** (chi –square= 3.52, p-value 0.06)

- 16) Hospice care is multidisciplinary. **TRUE** (chi –square= 20.06, p-value 7.49 e-06)

- 17) Regardless of insurance status, one can enter hospice. **TRUE** (chi –square= 17.11, p-value 3.52 e-05)

We can see that the ratio of incorrect to correct answers was substantial throughout the table except Questions 3, 4, 9, 11, 14 and 12. To break down, on Question 3 "Only patients with terminal cancer go into hospice," which is false, all 47 people who got the answer wrong during the first survey answered correctly in the post-education survey. On Question 4 "Hospice patients must come from a hospital," which is false, 61 patients got it right the second survey, compared to only 7 who got it right in the first survey but wrong in the second time. As for Question 9 "Primary care physicians cannot provide care after their patients enter hospice," which is false, 40 patients got the answer right post education who had been wrong during the pre-educational survey; 7 who were right in the first time but wrong in the second. Questions 11 and 14 were close in numbers; 44 and 43 respectively went from wrong to right answers for the second time while 1 and 5 respectively went from right to wrong answers in the second survey. The highest variation came in Question 12 "Mechanically ventilated patients can enter hospice," which is correct, 59 patients got the correct answer only after education compared to 4 who got it wrong after being right in the first time. However, as shown here throughout the table, all questions were ameliorated by a wide difference except for Question 6. The average of right answers went from 11.87 up to 15.02. This improvement was also seen in the breakdown of the racial groups. 14.6 was the average of right questions in the African Americans population during the second survey compared to 11.5 in the first. The same goes for the Caucasian population where 11.8 was the average compared to 15.4 during the second survey. As for questions about opting for hospice care within the patient population, 45 participants agreed to use hospice care after the education session, on top of the 75 who were willing to accept hospice before and after the session while 16 were still declining it in the post-test survey. Among 45 patients, who had not considered hospice care during the first test but changed their mind to opt for it, 25 were African Americans (56%), 16 White Caucasians (40%), and 4 were of the other race (4%).

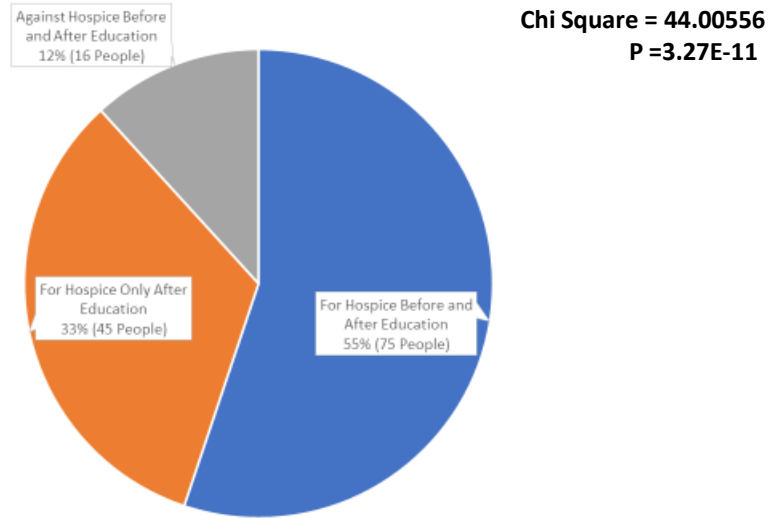**Questionnaire Data- Physicians (Figure 3)**
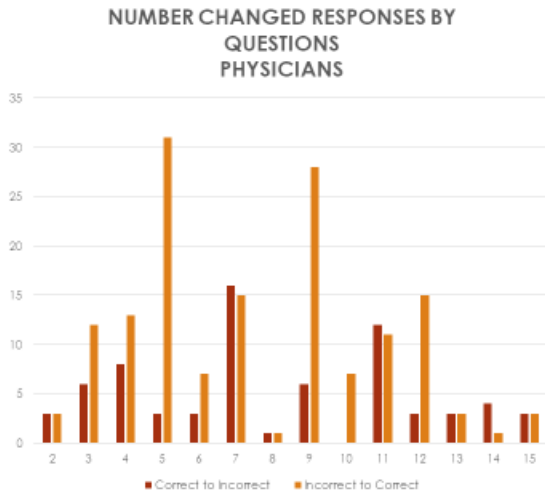
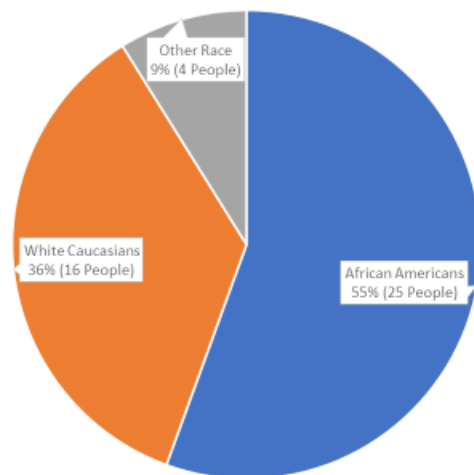**African Americans vs. Caucasians (Figure 4)**
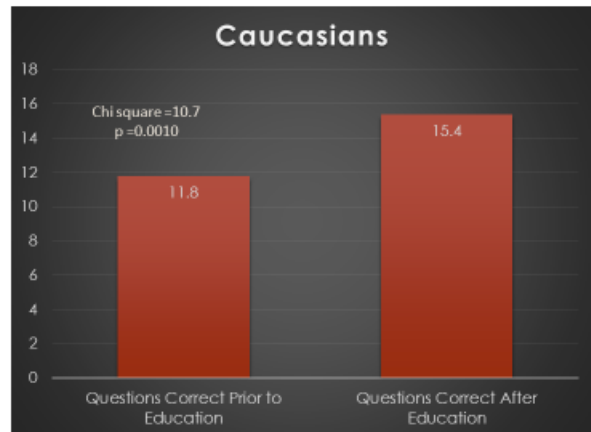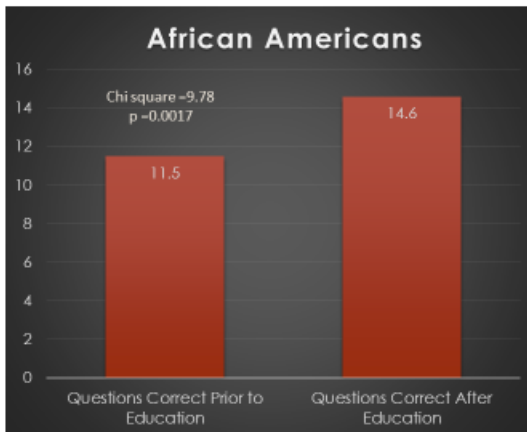
*Difference among both races were not statistically significant.

Patients – Would you choose hospice? (Figure 5)

Chi Square = 44.00556
P =3.27E-11

Against Hospice Before and After Education 12% (16 People)

For Hospice Only After Education 33% (45 People)

For Hospice Before and After Education 55% (75 People)

Patients by Race among 45 (Figure 6)

Other Race 9% (4 People)

White Caucasians 36% (16 People)

African Americans 55% (25 People)

On the other hand, the test results with doctors were a bit more complex and the variation more diverse. The following is how the physician test went. See, first, the data on values of the Chi-squared distribution.

Questions with Results – Physicians

- Question 2. Patients' chronic conditions can still be managed while in hospice. **TRUE** (chi–square= 0.04, p-value 0.84)

- Question 3. Hospice can only be provided at home or in an inpatient setting. **FALSE** (chi–square= 1.68, p-value 0.19)

- Question 4. Only essential medicine and comfort care is provided in hospice. **FALSE** (chi–square= 0.96, p-value 0.33)

- Question 5. Respite care is a term used to describe the care a patient gets while in hospice. **FALSE** (chi–square= 22.24, p-value 2.4 e-6)

- Question 6. Primary care physician must approve before a patient enters hospice. **FALSE** (chi–square= 1.23, p-value 0.27)

- Question 7. Cancer is the most common diagnosis of patients entering hospice. **TRUE** (chi–square= 0.008 p-value 0.93)

- Question 8. Palliative care and hospice are the same. **FALSE** (chi–square= 0.125, p-value 0.72)

- Question 9. Patients must have a DNR/DNI code status when entering hospice. **FALSE** (chi–square= 13.6, p-value 0.002)

- Question 10. Hospice candidates must have an end-stage or terminal condition to qualify. **TRUE** (chi–square= 6.03, p-value 0.014)

- Question 11. Hospice can only be provided for six months. **FALSE** (chi–square= 0.01, p-value 0.92)

- Question 12. Mechanically ventilated patients can enter hospice. **TRUE** (chi–square= 7.35, p-value 0.007)

- Question 13. Primary care physicians can follow their patients in hospice. **TRUE** (chi–square= 0.04, p-value 0.84)

- Question 14. Patients under the age of 30 cannot enter hospice. **FALSE** (chi–square= 1.25, p-value 0.26)

- Question 15. Hospice patients can be discharged home from hospice. **TRUE** (chi–square= 0.04, p-value 0.84)

It seems that the physicians were generally knowledgeable about hospice care. But what seems interesting is that more physicians answered Questions 7, 11 and 14 correctly pre-education but got them incorrect post-education. On the other hand, for the following seven questions, Questions 3, 4, 5, 6, 9, 10 and 12, an improvement was made in the responses after education. Last, about the most important questions, first and last, which address whether they would offer hospice care to their patients pre and post-education, 81 out of the 86 were consistent in their position, in the sense that the education did not have much impact upon their decisions. Only 4 went from not wanting to offer it to being affirmative while 1 stayed consistent with a negative answer.

Questionnaire Data – Physicians (Figure 7)
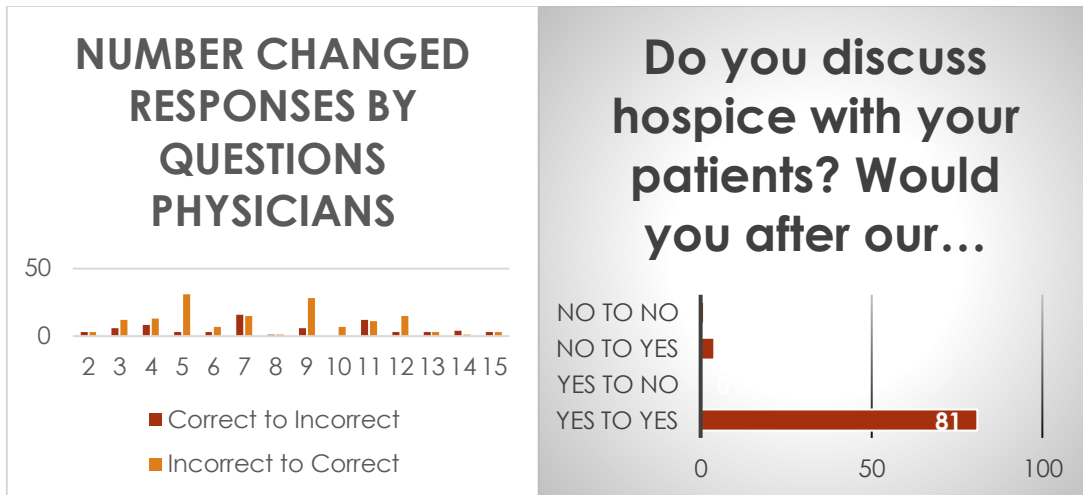
C. Discussion: Limitations and Conclusions of the Study

The study has apparent limitations. L1. The most significant limitation, as mentioned above, is that the sample size is not large enough for us to use the end data to arrive at a conclusion which may be universalizable in the U.S. context. The other limitations which might be considered of minor significance are as follows. L2. There was a time constraint on the physician side for participating in the study. L3. The patients who had family members in hospice care were not identified and the possible psychological impact on the patients was not considered. L4. The number of patients who did not wish to participate in the study was not tracked.

It is viewed that L2, the time constraint on the physicians, explains why the physicians are confused during the test. That is, they got answers to Questions 7, 11, and 14 wrong after education though they had answered them correctly before education. In contrast, given that L2 is absent during the patient test (i.e., patients were given relatively enough time) and that the patients were not literate about medical terms (note that the majority of patients at the Mercy hospitals are low-income African Americans with limited education), the case that the patient answered certain questions right pre-education and wrong post-education is rather random and sporadic, which in turn indicates that L2 is a significant factor that accounts for the confusion among the physicians.

Nevertheless, despite the limitations, the following conclusions might be made. First, physicians at Mercy Philadelphia and Mercy Fitzgerald, are learned about hospice care in general though the advanced level of knowledge related to hospice care (e.g., respite care, code status, and being able to be on a ventilator while in hospice care) is to be possessed through further education. Second, the physicians *are* discussing hospice care with their patients, which is positively evaluated. The last, which is the most important point, is that educating patients regardless of race, sex, age, *can* result in a positive perception of hospice care.

To expand the last point by focusing on the patient test, the following can be said. In the patient test, Questions 3, 4, 9, 11, 14 and 12 are those in which we witnessed the most changes in responses in the patient population, which are crucial information that can influence the mind of patients when they ponder upon hospice care. It is false to say that only patients with terminal cancer go into hospice. More than 60% of hospice patients nationwide have diagnoses other than cancer; many patients have other diagnoses or advanced stages of chronic diseases like pulmonary disease, Alzheimer's disease, renal disease, HIV/AIDS and cardiovascular or neuromuscular diseases.[76] Hospice services are available to patients of any age or illness whose prognosis is "six-month terminal condition" or "end-stage." It is false to believe that patients already admitted in the hospital are only eligible for hospice care. The care is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. But most patients

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[76] "Hospice Myths," Heartland Hospice, accessed August 28, 2017. https://www.heartlandhospice.com/patients-and-caregivers/hospice-myths/.

receive the care in their own homes.[77] It is also false to state that the patient's primary care physician (PCP) cannot provide care after the patient enters hospice care. Hospice physicians and team members can work with the patient's PCP to ensure that the patient's clinical and emotional needs are being met and that your care is being carried out appropriately; the PCP can also choose his or her level of participation in your care.[78] In addition, it is false to believe that hospice can only be discussed at the end of life. VITAS Healthcare, the nation's largest provider of end-of-life care, which is also the hospice organization in contract with Mercy Philadelphia and Mercy Fitzgerald, states:

> Ideally, the conversation begins when everyone is healthy, family members should fill out advanced directives and discuss what their healthcare wishes would be if they could not communicate themselves. Burial, funeral or memorial service plans should also be discussed. The conversations might be short in nature and continue over time, but decisions would be put in writing.[79]

It is false to believe that mechanically ventilated patients cannot enter hospice. All patients with six months or less to live can be admitted to hospice. Also, hospice provides care to family members involved; it provides bereavement care and counseling to surviving family and friends.[80] Bereavement is the period of mourning after a loss. The hospice care team works with surviving loved ones to help them through the grieving process. A trained volunteer, clergy member, or professional counselor provides support to survivors through visits, phone calls, and/or another contact methods, as well as through support groups. The hospice team can refer family members and caregiving friends to other medical or professional care if needed. Bereavement services are often provided for about a year after the patient's death.[81]

As the data shows, correcting the crucial misunderstandings about the hospice care, 45 out of 61 who had not considered hospice care during the first survey changed their mind to opt for the service. Among them, 25 were African Americans (56%), 16 White Caucasians (40%), and 4 were of the other race (4%). [See Figure 6] In other words, the education via the presentation had a positive impact on the patient group, regardless their race, in the sense that the patients were convinced that hospice care would benefit them. Alternatively put, the result is likely to evidence that African Americans' mistrust of medical profession is not proportionally a significant factor for their reluctance to the end-of-life care. Rather, the genuine misunderstanding and religious-cultural difference, which may be largely overcome via rather simply education, are the main causes.

Concerning the physician test, we expected that the physicians were not trained enough in knowledge about hospice care and that the (white) doctors after the education would move from not offering the service to recommending it. However, it turned out that the physicians at Mercy Philadelphia and Fitzgerald were generally trained in knowledge about hospice care and were recommending the service to their patients. Thus, we were not able to obtain the conjectured data based on which we could argue that black patients' reluctance of use of hospice care was attributed to their unfamiliarity to the service confused by own their physicians. Nevertheless, as the readers can see, this fact does not weaken the outcome of the patient test at all. In fact, the celebrated fact that the Mercy physicians are relatively well trained in the knowledge of the end-of-life care is due to their strong ethics education program. Affiliated with the Institute of Clinical Bioethics (ICB) at Saint Joseph's University, Philadelphia, the Mercy medical professionals (particularly ICU and ER residents, doctors, and nurses) are regularly trained at weekly Ethics Teaching Rounds by professional bioethicists from the ICB. The hospitals also hold monthly ethics committee meetings, provide ethics lectures for the residents, and promote ethics education for all physicians during the annual continuing medical education (CME) conferences.

IV. CONCLUSION

Historically rooted, the legacy of mistrust towards medical profession has been existing among African Americans. On the other hand, we have witnessed a great improvement in social justice including racial equality as our society has become culturally and

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[77] "Hospice FAQs: Everything You Need to Know," VITAS, accessed August 28, 2017. https://www.vitas.com/resources/hospice-care/hospice-faqs-everything-you-need-to-know; "Hospice Care," National Hospice and Palliative Care Organization, accessed August 28, 2017. https://www.nhpco.org/about/hospice-care.

[78] "Hospice FAQs: Everything You Need to Know."

[79] Ibid.

[80] Ibid.

[81] "What is hospice care?" American Cancer Society, accessed August 28, 2017. https://www.cancer.org/treatment/finding-and-paying-for-treatment/choosing-your-treatment-team/hospice-care/what-is-hospice-care.html.

racially diverse. Thus, it was conjectured among researchers that African Americans' mistrust might have been mitigated though it may be impossible for the positive change of some decades to completely do away with the suspicion formed over centuries. Nevertheless, our study may suggest that the change is real.

Although a large-scale research is needed to seize the data to make a universalizable appeal (which can be our next project), the current study may evidence that a brief form of education can convince black patients that end-of-life care benefits them as it rectifies misunderstanding about the service and overcomes the cultural-religious difference. This is a remarkable outcome because this process of epistemic engagement seems impossible without the preexistence of a substantive trust on the patient side. If so, among the list of reasons for black patients and family's reluctance to end-of-life care, the deep-seated racial mistrust is not a primary reason anymore in the sense that their skepticism and feeling of hurt are not too great to be overcome.

We do not take the result to say that all black patients, now, do trust their white doctors at hospitals or that racism has practically disappeared in society. Rather, it is our argument that, although unconscious racial biases as well as intentional hate-motive against black patients may exist at a personal level, the black patients tend to feel that the institutional racism of the medical profession may not exist the fact of which enables us to use education as a method of remedy to help overcome the legacy of mistrust. In other words, many black patients feel that the current institutional whiteness of the medical profession as a systemic or systematic racism does not exist, but just that the face of the medical profession has happened to be predominantly white. But with all this, it should be reminded that the research, after all, is about how the black patients *feel*, not the way it is now. A well-crafted system of ethics watchdog should be in place not to break the vulnerable trust.

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