

HOW LUPUS CROSSED THE COLOR LINE: CHRONIC ILLNESS AND THE
REPRODUCTION OF RACISM IN HEALTH CARE

by

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DEDICATION

To all of the young Black and brown women with lupus.

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ABSTRACT

The treatment of lupus speaks to the transformation of health care through civil rights and the ongoing indifference to Black pain. In one sense, the documented history of lupus dates to 400 BC, where skin diseases were commonly grouped together. In another sense, as research techniques changed, so did the understanding of the conditions that created lupus. Lupus and tuberculosis were thought to be of the same origin until antibiotics were discovered, curing TB but not lupus. Moreover, it took till the 1950s for researchers to investigate the epidemiology of this non-communicable disease. When they did, their research upended the assumption that middle-class white women were the most susceptible to this skin-disease. With the transformations that came with the Great Migration and the Medical Civil Rights Movement, Black people started getting more access to medical facilities that were previously “white only.” Now that Blacks had access to more equitable healthcare, awareness of Black health and Black illness grew. By the 1980s, researchers and clinicians started associating lupus with African Americans, effectively demonstrating how lupus had crossed the color line and become a civil rights issue. Today Black women are three times more likely to develop and be diagnosed with lupus than white women. Although some researchers have tried to attribute these staggering differences to genetic differences, this disproportionality can be better explained by the effects of structural racism. Overall, white Americans have higher socioeconomic status, live in better environments, and have better access to healthcare than Black Americans. By failing to address the systemic causes which have caused Black women to have the highest incidence of lupus, the healthcare system reproduces racism.

IN THE BEGINNING

“I have lupus and that is why I put it in ‘Queen Sugar.’ I have been in remission for twenty years but I did want to make sure that we create spaces to talk about.” – Ava Duvernay, July 2019

Diagnosing Lupus: A Short Story

Doctors have long used the appearance of sharp lesions and bruising to diagnose what they started to call lupus – wolf-like bites and bruising. Records of lupus as an illness can be found as early as 400 BC. Having gotten its name from the wolf-bite-like lesions, a distinguishing symptom of lupus was the large red lesions that appeared on the skin of those affected (Norman, 2016). While medical advancements allowed for the diagnosis of lupus, there was no way to distinguish this illness from other skin diseases (Norman, 2016). Evidence shows that Hippocrates may have even studied lupus, but improperly categorized it under herpes (Norman, 2016). In the 1800s, lupus was grouped with a variety of skin diseases including skin cancer, scrofula, military disease, and tuberculosis (TB) (Potter, 1993). The hardening of skin and lesions that appeared in those with TB were seen as being similar to those of lupus, thus being diagnosed as “lupus vulgaris” (Potter, 1993). Because of the prevalence of TB, lupus vulgaris was a common manifestation (Potter, 1993).

Physicians also identified a different kind of lupus in the 19th century. French dermatologist by the name of Cazenave first named one of the most common forms of lupus today, lupus erythematosus, in 1851 (Potter, 1993). The name “lupus erythematosus” was used to describe a form of lupus that was accompanied by erythema (Potter, 1993). After Robert Koch identified the TB bacterium and antibiotic treatment

for TB became more prevalent, lupus vulgaris seemed to dissipate, but some forms of lupus, including erythematosus, remained (Potter, 1993). The unresponsiveness to antibiotics across different treatments of lupus led doctors to question whether this disease had a foreign cause, focusing instead on origins from inside the body (Potter, 1993).

One of the first diagnosis of lupus as an internal disease happened in Eastern Europe. In 1872, Hungarian dermatologist Kaposi definitively defined lupus as a syndrome of the human body calling it “lupus erythematosus disseminates” (Potter, 1993). Over time, physicians associated this form of lupus with discoid lupus or lupus of the skin, but not with lupus vulgaris — an established symptom of TB. The internal origin of lupus drew attention from physicians and immunologists, giving rise to the argument that lupus was an autoimmune disorder (Potter, 1993). Researchers found that lupus caused autoantibodies to be deposited in the organs, eventually causing damage and organ failure (Potter, 1993). Various immunological tests went on to be developed, further defining what constitutes a positive lupus. Although medical advancements have allowed for the identification of autoantibodies, lupus-like many auto-immune disorders— cannot be diagnosed with one test. Only a doctor’s evaluation based on a combination of tests and symptoms can account for a positive diagnosis.

Early Demographics of Lupus: 1950 – 1970

Perhaps because of the association of lupus with internal conditions, the earliest published epidemiological study of lupus appeared in print in 1964 (Siegel et al., 1964). Siegel et al analyzed trends in the morbidity and mortality of patients with lupus in Manhattan and included race and national origin in their examination of lupus

occurrence. Siegel claimed they conducted this study and included demographics because they had not identified any scientific study focusing on the social distribution of lupus (Siegel et al., 1964). This report obtained information from hospital records and census information in the Manhattan area of New York from 1951-1960 (Siegel et al., 1964). Obtaining a clear lupus diagnosis was difficult at the time of the study, so researchers only used definite lupus cases in this report (Siegel et al., 2016).

Using Manhattan as a study area in the 1950s meant addressing a changing, deeply diverse, and deeply segregated urban situation. New York, as well as the rest of the United States, was undergoing what is now called the Second Great Migration, where many Blacks moved from the rural south to the urban north (Wilkerson, 2010). This study breaks the population of interest into three communities: Puerto Rican, non-white (Black), and white (Siegel et al., 1964). This breakdown differs from what a modern epidemiological study would do because today Puerto Ricans would likely be placed in the “non-white”/Black or even in the Latinx category.

Siegel et al found that lupus incidences were highest for Black people, followed by Puerto Ricans, and lastly whites (Siegel et al., 1964). These findings challenged the expectations of researchers because previously, “females with light hair, fair skin and the inability to tan” were considered to be the most susceptible to lupus (Siegel et al., 1964). That is, white women were considered to have higher incidences of lupus as compared to Black women. While this study claims that white women were considered to be the most susceptible to lupus, Siegel also claimed race (or community identity) had not previously been taken into account when analyzing lupus incidence (Siegel et al., 1964). Because the relationship between race and lupus had never been linked in an epidemiological study

before, the claim that white women were more susceptible became an artifact of a prejudiced opinion and an unquestioned medical narrative that ignored the epidemiology of the disease and the social characteristics of women with lupus. Siegel et al also reported that the demographics of lupus were thought to be proportionate to those of healthcare coverage (Siegel et al., 1964). Since Black people and other people of color have historically had lower insurance coverage rates, comparing health insurance rates to those of disease incidences will always leave substantial portions of the community out of the study.

Not only did Siegel et al show that before the 1970s white women were considered to be the most affected by lupus, but the study's methods also display some of the major biases of the health care system. This study took place at a time where Black people were having increased access to medical care because of the Second Great Migration – that is rural residents moving to urban areas with more clinics, more doctors, and a conditional guarantee of access – but even the Great Society reforms did not level access to medical care in an urban area. The next section explores how institutional racism after the passage of the 1964 civil rights act shaped the experience of lupus for Black women.

INSTITUTIONAL RACISM AND THE DIAGNOSIS OF LUPUS

Invalidation of Black Pain

Beliefs that Black people do not experience pain at the same levels as white people date back to slavery. African people were thought to be ideal slaves because of their perceived physical and mental strength (Hoffman et al., 2016). Science supported these ideas of biological superiority with findings that Black people had thicker skulls and even lacked a nervous system (Hoffman et al., 2016). Others even believed that Blacks could be operated on and feel no pain (Hoffman et al., 2016). Ideas that Black bodies are stronger than white bodies have led to various forms of medical discrimination against Black people. Studies show that Black people are less likely to be given pain medication, and even when they are given pain medication, it is in lower quantities (Hoffman et al., 2016). Todd et al. found that Black patients are significantly less likely to receive analgesics for bone fractures, although they report the same levels of pain as whites (Todd et al., 2000). Black people with known illnesses are also subject to medical negligence of their pain. When looking at Black people with cancer, reports show that only 35% of minority people receive the appropriate pain medications (Hoffman et al., 2016).

Failure to recognize Black pain in the medical industry can be attributed to the institutional racism of the medical industry, but more specifically to the biases of physicians. Hoffman et al. propose that racial differences in the management of pain arise from one of two physician biases. One bias being a physician's failure to treat Black pain, although they recognize it, because of noncompliance or insurance concerns, and the other being a physician's failure to recognize Black pain altogether. Research shows that

physicians are almost 50% more likely to underestimate pain in Black people. If physicians are not recognizing pain in Black people, then they are failing to recognize a key symptom in many diseases that create chronic pain or manifest through it.

For many, sickle cell anemia is an example of chronically dismissed Black pain. Sickle Cell Anemia is a genetic disorder that disproportionately affects Black people. . The 1970s marked a key shift in awareness of sickle cell anemia. Before then, physicians and clinicians under researched and under-diagnosed this “invisible malady” (Nelson, 2011). People with this disease complained of chronic pain and were often told that they simply had bad blood (Wailoo, 2000). Because this disease primarily affects Blacks and pain is a key symptom of this disease, the recognition of this disease required an awareness of the presence and claims of Black people on public and cultural resources. It is for these reasons that the Black Panthers and other health activists pushed for more awareness, more research, and more outreach for this disease that more people in Black communities demanded that their pain and their experience be recognized, diagnosed, and researched.

Like sickle cell anemia, lupus is a disease based around chronic pain that disproportionately affects Black people. Unlike sickle cell anemia, lupus was not always known to disproportionately affect Black people. Moreover, a more important difference between the two diseases is that sickle cell anemia can be detected with a simple blood test while lupus requires a battery of tests and observations. Because of this, the diagnosis of lupus is more dependent on the trained and skilled recognition of chronic pain. For someone to be diagnosed with lupus they must have positive blood tests, but more importantly symptoms of chronic pain and fatigue (Kuhn et al., 2015). If lupus is a

disease whose diagnosis is dependent on a physician recognizing the pain of a patient, and physicians are more likely to underestimate pain in Black patients, then Black patients are less likely to get diagnosed and thus, less likely to have access to symptom relief and medical treatments. Today, medical practices are more aware of the medical consequences of possible bias, but before the civil rights era, open medical discrimination was a shared fact of life. Failure to acknowledge pain in Black people because of racial bias is one contributing factor to lupus being diagnosed relatively less in Blacks and relatively more in whites suffering from this auto-immune disorder.

Lack of Information on Lupus

White women had more access to healthcare and health information surrounding lupus. This is another reason why physicians recognized and diagnosed lupus more frequently in white women before the 1970s. While health care inequalities still exist today, there were larger gaps before the civil rights era (Nelson, 2011). , In 1954, *Brown v. Board* called for the desegregation of public schools “with all deliberate speed,” but the mandate allowed publicly and privately funded medical facilities to continue providing or refusing segregated medical care. (Nelson, 2011). Of course, the “separate but equal” medical institutions Black people had access to were not equal to historically white medical institutions. Many of the hospitals that were for Blacks were few and far too far to reach (Nelson, 2011). Even if one was able to reach a hospital, Black people were subject to discrimination and maltreatment (Nelson, 2011). Black people also lacked access to many university medical centers because of segregation. Universities were considered to be places that had “the best knowledge of disease” and “greatest therapeutic power” (Wailoo, 2001).

From the United States Public Health Service Macon County Untreated Syphilis Study (usually referred to as the Tuskegee Syphilis Trials) to nonconsensual hysterectomies, physicians in the United States have a long history of medically maltreating Black people. Studies have even proved that physicians are more likely to negatively stereotype Black patients (Sabin et al., 2008). It is no surprise why many Black people distrust medical professionals. The civil rights era brought awareness to many of these malpractices, but before this time, the medical maltreatment of Black people had no federal regulation or oversight (Nelson, 2011). Before the 1970s, there was a higher level of distrust for the medical system amongst Black individuals. The fewer people began to trust the medical industry, the less they relied upon it, and the less information they garnered from this institution (Nelson, 2011). Since Black people already had poor access to healthcare, their movement away from this industry meant that they had less access to health information.

Today, there are still many unanswered questions regarding lupus. Clinical researchers only developed serological tests to better detect lupus in the 1950s. In the late 1970s, new forms of lupus were still being discovered (Norman, 2016). Even with these new blood tests, physicians still had difficulties reaching a positive lupus diagnosis because each patient did not always test positive for every lupus test (Kuhn et al., 2015). Diagnosing lupus proved to be murky for trained professionals. Unease regarding this murkiness meant the public knew even less about this disease. If the general public had not been made not aware of the signs, symptoms, and even the existence of this disease, Black people had even less access to this circulation of medical ideas. Given that Blacks had worse associations with the healthcare system than did whites, it may have been

difficult to become aware of the signs and symptoms of lupus. Recently, a Lupus Awareness survey found that more than half (54%) of Black people in America knew very little about the disease (LFA, 2019). Lack of general knowledge regarding lupus and poor associations by African Americans with the healthcare system help explain why lupus was initially being diagnosed more in white women and less an object of concern by African Americans

HOW LUPUS CROSSED THE COLOR LINE

Health Care Access and the Great Migration

In hopes of a new life and social mobility, millions of African-Americans moved from the rural south to the urban north and west (Wilkerson, 2011). This movement was called the Great Migration, and its peak occurred from 1940 – 1970 when 4 million African-Americans moved away from southern states (Derenoncourt, 2019). Shortages of factory workers because of World War I promoted the initial flood of Black Americans into the north. Similarly, World War II was largely responsible for the second wave of Blacks from the 40s – 70s.

World War II brought an increased desire for American improvement (Wailoo, 2011). As a result, Americans were more civically engaged, and willing to put their differences aside for the greater good (Wailoo, 2011). Revolutionary discoveries were made in science and technology, giving people the confidence to strive for innovations in other areas (Wailoo, 2011). The medical industry, like many other institutions at the time, was segregated as a result of Jim Crow (Wailoo, 2011). The more innovations the medical system saw, like working more closely with university research centers and getting government funding, the harder it became for Black people to access it (Wailoo, 2011).

Areas that saw the most medical improvement after WWII were the same areas that had gained large populations of Black citizens. Even more than the rest of the nation, Black people wanted innovation, especially in the industry that was central to life and wellbeing. Since their bodies now largely occupied these large cities such as Chicago and New York, their voices could not be ignored. Towards the end of the Great Migration, the

United States and its medical system experienced a civil rights movement that earned Blacks more access to resources previously reserved for the wealthier parts of white America.

Medical Civil Rights Movement

The Medical Civil Rights Movement largely focused on the desegregation of mainstream health care (Hoffman, 2016). From the late 1940s through the 60s, the National Association for the Advancement of Colored People (NAACP) worked closely with the National Medical Association (NMA) to end “separate-but-equal” healthcare (Nelson, 2011). Both the NAACP and the NMA were composed of Black health professionals, but the NMA was specifically created to counteract white-only medical associations (Nelson, 2011). Not only did these health activists work to bring Black people into the same medical sphere as white people, but they also sought to increase Black patient–Black physician interactions (Nelson, 2011). Health activists believed that for Black Americans to have equitable health care they must have access to the same facilities as whites, and they must have access to Black doctors.

A major accomplishment of the Medical Civil Rights movement was the amendment of the Hill-Burton Act of 1946 which provided funding for hospital construction and renovation in the US. Originally, this act contained a clause that sanctioned separate facilities for Blacks, but through litigation, the NAACP and NMA were able to get this clause overturned (Nelson, 2011). After being ruled unconstitutional (violating the 5th and 14th amendments) in 1964, President Lyndon B. Johnson replaced this clause with an anti-discriminatory one (Nelson, 2011). Later that year congress decided to end all federally backed institutional segregation (Nelson, 2011). Eventually,

these acts allowed Black people to have access to better medical institutions and better healthcare overall. They were no longer limited to Black-only medical institutions that were under resourced and overcrowded.

The fight to desegregate medical associations, like the American Medical Association (AMA), proved to be more difficult than integrating medical institutions. Because these organizations were privately funded, they could not be forced to integrate by court order (Nelson, 2011). Instead of using litigation, the NAACP and the NMA relied on moral persuasion and protesting to integrate the AMA and American Nurses Association (ANA) (Nelson, 2011). In the late 1960s, the AMA finally moved towards integration, allowing Black physicians to join this prestigious medical organization (Nelson, 2011). Often, physicians were not allowed access to medical facilities if they were not a part of the AMA, so the integration of this society meant that Black physicians had access to more hospitals and more Black patients.

Being granted access to the same health care facilities as whites and more Black doctors was a major turning point in Black history. Previously white-only institutions were better staffed and better funded, meaning that they had a better ability to diagnose and treat disease (Nelson, 2011). Since Black patients were able to be treated by Black doctors more than before, it meant that their pains were being considered and documented more seriously (Alsan et al., 2018). Studies even show that Black patients have better health outcomes when being treated by Black physicians (Alsan et al., 2018). With better medical resources and more Black doctors, it makes sense for Black patients to have been diagnosed with ailments that would have been previously overlooked in facilities that were underfunded and poorly staffed.

The accomplishments of the Medical Civil Rights Movement created conditions that improved the diagnosis and research of Black diseases. When looking at lupus, the first epidemiological study was conducted during the Medical Civil Rights period. Siegel et al. is the earliest study to show that lupus is more prevalent in Blacks (Siegel et al., 1964). Until the 60s, Black people did not have equal access to the medical resources necessary to diagnose a tricky disease like lupus. Increased access to Black physicians was also an important factor in the increased diagnosis of lupus in Black people since this disease is largely based around pain and Black doctors are more likely to diagnose Black pain. In this way, the advancements and victories of health activists in the 60s – 80s allowed lupus to be seen not as a white disease, but as a Black disease, and, like sickle cell earlier, a metaphor for Black suffering.

THE COLOR OF LUPUS TODAY

The LFA lists three things as being the causes of lupus: genetics, hormones, and the environment. There is no one gene known for causing lupus, but rather a variety of genes are involved. Mutations in these genes predispose people to developing lupus or another autoimmune disorder, but simply having these mutations is not enough to trigger the onset of lupus. Medical experts claim that these genes which cause lupus are more prevalent in people of color, and credit this as the cause of lupus being higher in these populations (LFA). While this claim exists, no scientific data has ever proved that people of color have a higher proportion of these lupus causing genes than do whites. (seems like there might be references here?) Genetics cannot explain why a disproportionate number of Blacks develop lupus.

The relationship between hormones and lupus development is more clear cut than that of genetics. While males produce estrogen, although they do not produce as much as females do. Estrogen is so prevalent in females that since the 1960's it has been referred to as the "women's hormone" (Gillies & McArthur, 2010). High levels of estrogen in women as compared to men are the reason why women are nine times more likely to develop lupus as compared to men (LFA).

THE ROLE OF THE ENVIRONMENT

While the cause of women being affected by lupus at a higher rate than men is understood, the question of why people of color are more affected by this disease remains. If genetics cannot explain why Black women are three times more likely to get lupus, then the relationship between lupus and the environment must be analyzed.

Environmental Risk Factors

The environment is arguably the most important factor in whether or not one will develop lupus. As stated above, one might be predisposed to lupus, but this does not guarantee that one will develop the disease. A case study on a pair of identical female twins showed the impact of the environment on disease development when one twin developed lupus and the other did not, although they had the same genes (LFA). But what about their environment led to lupus in one twin but not the other? The exact environmental causes of lupus are not known, but a few that have been associated with disease incidence are increased exposure to ultra-violet (UV) rays, certain chemicals and drugs, infections (bacterial and viral), and stress (physical and emotional) (LFA). Because lupus is an autoimmune disorder, meaning that the body's immune system attacks itself, any stressor that the body faces (UV rays, smoking, emotional trauma, etc.) could trigger the immune system, thus triggering lupus. Studies show that when predisposed individuals are exposed to at least one of these stressors, the onset of lupus is triggered. If people in a certain group are exposed to these environmental stressors at a higher rate, they are at higher risk for developing lupus. This could offer insight into why people of color, especially Black women, develop lupus at a much higher rate as compared to whites.

Disparities Faced by People of Color

When analyzing the environmental conditions of people of color, the stressors which are linked to lupus are disproportionately present. An “environment” is more than where someone lives it includes all of the factors surrounding them in their day-to-day life. People of color have historically faced some of the worst environmental factors. This includes “neighborhood exposures to dangerous workplace chemicals, smoking, alcohol consumption, and diet” (Wailoo, 2011). Toxic chemicals are one of the triggers listed by the LFA as being a causative agent of lupus, and cigarette smoking is linked to increased disease onset and activity (Cozier et al., 2018). Studies have also shown that these stressors have contributed to the overall worsened health of people of color (Williams et al., 2016). Many if not all of these factors can be linked to the low socioeconomic status (SES) of minorities, as race/ethnicity is intertwined with SES (Williams et al., 2016). Here are a few statistics on the physical health of people of color as they relate to SES from the American Psychological Association (APA):

- Racial and ethnic minorities have worse overall health than of White Americans. Health disparities may stem from economic determinants, education, geography and neighborhood, environment, lower-quality care, inadequate access to care, inability to navigate the system, provider ignorance or bias, and stress (Bahls, 2011).
- Socioeconomic status and race/ethnicity have been associated with avoidable procedures, avoidable hospitalizations, and untreated disease (Fiscella, Franks, Gold, & Clancy, 2008).

- At each level of income or education, African-Americans have worse outcomes than Whites. This could be due to adverse health effects of more concentrated disadvantage or a range of experiences related to racial bias (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010).

This data shows that when compared to whites, Blacks and other minorities consistently have worse health, and that this can be linked to the poor environmental factors such as “geography and neighborhood, environment, lower-quality care, inadequate access to care, inability to navigate the system, provider ignorance or bias, and stress” (APA). Other studies have even argued that an increase in the mortality rate of Blacks can be linked to “environmental factors” where “many of the jobs with the greatest exposure to health hazards are now filled by Blacks” (Wailoo, 2011). These are only some of the physical stressors faced by people of color disproportionately.

While poor health and high mortality rates are directly linked to the poor environments of people of color, resulting from their low SES, many psychological stressors also result from low SES. Some of the statistics that the APA lists are:

- Wealth partially explains racial and ethnic differences in depression. Negative net worth, zero net worth, and not owning a home in young adulthood are significantly associated with depressive symptoms, independent of the other socioeconomic indicators (Mossakowski, 2008).
- Hispanics and African-Americans report a lower risk of having a psychiatric disorder compared with their white counterparts, but those who become ill tend to have more persistent disorders (McGuire & Miranda, 2008).

- American Indians are at heightened risk for PTSD and alcohol dependence (McGuire & Miranda, 2008).
- Perceived discrimination has been shown to contribute to mental health disorders among racial/ethnic groups such as Asian Americans and African Americans (Jang, Chiriboga, Kim, & Rhew, 2010; Mezuk et al., 2010).
- Compared with Whites, African-Americans are more frequently diagnosed with schizophrenia, a low-prevalence but serious condition (McGuire & Miranda, 2008).

As this data shows, people of color are once again affected by SES factors at a higher rate than white people. Because any form of stress can trigger an onset of lupus, and people of color are afflicted with these stressors at a much higher rate than are white people, it can be said that people of color and especially Blacks are at a higher risk for developing lupus. Therefore, SES can explain why Black and other women of color develop lupus at a much higher rate than do white people and white women.

SOCIOLOGY NOT BIOLOGY

Lupus and SES

Although scientists have attempted to attribute the lupus disparity in people of color to genetic biological differences, they have been unsuccessful. Scientists have however found sociological support linking lowered SES to worsened environmental conditions, which leads to worse mental and physical health. Since lupus is largely triggered by environmental stressors, the increased incidence of lupus in Black women can be linked to the effects of these societal ills.

If scientific data directly links lupus to the effects of social issues rather than inherent biological ones, why does the idea that genetic differences cause Blacks to develop lupus more than whites persist? This idea has racialized a disease that is more dependent on one's social status than one's race. This level of bias not only limits scientific discovery, but also the treatment of patients with lupus. While race/ethnicity and SES are inseparable, they are both social phenomena that have resulted from historic inequalities (Williams et al., 2016). Races and ethnicities have never been biological, they are simply labels based on common perceptions about certain groups of people. To understand how these perceptions have led to the disparities which place people of color at the lowest social levels, the effects of systematic racism must be addressed.

Racism, SES, and Public Health

Racism can be explained in many ways. Systematic racism speaks to the ways that major institutions like the government, health care system, or education system have created inequalities based on race. In the United States, these systems have always

avored white Americans (Clair & Denis, 2015). Over time, the oppression of racial/ethnic minorities by this system has created a class structure that places them at the bottom and whites at the top. Most importantly, these systems have led to the environmental conditions which have led to the worsened health of minorities (Williams et al., 2016). In this way, systematic racism is to blame for the increased amount of stressors that predispose Black women to develop lupus.

While major institutions are responsible for the conditions which have led to the poor health of people of color, people of color are blamed for their worsened health. Views that individuals are solely responsible for their health are commonly held in society. Sir Arthur Newsholm, a famous public health activist from the 1800s believed that “only changes in human behavior, that is, moral reform could adequately address some of the most difficult health problems...” (Rosenberg & Golden, 1992). The society in which Newsholm lived was not much different from American society today. During these times, the poor suffered from more health conditions than any other group in society as they do today (Rosenberg & Golden, 1992). Knowing the environments in which the poor lived, Newsholm “blamed the living conditions of the poor for their irresponsible or destructive behavior” which then led to poor health (Rosenberg & Golden, 1992). Newsholm, who was raised as a conservative Methodist, believed that individual moral behavior alone determined one’s fate. This belief places all of the blame on an individual, absolving a society or government from accepting responsibility for the factors which have led to poverty and social ills. New liberal economic philosophers who studied the relationship of the economy to social problems offered a different view. They believed that the state was responsible for the creation of a just

society and they “argued mightily against blaming the poor for their own misery” (Rosenberg & Golden, 1992). A view that shifted the weight of poor health from being completely on the individual to the polity.

The continuation of an overtly individualistic society has protected institutions from taking the blame for the health disparities of today. Since this problem is seen as an individual issue and not the issue of the government and the healthcare system, these institutions have yet to create solutions to the ills which lead to poor health in people of color. If collective action could be taken by these institutions to improve the socio-economic conditions which burden minorities, health disparities faced by people of color, like lupus, could be lessened (Williams et al., 2016). A major part of this includes improving the insurance rates for people of color who have the lowest insurance rates (Sohn et al, 2017). For people with lupus especially, being uninsured significantly increases the chances of mortality (Oud et al., 2020). It seems as if there is no urgency to lessen these inequalities. A review of lupus research in Black women even stated that an emphasis needed to be placed on “therapeutic strategies for those who are identified as being at high risk” (Williams et al., 2016). Since the systems which have led to health disparity fail to take progressive actions, people of color will continue to be afflicted by disease at an alarming rate, and Black women will continue to be diagnosed with lupus three times more than white women. Black women will continue to deal with the effects of systematic racism at a disproportionate rate, and Black women with lupus at an even higher rate.

The Hypermarginalization of Black Women with Lupus

In the United States, the effects of racism are so interwoven with the SES of racial/ethnic minorities that the two cannot be separated (Williams et al., 2016). When analyzing the reasons why Black women are disproportionately diagnosed with lupus, this is particularly apparent. An already marginalized group (Black women) faces an additional load by having a chronic illness which only amplifies the disadvantages they face. It has already been discussed how minorities face poor physical and psychological health conditions as a result of their race/ethnicity and SES. These statistics speak of the conditions of people of color as a whole, but when looking at a smaller proportion of people of color, those who have lupus, the effects of race/ethnicity/SES are more pronounced.

A study done on African-American women with lupus showed that racism and vicarious (secondhand) racism are directly linked to higher disease incidence and activity (Drenkard & Lim, 2019). The stress experienced due to racism activates inflammatory pathways of the immune system that exacerbate lupus disease activity. This process occurs in all people with lupus, but the amplification occurs in Black women who face higher amounts of discrimination because of their gender and especially because of their race. Not only do Black women face discrimination more than white women, but Black women are affected by stressors like poor environmental conditions and poverty at a higher rate (Reeves, Rodrigue, & Kneebone, 2016). The conditions which have proved to increase a Black woman's risk for developing lupus also increase her risk for heightened disease activity and lupus-related mortality. Poor mental health is another stressor that is more prevalent in Black women with lupus that is linked to increased

disease activity (Drenkard & Lime et al., 2019). Although African-American individuals are less likely to be diagnosed with depression, studies show that 35% of Black women with lupus “reported moderate to severe depressive symptoms” (Drenkard & Lim, 2019). Additionally, while Black and Latinx people are diagnosed with mental health disorders less than whites, “those who become ill tend to have more persistent disorders” (McGuire & Miranda, 2008). In a study done on a predominantly Black female cohort, chronic cutaneous lupus, lupus of the skin, depression rates were found to be “three to five times higher than previously described in the general population from the same metropolitan Atlanta area” (Drenkard & Lime, 2019). Studies show that depressive symptoms in Black women with lupus have been “directly associated with patient's perceptions of staff disrespect and inversely associated with emotional support” (Drenkard & Lim, 2019). The fact that the poor mental health of Black women with lupus is related to “staff disrespect” and lack of “emotional support” shows the importance of the relationship between a patient and their medical staff. The history of “mistrust and resentments about maltreatment” can never be erased for Blacks, and this alone can strain a patient-doctor relationship (Wailoo, 2011). When you add “perceived staff disrespect” to this history, it becomes clear why lupus patients, who are predominantly Black, relate much of their depressive symptoms to their medical treatment (Drenkard & Lim, 2019). Patient and medical staff “attitudes shaped by the broader atmosphere of racial discrimination and by misunderstanding” persist today (Wailoo, 2011). The continuation of discriminatory beliefs by the American medical system which is linked to adverse health effects of racial/ethnic minorities perpetuates the effects of systematic racism. When analyzing the effects of “psychosocial stressors” faced by Black women with lupus, this is clear.

REPRODUCTION OF RACISM IN HEALTH CARE

Lupus accentuates the effects of systematic racism on the lives of people of color, particularly on Black women. At a three to one rate, Black women largely outweigh the proportion of white women with lupus. While hormonal differences explain why 90% of people with lupus are women, compared to only 10% for males, no clear explanation exists for why African-American women carry the largest burden. Researchers have attempted to explain this disparity through race-biology which states that certain genes responsible for causing lupus are more prevalent in Blacks and other people of color. While this idea negates the fact that race/ethnicity is merely sociological and that there are no genes that differ by race/ethnicity, it upholds eugenic views on the biological inferiority of Blacks as compared to whites (Wailoo, 2011). The skewed proportion of Black women with lupus also allowed for the racialization of this disease. Instead of supporting the belief that lupus impacts Blacks more because of their genes, data shows that the health disparities of Blacks are a result of their SES. History provides evidence that people of color hold a lower SES than do whites as a result of systematic racism. However, major institutions such as the government and the medical system have failed to acknowledge their role in the poor health outcomes of racial/ethnic minorities. This has resulted in a society that solely blames an individual for their poor health. In keeping ideas of individualism instead of collectivism, the healthcare system (and government) has allowed “poverty and disease, like many social ills [to form] a vicious cycle” (Rosenberg and Golden, 1992). This is evident in the effects of lupus in Black women, where the psychosocial effects of racism and discrimination are amplified. Lupus is only one example of a condition that affects Blacks at a much higher rate than whites. Data has

proven that overall, Blacks have worse health and higher mortality rates as compared to whites (APA). Unless the healthcare system and government work together to remedy the conditions which have placed racial/ethnic minorities at the bottom of nearly every system (health, education, etc.), health inequalities like lupus will only intensify. By remaining complacent, the American healthcare system above all has chosen to perpetuate racism.

The work here substantiates Keith Wailoo's extended meditation on the transformation of cancer in a society that uses color lines to distribute outcomes and consequences.

“No one concerned with group differences and social inequality can do without social categories of identity: they offer outlines (albeit impersonal ones) of the nation's divisions. The point here is not to do away with categories of difference, but rather to distinguish more carefully among the many meanings of race. Thus, a so-called race blind approach to studying health differences would be a failure, since it would only replicate the myopia blinders in the unequal representation In other words, the collecting of data using racial or ethnic categories are made essential for identifying health inequalities. At the same time though, we need to recognize that well racial analysis can tell us the differences exist across so-called racial groups they don't explain why those differences exist nor can the social differences be attributed to biological notions of race... such population categories are not timeless, and must be used with greater care — particularly by health experts who do the job of interpreting disease in relation to race. Those who have claimed that racial categories are proxies for biological

or genetic differences are proven to have erred many times in history. There is no need to repeat the mistakes of the past... The last one hundred years can be read as a guide to the ever-changing complexity of race — a biological, epidemiological, political, social, and ideological concept. The last hundred years can also be read as a historical warning teaching us avoid the easy allure of oversimplified narratives of biological difference and to expand the American radical vocabulary” (Wailoo, 2010).

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