

# Beyond Misdiagnosis, Misunderstanding and Mistrust: Relevance of the Historical Perspective in the Medical and Mental Health Treatment of People of Color

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In this article, we discuss the relationship and relevance of the historical interaction primarily between African-American culture and the medical and mental health communities, and explore the role of historical experience in contributing to mistrust and underutilization of services by people of color. We conclude that failure on the part of practitioners to go beyond clinical history gathering to recognize and acknowledge the larger historical perspectives from which they and their patients of color draw conclusions and make decisions contributes to the mistrust of the medical and mental health communities and to perpetuation of the current climate of healthcare disparities.

**Key words:** racism ■ mental health ■ cultural competence

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## INTRODUCTION

The former surgeon general's supplementary report on race and mental health identifies mistrust as a major barrier to people of color receiving mental health treatment.<sup>1</sup> Indeed, an impressive body of evidence suggests that the reason people of color mistrust medicine in general, and the mental health system in

particular, is linked to a unique and troubling history—a history of racism entrenched in medical research, diagnosis and clinical management.<sup>2-10</sup> The importance of historical context is not unfamiliar to healthcare practitioners who regularly elicit a present, past and familial history of illness from their patients. Mental health providers must often explore the meaning and interpretation patients assign to their histories, an approach we refer to as “history sensitive.”

Beyond providing useful information that can be gleaned to determine an accurate diagnosis and course of treatment, a history-sensitive approach to treatment of people of color offers motivated clinicians a unique opportunity to explore their histories as well. Consideration of one's intentional or unintentional racial biases or assumptions, for example, may not only increase clinician sensitivity but provides an important internal resource from which they can draw to help implement culturally attractive and nuanced healthcare.<sup>11</sup> On the most fundamental level, history-sensitive mental healthcare represents one important way in which the mental health system can reduce people of color's “cultural mistrust” of mental health, thereby enhancing utilization and reducing morbidity and mortality in these populations. An approach as such should also decrease patient–clinician misunderstanding and yield greater precision in diagnostic and prognostic judgments.

In this discussion, we shall: 1) offer a thumbnail sketch of the history of racism vis à vis the practice of American medicine and mental health in particular; 2) exposit specific skeptical attitudes many people of color harbor toward medicine based on their historical experiences, and 3) explore important challenges facing mental health clinicians in light of the impact, dynamics and consequences of racism and mental health.

## HISTORY OF RACISM IN MEDICINE

In offering a thumbnail sketch of the history of racism in American medicine and mental health, we make

no attempt to include every possible historical influence, statistic or figure in this article. For a fuller and nuanced account of the historical trends of race and medicine in the United States, the authors suggest that the readers refer to the ground-breaking scholarship of Todd Savitt and Harriet Washington, among others. Medical experimentation on African Americans during slavery represents an excellent starting point for our discussion of racism's diabolical legacy in American medicine.<sup>12</sup> Noting how black bodies were viewed as preferential experimental targets by the medical establishment during the antebellum South, Harris, Gorleick, Samuels and Bempong sketch a "legacy of mistrust" belonging to African Americans early in American history:

*Southern blacks became a prime source for medical school dissection experiments and autopsy specimens. This practice continued in the postbellum South in the form of 'night-doctors' who stole and dissected the bodies of blacks.*<sup>13</sup>

The outcomes of such "medical experimentation" and "research" were unfavorable, if not deleterious, to African-American culture as the medical establishment provided numerous "scholarly" opinions and articles indicating that African Americans were a lower order of human beings.<sup>14</sup> Racist sentiments defended by medical "experts" stated that African Americans were untrustworthy,<sup>14</sup> sexually promiscuous,<sup>14</sup> had an "instinct of submission"<sup>15</sup> and were ill-equipped mentally to handle work that was intellectually rigorous,<sup>16</sup> to name a few. Such pseudoscientific characterizations often justified heinous experimentation and treatment of African Americans and instilled fear and distrust.

Consider the experimentations of Thomas Hamilton, MD, a physician of the antebellum era, who in an attempt to create a medication to treat the effects of heat stroke, placed his male slave in a pit for several days with only his head exposed; the slave was given different formulas to take, after each one he would faint and had to be revived in order to continue the experiment.<sup>12,14,17</sup> In another example, Dr. J. Marion Sims, "the so-called father of modern gynecology,"<sup>12</sup> used three women slaves from Alabama to construct an operation to repair vesicovaginal fistulas.<sup>12</sup> During the span between 1845–1849, these women on whom Sims operated would each endure up to 30 painful operations.<sup>18</sup> Sims tells of the agony correlated to some of these operations:<sup>17</sup>

*The first patient I operated on was Lucy ... That was before the days of anesthetics, and the poor girl, on her knees, bore the operation with great heroism and bravery.*<sup>17</sup>

Vanessa Northington Gamble notes that this operation was a failure and Sims later tried to repair the defect by

placing a sponge in her bladder, which ended too in failure.<sup>12</sup> Only upon perfecting the procedure did Sims attempt it on white women (with anesthesia).<sup>12</sup>

Washington, author of *Medical Apartheid*, writes that Sims "was widely criticized not only by today's ethicists but also by some 19th-century contemporaries on medical and moral grounds."<sup>19</sup> Nevertheless, a marble colossus in New York's Central Park, adjacent to the New York Academy of Medicine, pays tribute to Sims, "whose brilliant achievement carried the fame of American surgery throughout the entire world."<sup>20</sup>

Based on these experiments early in American history, Alvin F. Poussaint and Amy Alexander remark:

*It is not hard to imagine, however, that news of this and similar incidents spread through the local black population, giving rise to a not unreasonable fear of white medical doctors.*<sup>14</sup>

Acts of violence by the medical establishment are illustrated by sterilization abuses on women of color. "Mississippi appendectomy"<sup>20</sup> was a phrase created by African Americans from the South to denote the routine medical practice of sterilizing African-American women who were admitted to the hospital for other operations, which continued into the early 1970s.<sup>21</sup> Such sterilization abuses have also affected Puerto Ricans and Chicanas. Joyce Wilcox writes: "by 1968, in a 30-year period, a third of the women of childbearing age had been sterilized in Puerto Rico."<sup>22</sup> During the years between 1971–1974, there were several examples of Chicana sterilization abuses where doctors misinformed Chicanas about the procedure.<sup>23</sup> In the case of Dolores Madrigal, she was told that she would die if she became pregnant too quickly after the birth of her child.<sup>24</sup> Madrigal was not alone. Nine other Chicanas also testified that they too were sterilized at the University of Southern California–Los Angeles (USC-LA) Medical Center without fully consenting the sterilization procedure they would undergo. Common themes in the class-action lawsuit against USC-LA included being "threatened" into signing consent forms and not being able to understand what was being signed because the form was written in English.<sup>25</sup>

Not only do these sterilization abuses represent a direct assault on women of color's "needs, wishes, hopes"<sup>24</sup> and bodies, but also signify a wholesale disregard for the racial and ethnic existential claims of the communities in which these women are embedded. It is not difficult to imagine how those experiences, communicated to families and children, fostered mistrust in medical practices.

Perhaps no other inhumane and unethical treatment of human beings has seized the consciousness and characterized the healthcare experience of African Americans more than The Tuskegee Syphilis experiments.<sup>12,25-28</sup> Beginning in 1932, teams of government scientists conducted a long-term study of the effects of syphilis on a

group of black men in Alabama.<sup>14</sup> It ran for more than 40 years.<sup>14</sup> Initially, the study was well intended, but it eventually went horribly awry.<sup>14</sup> Although an antibiotic treatment for syphilis was developed in the 1940s, the scientists withheld the medicines, and without the knowledge or consent of dozens of black men, they allowed the disease to run its course in them, with fatal results in some cases.<sup>14</sup> Now, 25 years after its exposure in the national media, the story of the Tuskegee Syphilis Study has arguably been crystallized in the minds of many African Americans as the quintessential motif of how the medical and scientific communities abuse, neglect and silence African Americans.<sup>14</sup>

An important question centers on just how far has the medical establishment come since the days of Hamilton, Sims, “Mississippi appendectomies,” unethical sterilizations of Latinas and the Tuskegee tragedy. A recent study by Georgetown University researchers, published in the *New England Journal of Medicine*<sup>29</sup> and recent research findings from Johns Hopkins University School of Public Health and Hygiene<sup>30</sup> suggest that many physicians practicing today still hold prejudices which might prevent them from adequately treating their patients of color, suggesting that much more work still needs to be done to cleave racism from medicine.<sup>14</sup>

## HISTORY OF RACISM IN MENTAL HEALTH

Medicine and scientific research aside, mental health bears a racist legacy too. In fact, many scholars advance that racism in medicine is interconnected with mental healthcare.<sup>14,31,32</sup> Although a full-scale genealogy of such a legacy is beyond the scope of this discussion, it is imperative to offer a brief account of mental health’s racist past to illumine the present and point to constructive suggestions for the future of mental healthcare for people of color. We cite an 1840 U.S. Census Report that deliberately falsified the insanity rates among African Americans to show that the further north blacks lived, the higher their rates of mental illness.<sup>14</sup> Also, during the 19th-century, Samuel A. Cartwright, MD invented a mental health disorder called “drapetomania,” and it was characterized by African slaves’ uncontrollable urge to escape slavery, destroy property on the plantation, be disobedient, talk back, fight with their masters and refuse to work.<sup>14,33</sup> While Cartwright’s ideas and theories were met with rejoinders from other white physicians,<sup>34</sup> we must keep in mind that a plethora of his work depicting African Americans as inferior to whites was accepted for publication in Southern medical journals, newspapers and magazines. These historical facts point to the notion that Cartwright’s hypotheses were not isolated creations, but were by-products of an American culture taken under siege by racism.<sup>19</sup>

Contemporary research on people of color is no longer characterized by such blatant racism—rather, it sub-

tlety echoes the sentiments of 19th-century race science,<sup>6</sup> and they chronicle centuries’ worth of medical misinformation, misrepresentation and hurtful practices that have led to current psychiatric practices that privilege theories of ethnogenetic vulnerability or inferiority.<sup>14</sup> Modern-day examples of psychiatry’s crypto-racism are rampant. For example, in 1955, the *Armed Forces Medical Journal*<sup>35</sup> represented the first published account of the highly debated “Puerto-Rican syndrome.” The Puerto-Rican syndrome has not been well understood and represents a slippery mental disorder to define. According to Margarite Fernandez Olmos and L. Paravisini-Gebert, “[the] Puerto Rican syndrome is a malady that varies in description depending on one’s medical/anthropological/political perspective and/or agenda.”<sup>36</sup> Patricia Gherovici, in her award-winning book *Puerto Rican Syndrome* attempts to clarify this pathology further and argues that “... the Puerto Rican syndrome returns disguised under a different name ... *ataque de nervios* in [the DSM-IV’s]<sup>37</sup> Culture-Bound Syndromes Appendix.”<sup>38</sup> Gherovici levels a stinging critique on the racist trappings of this disorder and writes:

*The Puerto Rican syndrome was a new label for manifestations that were old, known, and culturally sanctioned ... the denomination of Puerto Rican syndrome superficially stereotyped an entire national group and transformed a customary experience into a serious mental health problem with an eccentric location.*<sup>42</sup>

Having said these things, it’s fair to say that the inventions of Puerto Rican syndrome and *ataque de nervios* are not far removed from drapetomania to the extent to which all three disorders are cultural or racial pathologies that have been determined by Anglo-American mainstream culture that has considered its own way of being as the universal norm and categorizes “the other” as the exception.<sup>39</sup>

Pathologizing cultural and racial difference has taken various forms through the years. International research<sup>4,6,40</sup> has found a positive correlation between racism and overdiagnosis of serious<sup>41-43</sup> and underdiagnosis of less serious mental disorders.<sup>4</sup> For example, since the 1970s to the present, international studies have reported overdiagnosis of schizophrenia and underdiagnosis of affective disorders among African Americans, Afro-Caribbeans and Latinas/os,<sup>44</sup> compared with the overall prevalence of these disorders in the psychiatric inpatient population.<sup>7,8,45,46</sup> Studies indicate at least two reasons for this trend: clinician prejudice<sup>4</sup> and lack of contextual diagnostic analysis.<sup>5,6,47-49</sup>

One form of clinician prejudice is when the clinician intentionally or unintentionally views the patient of color as incapable of complex structured cognitive mechanisms typical of psychoneurosis.<sup>4</sup> As such, the

psychological issues of people of color seem simpler, elementary and typical of textbook sociopathic behavior, and may be further characterized as emotionally unstable, inadequate personality, simple maladjustment and temperamental unsuitability.<sup>4</sup> Research literature suggests that weak-willed contextual diagnostic analyses have disproportionately led clinicians to misinterpret spiritual beliefs<sup>50</sup> and “cultural mistrust”<sup>14,51</sup> as pathological.<sup>52</sup> Overall, racist ideologies and paper-thin contextual diagnostic analysis are believed to contribute to inappropriately admitting people of color to psychiatric hospitals and consequently further heightening their mistrust of mental healthcare.

When referring to the object of African Americans’ distrust of mental healthcare, it may be posed which came first: the chicken of the structural factors that shape the entire mental healthcare *system*, or the eggs of *individual* clinicians in that system. In our minds, the chicken came first. According to the surgeon general, “Research documents that many members of minority groups fear, or feel ill at ease with, the mental health system.”<sup>53</sup> The structure of the American medical and mental healthcare systems has inherited and been deeply shaped by the Anglo-American culture and its subsequent downbeats of racial injustice.<sup>56</sup> Washington comments how that culture negatively influenced the culture of medicine and writes:

*... physicians had every motive to skew narratives against their black subjects, not because they were especially racist or unfair (although many were) but because the culture of American medicine has mirrored the larger culture that encompassed enslavement, segregation and less dramatic forms of racial inequality.”<sup>20</sup>*

## HISTORY OF RACISM AND PUBLIC HEALTH

Although African Americans, Latinas/os, Asians and other people of color have experienced racial subordination in different ways and degrees, the fact still remains that being treated without dignity and decency by the medical establishment has fostered distrust, discontent and disconnect among people of color towards medicine.<sup>14,54,59</sup> Such dynamics have played out in some interesting ways. For instance, several empirical studies have found that African Americans disclose significantly less to white therapists than their black counterparts. Several studies reported by The Commonwealth Fund 2001 Health Care Quality Survey reveal other discrepancies between people of color and medical care.<sup>55</sup>

One such report indicated that Latinas/os, African Americans and Asian Americans are more likely to feel treated with disrespect by healthcare professionals than whites.<sup>62</sup> Likewise, 18% of Latinas/os, 16% of African Americans and 13% of Asian Americans said that they

felt disrespected because of inability to pay, to speak English or of their race/ethnicity, whereas only 9% of whites were in sympathy with that feeling.<sup>62</sup> Furthermore, research points to the idea that people of color are also skeptical of the effectiveness of communication between them and physicians. In one study, 32% of Latinas/os, 25% of Asian Americans and 23% of African Americans said that they had problems understanding the doctor, feeling the doctor listened and had questions but did not ask, whereas only 15% of whites felt the same way.<sup>62</sup> All in all, 15% of African Americans, 13% of Latinas/os and 11% of Asian Americans believed that they would receive better healthcare if they were of a different race/ethnicity, as compared to 1% of whites who felt the same way.<sup>62</sup> Such findings reveal the widespread skepticism that many people of color continue to hold towards the mental health system and suggest that an awareness of how their unique historical context shapes their perception of ‘traditional’ medicine may be important first steps to providing culturally sensitive and relevant healthcare.

For example, it may not be readily apparent to the treatment provider who interacts with a person of color that more than *200 years’* worth of anecdotal and documentary evidence on racism in medicine and mental health cuts across age, gender and different racial/ethnic groups, leading to a high degree of vigilance, mistrust and disdain towards the medical establishment in general and mental health in particular.<sup>14,56-57</sup> Despite any perceived benefits, which might accompany the “cultural mistrust” on the part of people of color, the devastating effects are clear. Mistrust forecloses engagement with mental health services,<sup>56,58</sup> thereby increasing and exacerbating mental health issues that pose serious health conditions leading to increases of mortality and morbidity. The World Health Organization (WHO) reports that:

*Mental illnesses affect ... chronic conditions such as cancer, heart and cardiovascular diseases, diabetes and HIV/AIDS. Untreated, they bring about unhealthy behavior, non-compliance with prescribed medical regimes, diminished immune functioning, and poor prognosis.*<sup>59</sup>

Studies indicate that untreated or undertreated depression (the leading cause of disability ahead of all other diseases and what will be the second largest killer after heart disease by 2020)<sup>60</sup> represents a risk factor for comorbid life-threatening behaviors such as alcohol consumption, drug abuse and suicide.<sup>61</sup> In light of these realities, racism in mental health is not merely a historical event or artifact but a glaring public health issue with its roots firmly planted in the soil of historical atrocities.<sup>20</sup>

## Challenges Facing Clinicians

In attempting to provide meaningful treatment to people of color in the current climate of mistrust and healthcare disparities, clinicians of all ethnic and racial backgrounds are faced with myriad challenges. The first challenge, and arguably the most illuminating and difficult, demands an honest and thorough self-examination of conscious and unconscious attitudes about race and the legacy of racism in the United States.<sup>62</sup> The second challenge for clinicians will be to keep at arm's length assumptions of cultural homogeneity<sup>4</sup> and offer contextually based mental healthcare.<sup>63</sup> "Contextually based" care means that the mental health professional can offer an extensive and critical interpretation of the historical, cultural, spiritual,<sup>64</sup> political, social and philosophical underpinnings of racism in medicine and draw connections on how these factors impact the self-identities of communities and individuals therein.<sup>52</sup> Such activities, which require conscientious practice and ongoing cross-cultural training, should result in more accurate assessments of the needs of people of color and relevant environmental influences.<sup>65</sup>

While the effectiveness of cultural competence strategies merits further investigation,<sup>66</sup> preliminary studies indicate that some of these strategies represent potential ways to improve quality and eliminate racial/cultural disparities in medical care.<sup>67</sup> A quick review of current literature suggests that cultural competence educational programs that are effectively integrated throughout all years of medical school<sup>68</sup> coupled with one year of ongoing training during residency, when it might be most relevant and memorable,<sup>69</sup> signifies an important step in training culturally competent physicians.<sup>70</sup>

Another important way to enrich the climate of medical education and research is admitting into medical school students and professors of color who have demonstrated an understanding of the manner in which people of diverse cultures, different socioeconomic status and belief systems perceive health and illness and respond to various symptoms, diseases and treatments.<sup>71</sup>

The last, but certainly not the least, potential method for cultural competence training is mandatory continuing medical education credits that include small group and countergroups (didactic and experimental) to foster self-examination of unconscious and or calculated cultural insensitivities,<sup>72</sup> and board examinations dealing with matters of cultural competency, sensitivity and healthcare disparities.<sup>73</sup>

An appreciation of the historical burden as outlined above will hopefully lead clinicians to provide more enriched clinical encounters and help clinicians discern milder forms of paranoia (such as distrust) as nonpathological and, in turn, lower the high incidence of psychiatric hospitalizations among people of color, particularly African-American men.<sup>63</sup> Furthermore, assessments informed by an understanding of the patient's cultural

and ethnic identity within the context of his or her social environment<sup>53</sup> can function as a primer to other forms of culturally competent methods of treatment such as ego psychology, empowerment and complementary and alternative medicine (CAM)<sup>74-78</sup> from a particular racial/ethnic slant.<sup>79</sup>

## CONCLUSIONS

The National Alliance on Mental Illness 2006 study issued the United States a grade of "D" for helping adults with serious mental illnesses, after conducting the first comprehensive, state-by-state analysis of mental healthcare systems in 15 years.<sup>80</sup> In light of the dual burden created by the legacy of racism and the reality of cultural mistrust, mental health clinicians must be willing to embrace and employ clinical assessments and interventions that are contextual and multidimensional, fashioned on the complexity of the historical experience of each patient of color and not on oversimplification and reductionism. Such an approach will reduce the likelihood that "history will repeat itself" through future reports identifying chronic mistrust as a major barrier to people of color receiving mental health treatment.

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## MEDICAL ONCOLOGIST – GERIATRIC MEDICINE

The H. Lee Moffitt Cancer Center & Research Institute and the Department of Interdisciplinary Oncology at the University of South Florida College of Medicine are seeking an Assistant/Associate/Full Professor to work in the Senior Adult Oncology Division. The H. Lee Moffitt Cancer Center & Research Institute is an NCI-designated Comprehensive Center, and adjacent to the Health Sciences Center of the University of South Florida.

Successful candidates must have a M.D., be ABIM board certified in Internal Medicine and board certified or board eligible in Hematology and/or Medical Oncology. Experience in a multi-disciplinary university clinical practice setting is preferred. A strong background and commitment to develop translational and clinical research studies is required. A track record of funding and clinical experience in Geriatric Oncology is highly preferred.

Florida medical license or eligibility required. The position may be tenure earning and salary is negotiable. Appointment at the level of Associate/Full Professor requires a minimum of five years experience at the Assistant/Associate Professor rank.

**Please reference position no. 13194.** Interested candidates should send a curriculum vitae to Lodovico Balducci, M.D., Professor and Chief, Senior Adult Oncology Division, c/o Kathy Jordan, MBA, Supervisor Recruitment & Appointment, Department of Interdisciplinary Oncology, 12902 Magnolia Drive, Tampa, Florida 33612. For inquiries contact Dr. Balducci at 813-745-8658 or [lodovico.balducci@moffitt.org](mailto:lodovico.balducci@moffitt.org). The position is open until filled and application review begins July 16, 2007.

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