

## A Culture of Stigma: Black Women and Mental Health

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The exploitation of Black bodies for scientific purposes has occurred throughout U.S. history at the hands of White scientists (Achter 62). Two of the most notable cases that resulted from scientific testing of African Americans are the Tuskegee Syphilis Study of the 1930s on African American men, and the experimentation of enslaved Black women that led to the founding of modern gynecology in the late 1850s (Ojanuga 28). In African American communities, a distrust of professional medicine related to unethical human testing still exists (Wasserman et al 177). This becomes a larger issue when it impacts pursuit of treatment, which may pose a disadvantage to those in African American communities. For Black women in particular, the issue of stereotype has been another intersecting factor affecting use of medical care and support, especially for mental illness. The image of the “strong Black woman” disinclines Black women to show vulnerability, while also adding to a culture of stigma regarding mental illness (Beauboeuf-Lafontant, “Listening Past the Lies that make Us Sick” 394). Through performance of such controlling scripts, Black women with mental illness may not be treating their mental issues, but instead masking them. Historical medical experimentation, distrust of medical institutions, the trope of the “strong Black woman,” which operate uniquely to Black communities, stresses the need for culturally inclusive mental healthcare. This research also has implications for mental health initiatives and public policy imperatives in other communities of color.

This project explores the history of medical experimentation on African Americans, the resulting distrust of medical institutions, and the stereotypes of Black women that may affect cultural views of mental illness. Using case study method, this research suggests that the intersection of these three factors influences Black women’s pursuit of and experiences with mental healthcare. This research examines and draws from the oral history of three Black women

under the age of 25 who live in the Atlanta area, and are in the process of diagnosis or diagnosed with mental illnesses. All three women currently attend college in Atlanta. To protect their privacy, the names the participants in this project have been shortened or changed. While data is descriptive rather than conclusive, the narrative of each subject reveals important themes useful for larger studies and mental health discourse about Black women.

The literature used in this project fall into four main categories: The history of sexual and scientific exploitation of Black people; medical mistrust and its implications for mental health pursuit; race, gender, and culture's role in experiencing mental illness; and imperatives for culturally inclusive mental healthcare.

### **A History of Experimentation and Medical Mistrust**

The experimentation of Black bodies has a long and disturbing history in the United States. One of the most known events tied to that history is with physician J. Marion Sims. He is mostly known as the “father of modern gynecology,” given that title because of his discovery of an effective cure for the vesicovaginal fistula, and because he held the most breakthroughs in the field of gynecology. What is not discussed enough are the people used as his testing subjects: enslaved Black women.

In his experiments on slave women, he would not ask for their consent. Because the women were enslaved, they were volunteered to Sims by their slave masters, thus providing them no agency in the exploitation of their bodies. Sims conducted experiments and essentially perfected his craft on these women's bodies (Ojanuga 29). It is recalled from his autobiography that he praises three slave women, Lucy, Betsy, and Anarcha, “...whose endurance allowed him to make a breakthrough that would aid all women” (Lederer 20). The sentiment that Sims had

toward the three women he forcefully experimented on is one seen repeatedly as the general population benefits through the dehumanization of a systematically disenfranchised group.

The utilization of Black bodies for scientific and medical breakthrough shaped Black Americans views of the medical profession and medical institutions. Even outside of the founding of gynecology, poor and enslaved people were used to guinea pigs for doctors to practice medical procedures on. This “legacy of mistrust,” or the continuation of a discomfort of medical institutions, carried on after slavery into the 20<sup>th</sup> century. By the 1930s, the fear and suspicion became justified again as Tuskegee Syphilis Study began (Harris et al 631).

The Tuskegee Syphilis Study of the 1930s joins the list another horrible event in the medical history of Black Americans. In the 1930s, general fear arose about the syphilis disease, given the euphemism “Bad Blood” (Lederer 21). Scientists at the United States Public Health Service began the study by testing around 400 African American men in Alabama. Deceit was practiced in this study by misinforming the participants about what they would be doing. The 400 men were told that they would be receiving treatment for syphilis, when they were being injected the blood. This study spans from 1932 to 1972, when the study was terminated by the Department of Health, Education, and Welfare.

Contemporarily, medical abuse has taken the form of involuntary sterilization of poor women and women of color. In *Voices of the Sterilized*, scholar Rebecca Kulchin argues that in pre-World War II 20<sup>th</sup> century America at the height of the eugenics movement, impoverished white women were more vulnerable than women of color. Black women and Latinas were typically not targeted because hospitals where sterilizations took place were segregated hospitals (Wasserman et al 178). It is not until the postwar era when *Plessy v. Ferguson* is overturned that women of color begin being targeted. By the 1960s and 1970s, with controlling images such as

the “welfare queen” and the “pregnant pilgrim” coming into political discourse, the overlap of race and poverty take shape in a new way (Kulchin 133).

The concept of consent makes the United States’ history with sterilization very disturbing. As with the forced dissection of enslaved women’s bodies and the deception involved in the Tuskegee study, sterilization often involved the gaining “consent” from women in drugged states after surgery, days after the sterilization took place, and sometimes never getting consent from women at all (Kulchin 134). Often when looking at medical history and documentation, it seems as if patients were consenting. However if one notices how the “consent” was earned, it becomes evident that many of the surgeries that took place were, in a sense, forced.

As with the enslaved women who were victim to J. Marion Sims’ experimentation, the 400 African American men who participated in the Tuskegee Syphilis Study under false premises were used to benefit the greater population. While other groups benefit from the suffering experienced by Black Americans, one is left wondering how this traumatic history of subjugation impacts Black Americans contemporarily.

In a study produced by Shavers, Lynch, and Burmeister, African Americans’ willingness to participate in medical research was observed. Nearly 200 individuals from various ethnic backgrounds participated, majority of which were African American. When asked if they had prior knowledge about the Tuskegee Syphilis Study, majority of participants responded that they did have prior knowledge of the study. Of those participants, it was noted that majority had decreased trust in medical research as a result of their knowledge of the Tuskegee study. Upon analysis of this research, Shavers et al posits that “...the suspicion and distrust resulting from racial discrimination more than likely contribute to the distrust that impedes African American

participation in medical research studies...” The concept of medical mistrust can not only be seen from a historical perspective but also from the perspective of sociological “social distance.”

“Social distance” is a concept that refers to one's place in society compared to someone else's place in society. Social distance includes race and ethnicity, gender, sex, sexuality, age, and social class. In his research *Social Distance in the Clinical Encounter*, Jason Schnittker applies the social distance perspective to physician trust. Throughout his research he finds that people of lower socioeconomic statuses and people of color are more skeptical toward medicine in general, which may be tied to their knowledge of historical medical abuse. Schnittker also finds that patients of lower income and patients of color are not given as much information and “...less elaborate justification for treatment decisions” (219). These same groups may experience less responsiveness from physicians when seeking medical care because of their place in society relative to their physician's social distance.

Knowledge of historical abuses in medical care as well as social distance prove to be some driving factors in uneasiness that African Americans, as well as other people of color, feel toward medical institutions. In their 2001 study on the willingness of African Americans to participate in medical research studies, Shavers et al found that participants believed that racial and ethnic groups were treated differently by medical research studies. Participants also indicated that minorities bear the most risk in medical research studies. The researchers also noted that there was a “reduction in the level of trust in medical research as a result of knowledge of the Tuskegee study” and that this trust was greatly related to misgivings about partaking in medical research.

One study that surveyed only African Americans show that patients believe that “...[being] treated like ‘guinea pigs’..., [lack of] trust in the medical system, and...not being

approached for enrollment in a proper manner” were all major reasons to not participate in clinical trials (Harris et al 632). With this, we see that patients are aware of historical treatment of African Americans as testing subjects, roles that are often relegated for animals. Social distance is also present in how they are approached for participation. This may be interpreted as not being acknowledged as proper subjects for clinical trials based on race or class.

### **The “Strong Black Woman” and the Impact of Culture and Gender on Perceptions of Mental Illness**

The concept of “controlling images,” developed by Patricia Hill Collins, explores the control of the white elite on confining Black womanhood to negative stereotypes. She writes that “[the] dominant ideology of the slave era fostered the creation of several interrelated, socially constructed controlling images of Black womanhood, each reflecting the dominant group’s interest in maintaining Black women’s subordination” (78). While Black women have renounced those images as representations of themselves (Beaubouef-LaFontant, “You have to Show Strength” 31), they created the “strong Black woman” in response. The image of the “strong Black woman” conveys that Black women have “...built-in capacities to deal with all manner of hardship without breaking down, physically or mentally” (hooks 70). While physically the “strong Black woman” seems like a “controlling image,” emphasis should be placed on the role that Black women take in developing the term. Development of this term should be seen as a form of resistance to “controlling images,” which are noted by Hill Collins to have been created by the white elite to oppress Black women. One of the oral histories that I collected was from a nineteen year old Atlanta student of East African heritage, ZK. She felt positively about the “strong Black woman” image, explaining:

...she's compassionate, she's caring, and she's understanding, she's willing to help...but mostly she's taking care of herself because honestly, as a black woman, I feel like no one else will take care of me if I don't...Unless you really care about me and love me, I don't trust you.

ZK's description of the "strong Black woman" emphasizes the societal place of black women in U.S. society and how Black women have to possess strength to carry them through rough times. Even though the image may be used for self-empowerment, it should still be questioned because it is often used as a way to chastise Black women who openly suffer from mental illness (Beauboeuf-LaFontant, "You have to Show Strength" 31). Another interviewee, twenty-three year old writer Ashley, views the image negatively:

...With Black women, we're told we need to be strong, we need to take on the worries of the world...So when we break down, or it comes out that we have a mental illness I think a lot of times we feel like we failed [at being strong], like we're not as strong as we should be, or we might feel guilt...I know I've felt like that...

Ashley's belief that the "strong Black woman" image is problematic because of its emphasis on caring for others and attaching the stigma of failure to any woman who exposes her mental health status attests that the Black woman "is the mule of the world" (Neale Hurston 1937). Black women must do the duties of others and closet their personal struggles.

Openly suffering from mental illness is something that is highly tabooed in the cultural relations of Black women (Schreiber et al 41). Among researchers of Black women's experiences with depression, being strong repeatedly emerges as a key factor in their experiences



(Beauboeuf-LaFontant, “You have to Show Strength” 35). Because of Black women’s history of subjugation, often Black communities may possess the idea that due to their long history overcoming racism and discrimination, which attacked their mental states as “inferior,” Black women have the ability to muster through adversity (hooks 70). Interviewee ZK had this to say about Black and African communities’ views on mental illness:

There’s a lot less compassion in the Black community [toward mental illness]...mostly because of our history...because we are an oppressed race as Black people...so, there’s a lot less compassion because we’ve had such a hard history, because we’ve been expected to just go through it.

Another common perception in Black communities is that mental illness is not something that affects Black people (Clark Amankwaa 26). The pressure of having one’s mental ability and authenticity as a racial or ethnic minority questioned due to mental illness can be extremely stressing on Black women. Some Black women living with mental illness have expressed donning the “strong Black woman” façade so much that they came to believe it was real (Beauboeuf-LaFontant, “You have to Show Strength” 32).

In her 2007 study of Black women who have mental illness, scholar Tamara Beauboeuf-LaFontant interviewed forty-four Black women and focused on their perceptions of strength in its relationship to their own mental illness. Many of the women felt that they were expected from childhood to possess the characteristics of the “strong Black woman.” The women felt that they were pushed to place others’ needs before their own, and that asking for “help,” “assistance,” or “support” revealed their weaknesses.

What remains significant about dialogue related to the “strong Black woman” and its impact on Black women who live with mental illness is the understanding of how culture and gender impact women’s initiative to pursue mental health care. In 2000, Schreiber et al produced a study of Black West-Indian Canadian women’s management of depression and the stigma associated with it. The concept of strength as a management tool for depression recurred in their study. They broke down the “strength” into four categories: dwelling on their depression in which the women felt their depression was controlling them; diverting themselves from their depression is when the women would distract themselves so they would not constantly think about their depression; regaining composure consisted of regaining control of their lives and returning to a more positive mood (spirituality is involved in this faction); and trying new approaches, which is when the women would be opening up about their depression. In conclusion, Schreiber et al stresses the importance of a “culturally competent care” that addresses the needs of non-white, non-Western groups. Emphasis is also placed on how clinicians should address their own prejudices and understand that some patients are not comfortable discussing aspects of their depression due to sociocultural stigma.

Linda Clark Amankwaa also addresses culture as an important factor in treating and dealing with depression. In her research of postpartum depression, culture and African American women, Clark Amankwaa underlines that culture is instrumental in how groups talk about the depression they experience, explaining that there is “...a distinct language related to depression” for non-white groups. What is perhaps most interesting about Clark Amankwaa’s research is her utilization of the concept of “blues” related to African American women’s experience with depression. She writes that “...the blues’ [are] a mid-point between feeling down and serious depression...” (26). This unique use of language in dialogue about depression among African

American women should be used and comprehended by clinicians when working with African American female patients. It may be suggested that the inclusion of cultural sensitivity in mental health care would prove beneficial for those of non-majority groups.

### **Imperatives for Inclusive Health Care for Communities of Color**

Throughout this project multiple issues related to the reluctance of Black women to pursue mental health care have been addressed, such as possessing strength as a sign of emotional stability, and the lack of cultural sensitivity in mental health treatment. How can these issues help improve the state of mental health care for Black and of color communities? Trust as a mechanism for inclusion of Black communities should be considered by mental health institutions. This can be done by opening dialogue about past abuses of minority participants in medical research studies (Shavers et al). The acknowledgement of the history between the minority group and the institution can allow for a new relationship to begin.

Involvement of religious institutions can also prove beneficial. Karen Edwards' 1987 study on the importance of spirituality and religion on the psychological health of Black people displayed that majority of the participants in her study (all of which were Black) responded that religion was central to their mental health and well being. They expressed that because their ancestors were able to overcome hardship with religion, they could do the same. Possibly hosting community-based awareness sessions about mental health in religious and spiritual facilities would help to not only inform the public but to integrate spirituality and religion into mental health treatment.

The integration of religion into private sessions between clinician and patient can also help clinicians understand the "nature...and strength of [their] beliefs" (Schreiber et al 43).

Delving outside of the Western model of secularizing mental health care, institutions and clinicians should incorporate religion and spirituality in a non-Western sense to understand how the mind and the body intertwine and co-exist (Wilson 49).

Due to the higher use of public mental and medical health facilities of minority groups in the U.S. than of white Americans (Smith 133), an increase of community health centers may benefit communities of color. Within these health centers, adequate and timely care should be given to all patients. The issue of ranking patients by severity of disorder should not happen. Interviewee ZK explains her difficulty with seeking therapy on her university's campus:

I tried seeking it on campus...I was put on a waitlist because I wasn't suicidal enough...So, if you aren't having suicidal thoughts, and if it's not impeding on your life enough, then you're put on a waiting list and you're usually put at the bottom of that waiting list...and even though I was panicking every day, I wasn't important enough...

With community health centers, health workers that match the racial or ethnic background of the target group should be included in the expansion of mental healthcare (Harris et al 633; Smith 139; Thompson et al 216). A study of Black women and Latina women's responsiveness and experiences with their physicians conducted by Thompson, Valdimarsdottir, Winkel, and Jandorf displays that the women felt less comfortable with physicians of a different race or ethnic background than their own. The social distance perspective explains this: the higher the social distance between the patient and physician, the lower the comfort of the patient" (Schnittker 231). Patient comfort is imperative to their willingness to pursue treatment, thus their needs the most significant. Similar racial and ethnic background can also be beneficial to

understanding how certain groups deal with mental illness (Schreiber et al, “Being Strong” 44; Schreiber et al, “The Contexts for Managing Depression...” 516).

When asked if mental healthcare is accessible, all three interviewees agreed that mental healthcare is inaccessible to many who need care. Twenty year old poet Danielle shares her views:

Is it accessible? Definitely not. Because the experiences that I have, I’ve always been asked if I have insurance...and if you don’t have insurance, it’s going to be extremely expensive...I think it’s only accessible for...those who are...in a better circumstance. And I think that’s extremely unfair. Mental health is important for every single person...and not just for those who can afford it.

Researching and observing successful mental health groups and organizations may help. These groups and organizations should serve as a template for future initiatives for communities with little or no mental health resources for constituents. For example, The Black Women’s Mental Health Project based in London, England is an organization managed by Black women who live with mental illness. They serve as a support system for Black women to speak for themselves and demand adequate care and service that mental health institutions should provide (Wilson 47-48).

The National Alliance on Mental Illness (NAMI) dedicates itself to support, educate, provides awareness, advocate, and research for mental illness. NAMI functions in multiple locations around the United States providing a support system to those living with mental illness and their families and friends. The organization steps above community support by taking action in legislation that impacts mental illness (NAMI.org).

## **Conclusion**

The intersection of history, distrust in medical institutions, and controlling script of the “strong Black woman” impact Black women’s willingness to partake in mental health services. Through the analysis and understanding of four women’s oral histories about their growth and experiences with mental illness, we understand and learn how mental illness and the surrounding culture of mental illness in culturally based communities impacts the lives of Black women. Their stories impact and influence initiatives for mental health care in disadvantaged locations. The continuation and expansion of the various studies and research about mental illness and minority groups discussed in this project remain imperative to transforming the current state of mental health and medical institutions.

### Works Cited

- "About NAMI." *NAMI*. N.p., n.d. Web. 26 Mar. 2013.
- Achter, Paul, Roxanne Parrot, and Kami Silk. "African Americans' Opinions about Human-Genetics Research." *Politics and the Life Sciences* 23.1 (2004): 60-66. Web. 13 Jan. 2013.
- Beauboeuf-LaFontant, Tamara. "Listening Past the Lies That Make Us Sick: A Voice-Centered Analysis of Strength and Depression among Black Women." *Springer Science and Business Media* (2008): 391-406. Web. 14 Jan. 2013.
- Beauboeuf-LaFontant, Tamara. "You Have to Show Strength: An Exploration of Gender, Race, and Depression." *Gender & Society* 21.1 (2007): 28-51. Web. 14 Jan. 2013.
- Clark Amankwaa, Linda. "Postpartum Depression, Culture and African-American Women." *Journal of Cultural Diversity* 10.1 (2003): 23-29. Web. 26 Feb. 2013.
- Edwards, Karen L. "Exploratory Study of Black Psychological Health." *Journal of Religion and Health* 26.1 (1987): 73-80. Web. 14 Jan. 2013.
- Harris, Yvonne, Philip B. Gorelick, Patricia Samuels, and Isaac Bempong. "Why African Americans May Not Be Participating in Clinical Trials." *Journal of the National Medical Association* 88.10 (1996): 630-34. Web. 26 Feb. 2013.
- Hill Collins, Patricia. *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. New York: Routledge, 2000. Print.
- Hooks, Bell. *Sisters of the Yam: Black Women and Self-Recovery*. Boston, MA: South End, 1993. Print.
- Kluchin, Rebecca M. "Locating the Voices of the Sterilized." *The Public Historian* 29.3 (2007): 131-44. Web. 13 Jan. 2013.
- Lederer, Susan. "Experimentation on Human Beings." *OAH Magazine of History* 19.5 (2005): 20-22. Web. 26 Feb. 2013.
- Neale Hurston, Zora. *Their Eyes Were Watching God: A Novel*. New York: Perennial Library, 1990. Print.
- Ojanuga, Durrenda. "The Medical Ethics of the 'Father of Gynaecology', Dr. J. Marion Sims." *Journal of Medical Ethics* 19.1 (1993): 28-31. Web. 13 Jan. 2013.
- Smith, Elsie J. "Mental Health and Service Delivery Systems for Black Women." *Journal of Black Studies* 12.2 (1981): 126-41. Web. 14 Jan. 2013.

- Schreiber, Rita, Phyllis Noerager Stern, and Charmaine Wilson. "Being Strong: How Black West-Indian Canadian Women Manage Depression and Its Stigma." *Journal of Nursing Scholarship* 32.1 (2000): 39-45. Web. 26 Feb. 2013.
- Schreiber, Rita, Phyllis Noerager Stern, and Charmaine Wilson. "The Contexts for Managing Depression and Its Stigma among Black West Indian Canadian Women." *Journal of Advanced Nursing* 27 (1998): 510-17. Web. 26 Feb. 2013.
- Schnittker, Jason. "Social Distance in the Clinical Encounter: Interactional and Sociodemographic Foundations for Mistrust in Physicians." *Social Psychology Quarterly* 67.3 (2004): 217-35. Web. 26 Feb. 2013.
- Shavers, Vickie L., Charles F. Lynch, and Leon F. Burmeister. "Factors That Influence African-American' Willingness to Participate in Medical Research Studies." *American Cancer Society* 15.91 (2001): 233-36. Web. 26 Feb. 2013.
- Thompson, Hayley S., Heiddis B. Valdimarsdottir, Gary Winkel, Linda Jandorf, and William Redd. "The Group-Based Medical Mistrust Scale: Psychometric Properties and Association with Breast Cancer Screening." *Prevention Medicin* 38.1 (2004): 209-18. Web. 26 Feb. 2013.
- Wasserman, J., M. A. Flannery, and J. M. Clair. "Raising the Ivory Tower: The Production of Knowledge and Distrust of Medicine among African Americans." *Journal of Medical Ethics* 33.3 (2007): 177-80. Web. 13 Jan. 2013.
- Wilson, Melba. "Black Women and Mental Health: Working Towards Inclusive Mental Health Services." *Women and Mental Health* 68 (2001): 34-51. Web. 14 Jan. 2013.