

CULTURAL HUMILITY TRAINING FOR MEDICAL PROFESSIONALS
SERVING AFRICAN AMERICAN WOMEN WITH LUPUS

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Chapter 1: Executive Summary

We Are Lupus Strong: Cultural Humility Training for Medical Professionals

Serving African American Women with Lupus

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Problem Identification and Background: African American women with lupus experience poor health outcomes, including organ damage, depression, and higher mortality rates. Systemic Lupus Erythematosus (SLE) or lupus is a chronic, inflammatory, autoimmune disease described by many unpredictable symptoms in timing and severity (Martz et al., 2019). As culture informs many aspects of life, including how health and illness are perceived and understood, cultural humility training for medical professionals may improve these outcomes. African American women with lupus have the highest mortality rate compared to women of other ethnicities and are diagnosed with lupus two to three times more than any other ethnicity (Krisnon et al., 2006). In managing the disease symptoms and daily living, 45% to 65% of African American women with lupus report experiencing high psychological indicators, including anxiety, psychiatric and mood disorders, and depression (Williams, 2017). African American women face further challenges in gaps in care between themselves, their providers, and the healthcare system. It is beneficial for lupus patients to have culturally sensitive medical providers act as the conduit to improved health outcomes in terms of provider and patient relationships, adherence to medication regimens, following a proper treatment plan, maintaining social support, and experiencing an overall quality of life. Thus, there is a

need for cultural humility training aimed at understanding African American women with lupus - the focus of this researcher's social innovation.

There is a well-documented history of mistrust between the African American community and the health care system, with a distinct disconnect experienced among women. While many outstanding, well-intended medical professionals serve African American women, there remains an apparent lack of cultural humility, which fosters high levels of tension, apprehension, and distrust for African American women with lupus. The report *Unequal Treatment* brought increased attention to inequities in healthcare, including racial/ethnic disparities in the incidence, prevalence, and complications of hypertension, heart disease, and diabetes (Mainia et al., 2018). As long as African American women with lupus do not trust the medical professionals caring for them, they may not move toward positive health outcomes. This dynamic must shift to build trust between the healthcare provider and African American women with lupus. One way to accomplish this is to focus on the healthcare provider and their interaction with this community.

Community Engagement: To help health outcomes for lupus patients, Mrs. Kimberly Howse of the Lupus Howse Foundation and Dr. Long Pham of Cedars-Sinai Medical Center, Department of Rheumatology, have offered their knowledge and time to contribute to the process of developing the cultural humility training. Both community members were interviewed and shared valuable information to assist in creating the innovation, a cultural humility training specifically for medical professionals who treat African American lupus patients. Further, interactions with many fellow lupus patients as

part of a supportive community have allowed for a deeper, relational understanding of the problem.

Conceptual Model: Cultural humility training is driven by a clear conceptual framework and is informed by three theories: Historical particularism, learning theory, and the socialization model. All three approaches support the need for an understanding and openness among health care providers to improve health outcomes for African American women in the lupus community.

The proposed evidence-based curriculum aims to reduce the tension and bridge the gap between African American lupus patients and their healthcare providers by building the cultural humility of the medical professionals. Based on the Declaration of Geneva (World Medical Association, 2006), an oath that has been adopted as part of the finalization of having been conferred a medical degree, medical professionals solemnly pledge that they will not permit consideration of age, disease, or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing, or any other factor to intervene between their duty to their patient and the patient's experiencing well-being. Although medical professionals have taken this pledge upon degree completion, health disparities based on race still exist. Reasons for this vary, including geography, personal and societal bias and influences, and systemic imbalances. Nevertheless, there is often no formal training to help professionals understand how influential a patient's culture is in managing their health care.

Social Innovation: Cultural humility training explores and deconstructs personal biases toward different ethnic or cultural groups that will allow medical students, doctors, nurses, and other medical professionals to expand their knowledge of various cultures,

influencing them to be more sensitive when serving their patients. The training may also provide a greater sense of fair and equitable treatment, helping dismantle the barriers of distrust so African American women with lupus can feel acknowledged and experience improved health outcomes.

The cultural humility training is designed into four modules covering topics from historical interactions between African American women and the healthcare system, the significance of community engagement, cultural humility defined, and implementation of cultural humility. Each of the four training modules will be approximately an hour and a half long. The training may be conducted in person or virtually. The facilitator will be a lupus survivor or will have a close personal connection with the lived experience of lupus. The participants will be medical students, healthcare workers, or healthcare professionals. The number of participants will consist of a maximum of 40 people per training.

Evaluation, Methodology, & Results Summary: Students studying to be health care professionals were evaluated by completing a pre-and post-measure during the soft roll-out presentation of the cultural humility training. This assessment was utilized to inform and create the modules and explore areas where students may lack knowledge of lupus, cultural humility, and the tools to address healthcare disparities. Further, as the modules are completed and presented, feedback regarding the efficacy from participants will be considered for additional modifications. As healthcare and culture are dynamic, the researcher will continually connect with the community, patients, and stakeholders to inform the development of this innovation.

Implications for this include improved health outcomes, early diagnosis, decreased mortality rates, lessened organ damage, and enhanced patient and provider relationships. This will not only affect the African American lupus community but has the potential to impact Native American, Hispanic, Pacific Islanders, Asian, and White American women with lupus. It will also affect males with lupus. The cultural humility training will span far beyond the lupus community to influence marginalized groups and healthcare relationships. Providers may be open and willing to learn about the cultural ideals that inform their patient's healthcare decisions.

Conclusion and Implications: The cultural humility training aims to improve health outcomes, decrease health disparities, and bridge the gap between healthcare providers and African American women with lupus. The training will allow the healthcare providers to understand the culture of this marginalized population and what they can do to improve relations and overall patient care.

Chapter 2: Problem Identification and Background

Health disparities among minority groups throughout the United States are a growing national concern. Over the last decade, the enactment of the Affordable Care Act and extension of Medicare has presented unexpected data that many were unaware. Among the minority groups enduring health care disparities, African American women suffer the most significant disparities within the health care system. These disparities include fertility and reproductive care, maternal mortality, and increasing numbers of African American women suffering and losing their lives from preventable and treatable conditions. Ailments like diabetes, heart disease, and autoimmune disorders like lupus are known to be treatable but deadly if not properly managed. Today 1.5 million people in the United States live with Systemic Lupus Erythematosus (SLE); nine out of ten diagnosed with lupus are women. (Lupus Foundation of America, 2020). African American women are three times more likely to be diagnosed with this disease. Systemic Lupus Erythematosus (SLE) or lupus is a chronic, inflammatory, autoimmune disease characterized by countless unpredictable symptoms in timing and severity (Martz et al., 2019). Lupus is also characterized by various symptoms, including pain, alopecia, skin rashes, mouth ulcers, arthritis, and damage to vital internal organ systems, resulting in death (Twumasi et al., 2019). Further, African American women are three to four times more likely to develop the disease than their white female counterparts (Williams et al., 2018). African American women face the disparate risk of SLE, and challenging gaps in care, particularly between themselves and their providers (Hall et al., 2015).

In the United States of America, 30%-43% of lupus patients are of African Ancestry (Anjorin et al., 2018). Compared to White American patients, African American patients have significantly more organ damage, including damage caused by diabetes and alopecia due to the effects of lupus (Anjorin et al., 2018). Results from the Center for Disease Control and Prevention (CDC) lupus registries assessed that the prevalence from 2002 to 2004 was much more significant for African Americans than White Americans in Michigan (111.6 vs. 47.5 per 100,000 people) and in Georgia (128.0 vs. 39.9 per 100,000 people) (CDC, 2018). These statistics document the disparities between the ratio of African Americans and Whites with lupus. Though receiving a formal diagnosis can be lengthy, African American women are diagnosed with lupus two to three times more than White women. However, the complications from lupus and the care African American women receive lead to poor outcomes. According to Krishn and Hurbert (2006), African American women had the highest mortality rate due to lupus and were two to three times more likely to have premature deaths caused by lupus (Bartels et al., 2020). Three studies found a significant correlation between high levels of physicians' implicit bias against African Americans as measured by Implicit Association Test scores and interactions negatively rated by Black patients (FitzGerald and Hurts, 2017). Additionally, Fitzgerald and Hurts argue that the interactions that Black patients negatively rated were also negatively rated by external observers. Further, Hall et al. (2015) showed that implicit bias was significantly related to patient-provider interactions, treatment decisions, treatment adherence, and patient health outcomes.

According to Hall et al. (2015), people of color face disparities in access to health care, the quality of care received, and health outcomes. Hall et al. (2015) also compared Whites with people of color who face more barriers to accessing care, including preventive services, acute treatment, and chronic disease management. The National Healthcare Disparities Report showed that White patients received better quality care than Black Americans (Hall et al., 2015). Current medical research purports that many health disparities African American women suffer may be caused by the implicit and explicit biases held by numerous medical professionals throughout this nation (Hall et al., 2015). To reduce the health care disparities experienced by African American women, cultural humility training may mitigate the adverse outcomes experienced by African American women with lupus.

It is also important to note that the experiences of neglect and dehumanization of African American women with lupus have produced a high prevalence of anxiety. Often, others do not believe their symptoms or pain are real. In managing the disease symptoms and daily living, patients often experience high psychological indicators (45%-65%), including anxiety, psychiatric and mood disorders, and depression (Williams, 2017). To better serve African American women patients with lupus and to increase positive health outcomes, it would be beneficial to have medical professionals understand what they are going through and how they are processing their diagnosis.

The current project focuses on providing critical content about lupus and understanding cultural humility in delivering healthcare. Cultural humility training will assist medical professionals in gaining an experience of cultural factors that influence

African Americans surrounding health and healing. Training will also help medical professionals avoid inaccurate assumptions and ultimately improve the outcome of care, especially for African American women.

Historical Context

Government, employment, and medical care have contributed to minority groups' substandard treatment throughout the United States history (Williams et al., 2000). Factors such as bias, stereotyping, and prejudice contribute to the racial and ethnic disparities exhibited by health care providers (Nelson, 2002). Bronson and Nuriddin (2014) explain that the 1730s was the beginning of the first recognizable seeds of the modern formal health care system, including the unequal care of African Americans.

Further, Hoffman (2016) explains that in the 19th century, Dr. Samuel Cartwright sought to prove that African Americans were biologically different from Caucasians. He tried establishing research to prove African Americans had thicker skulls, less sensitive nervous systems, and diseases inherent to dark skin. One outcome of Cartwright's work was the sentiment that African Americans feel less pain than their White counterparts. In a recent study conducted by the University of Virginia, 50% of White medical students and residents endorsed the belief that African Americans' pain perception differed from their White counterparts (Hoffman, 2016). This is important to note because this sustains the inherited mistrust between African American women and the health care system. Such myths have been passed down through social learning among medical students; thus, the misconceptions continue. African Americans can do little during one doctor visit to help reduce the belief in this myth. However, providing systematic training about this

myth and others like it may be the key to undoing Cartwright's influence and the misinformation offered by others since

Even more, African Americans have received inferior and dehumanizing care from the healthcare establishment in the U.S. For example, in 1845, Dr. J. Marian Sims carried out repeated experimental operations on three enslaved African American women to repair injuries sustained during childbirth (Walls, 2005). One enslaved woman named Anarcha suffered from a vesicovaginal fistula and underwent over thirty operations before Dr. Sims could repair her wound (Walls, 2005). Dr. Sims performed the procedures without anesthesia. Later, Dr. Sims considered that the fistula surgery was minor and did not need anesthesia.

Consequently, Dr. Sims would not administer anesthesia to African American patients. However, he suggested that rich White women could not tolerate the procedure without anesthesia (Sartin, 2004). These types of horrific medical experiments have not only plagued African American women, but African American men have also been the subjects of inhumane medical experimentation.

Moreover, from 1932 to 1972, the Tuskegee Syphilis Experiment was conducted on four hundred African American men. In 1966 over one hundred African American women were added to this experiment. The medical professionals withheld treatment for syphilis from them to observe the disease's progression (Paul et al., 2015). Using African Americans as test subjects for medical purposes has led to intergenerational mistrust. This discrimination extended to free and enslaved African Americans and affected every social determinant of health and illness (Byrd & Clayton, 1992, as cited in Bronson & Nuriddin, 2014). Unfortunately, unfair treatment persists today in healthcare.

While this is not a comprehensive history of the treatment imposed on African Americans in the medical field, these historical traumas demonstrate how the seeds of mistrust in the healthcare system have been established. The research shows that there is bias on the provider side that may contribute to adverse health outcomes.

Social Work Principles

This project aligns with the National Association of Social Workers (NASW) priorities, Code of Ethics: Service and Social Justice (NASW, 2021). Service is represented by addressing the social problem of the lack of training addressing health outcomes of African American women with lupus and the subsequent shortage of culturally sensitive healthcare providers. Conducting research about addressing the social issue, keeping communication open, and having courageous conversations about African American women with lupus' health disparities while battling this disease is one means of providing service. Raising awareness of the needs of this underserved population while promoting equitable care is a method of fighting for social justice. This work builds toward upholding the social work Grand Challenge of Closing the Health Gap (American Academy of Social Work and Social Welfare, 2020). Social workers can help physicians begin to display cultural humility and fulfill their oath of the Declaration of Geneva of the World Medical Association so that the lupus community and health care system can close the health gap together.

Biblical Principles

The principle of humility is found throughout the word of God. The word admonishes believers to value others above themselves. Philippians 2:3 says, “do nothing out of selfish ambition or vain conceit. Instead, in humility, value others above

yourselves.” Here the Apostle Paul is encouraging the church to adopt a new and perhaps unorthodox model of thinking at that time. He challenges people to shift their focus from a self-centered and self-absorbed mindset to a humble, empathetic, and selfless mindset. As a social worker, it is essential always to consider the interests and well-being of others and present the situation to others. The same can be said of medical professionals, which is why cultural humility is key to bridging the gap between African American women and the healthcare system. Medical professionals must understand that every individual they see is imbued in their culture and way of life. Still, the provider must acknowledge and respect that culture to be effective. Paul reminds in Philippians 3 that his degrees and accolades were not the essential part of his ministry. Still, humility, care, compassion, empathy, and love made him most effective.

Doctors, nurses, medical students, professors, and healthcare system professionals must self-introspect to ensure they are not serving in selfish ambition or vain conceit but in humility. They should aim to be a servant to those they encounter to treat and help with their medical issues.

Chapter 3: Community Engagement

A community is a group of people with diverse characteristics linked by social ties who share common perspectives and engage in joint action in geographical locations or settings (MacQueen et al., 2001). When examining the lupus community and the relationships of the people who belong to it, healthcare providers are a necessary part of the community. Though they are not often welcomed in with open arms, the healthcare system is needed to turn the course of this disease around. There is a connection shared through the experiences faced living with lupus.

To address issues as complicated as racial disparities in lupus care, we must utilize a community engagement approach that partners scholars with community members and stakeholders to develop sustainable solutions. Community engagement is working collaboratively with and through groups of people associated by geographic proximity, a particular interest, or related circumstances to address issues affecting the well-being of those people (Centers for Disease Control and Prevention, 2011).

“Research suggests that community involvement in the design, governance and delivery of services can improve health and make policy initiatives more sustainable” (Milton et al. 2011, p. 317). Community engagement has different levels and utilizes various methods. It depends on the preferred direction of the stakeholders guiding the work. Community engagement can take many forms, and partners can include organized groups, agencies, institutions, or individuals. Partners are involved in health promotions, research, or policymaking (Centers for Disease Control and Prevention, 2011). Some organizations take different approaches to community involvement; from outreach to shared leadership, their decision is based upon the desired outcome of the organization or

individual leading the work. In this work of shared leadership with the lupus patient and the healthcare provider, they will have a respectful relationship to improve health outcomes.

Considering the continuum of community engagement methodologies, shared leadership is the preferred method of community engagement for the African American lupus community with the healthcare system. The ideal collaborative experience would facilitate an opportunity for individuals representing the lupus community to partner with healthcare agencies and researchers to create solutions that meet the needs of African American women who have lupus. Research indicated that being the “group social worker and tasked with helping group members identify collective strategies that are likely to be successful is simultaneously empowering to them” (Knight et al. 2018, p. 10).

Several community engagement strategies were used in this project to inform both the understanding of the social problem and its solutions. Specifically, this researcher engaged with stakeholders such as the Lupus Howse Foundation and Cedars Sinai Medical Center. Also, community members who are women experiencing Lupus were consulted to identify personal experiences and gain insight regarding the lupus community’s needs. Lastly, the researcher engaged with pre-nursing and pre-med students from California Baptist University and the Medical University of South Carolina.

Patients and Stakeholders

Not only are research findings helpful in understanding the problem of lupus among African American women, but personal stories also illuminate the issue. Many

personal stories expressed during lupus support groups conducted by the Lupus Howse Foundation offer similar experiences. Everyday experiences emerged, such as diagnosis taking an extended time and patients feeling dismissed. It is an informal but intentional collection of people's stories that data is collected over seven years. The following are personal stories shared during the lupus support groups. One woman shared that when she was finally referred to a rheumatologist after several visits to the doctor, she was told that she did not have lupus because she did not have the butterfly rash. The doctor walked out of the room. There was no test run, and she felt the doctor dismissed her symptoms. Another woman lost over fifty pounds and could not eat, and the doctors said there was nothing more they could do. When the woman's mother spoke with the support group and was asked about the medications her daughter was taking, she named two prescribed for lupus. However, the drug therapy that typically works for lupus patients was not helpful or practical. The support group member asked the mother if they were offered Benlysta, the first medication specifically developed for lupus; unfortunately, her daughter had not been provided Benlysta. These are only two stories from the support group. However, numerous African American female patients felt they were being dismissed or that physicians were not conducting comprehensive exams and testing to ensure adequate diagnosis and treatment.

Kim Howse

To gain further insight into the patient's experiences, this researcher approached the founder of the Lupus Howse Foundation, a foundation established to dedicate time and care to lupus patients. Ms. Howse's core service is support groups designed to help lupus patients cope with their diagnosis and relate to others through shared experiences.

The researcher asked Mrs. Howse to describe her experience with lupus and her experience with the women she serviced. She was asked to describe her insight into the understanding of health disparities and issues of the women she serviced for many years. She was also asked to explain from the lupus communities' point of view the issues between the healthcare system and African American women with lupus. Mrs. Howse gave insight into the experiences of the women who attend the support groups. Howse explained that African American women received poor medical treatment when seeking medical assistance. She stated that she had heard this from multiple African American women she has mentored through the years. Ms. Howse explained her experience with an emergency room physician. She explained that her pain was not taken seriously when she stated that the pain was a ten on a scale of one to ten, to which the physical replied smugly that she was not "acting like" it was a ten. Howse felt that the physician assumed she was someone looking for drugs, not a patient seeking pain relief. This led to the conversation where she explained that African American women are taught to be strong and not to show too much of their emotions from a young age. Mrs. Howse continued to share those suppressing feelings go back generations and are an unfortunate learned behavior. She continued to say that if physicians understood the culture of African American women and the culture of the lupus community, the health outcomes would improve.

Mrs. Howse's experience and insight confirmed what the research indicates African American women with lupus disproportionately receive poor treatment in the healthcare system. This insight helps the researcher understand the importance of cultural humility in healthcare for favorable treatment and health outcomes.

Dr. Long Pham

The researcher contacted Dr. Long Pham from the Department of Rheumatology at Cedars-Sinai Medical Center about his professional outlook on cultural humility towards African American women with lupus. Dr. Pham was asked about his experience working with African American women with lupus and if he had witnessed a lack of cultural humility toward these marginalized populations from his counterparts. Dr. Pham stated that he had seen a lack of cultural humility while working with this population. He explained that many African American women have lupus, and in the Los Angeles area, most lupus patients are women of African, Asian, or Hispanic descent. He explained that in his practice, he does not necessarily see more African American women being diagnosed with lupus; due to the demographics of the Los Angeles area, he sees more Caucasians in this private practice. However, he says he services more African American women when he sees patients in a clinic.

The core question the researcher posed to Dr. Pham pertained to what he saw as what the medical community needed to understand about cultural humility to bridge the gap. Dr. Pham's response aligned with the research; we must always be humble and have an open mind. We do not know what we do not know. Dr. Pham was also asked what it would take for African American women to receive the medical care needed to reduce disparities and improve health outcomes. His suggestions were manifold. Working with their doctor would improve outcomes, get a second opinion early, and not wait too long. He also stated there is a rheumatologist shortage, and seeing multiple doctors takes time away from other patients. Dr. Pham suggests that if patients have additional questions for their provider to make more frequent appointments because this is an opportunity to learn

more about the condition. This qualitative data makes it clear that understanding lupus and its effects means learning more about the disease, increasing the number of doctors in the field, and understanding culture more clearly. The problem is as multifaceted as the solution: training needs to provide a multi-pronged approach which cultural humility training aims to do. Dr. Pham explains that their jobs are also complex, and doctors are often told that we do not get it when sometimes we are not given the opportunity. Dr. Pham offers an example: patients often make decisions without doctors regarding which medicines to take and not take, which in some cases inevitably leads to a 'lupus flare.' He also explains that transparency and openness about getting more follow-ups would be ideal. If someone stops taking medication three days after an appointment, and their next appointment is in 27 days, then there are good chance things will not go right after that much time has passed, especially if the doctor is not in the loop.

Many non-medical factors and barriers to care include mental health, other medical conditions, lack of family support, the financial strain of copays and transportation, and insurance coverages/lapses. Social stressors include children, caring for sick family members, personal beliefs, and misinformation. Many of these obstacles impede positive health outcomes for lupus patients.

Dr. Pham stated that sometimes patients do not communicate the entire truth about their health, which reduces positive health outcomes. Dr. Pham emphasizes an excellent old-fashioned detailed history is the most important thing beyond any labs/CT scans / MRI, which takes time. Dr. Pham regretfully states that some doctors do not necessarily invite the truth, which makes patients FEEL like they have to say the RIGHT things. He often hears this from patients: "I am not sure what I am supposed to tell you."

Dr. Pham shares with the patients they are supposed to say whatever they feel like and answer truthfully when there is a question about their health. Dr. Pham noted that diagnosis is often about truth, and a wrong diagnosis/assessment (sometimes based on lies) will inevitably lead to a wrong or unnecessary treatment.

Dr. Pham ended with this statistic. That research shows that only 30–60% of Systemic Lupus Erythematosus patients take their medications as prescribed. Inevitably, 40-70% of people will get worse when not taking the purported treatment or if they do not even come to see the doctor (Feldman et al., 2015).

Kim Howse and Dr. Pham are stakeholders who have demonstrated great value to the lupus community. Both add a tremendous wealth of knowledge, understanding the community's needs and what can improve health outcomes.

Chapter 4: Conceptual Model

It is essential to examine how theory contributes to understanding the usefulness of cultural humility to improve health outcomes for African American women. The Cultural Humility Training for Medical Professionals Serving African Americans Women with Lupus is designed to improve the overall health outcomes of African American women with lupus by equipping healthcare providers with the tools needed to enhance their understanding of the culture they are serving. The cultural humility training aims to help the healthcare system transform systemic racism into openness and acceptance. A clear conceptual framework drives Cultural Humility Training for Medical Professionals Serving African Americans Women with Lupus. It is informed by three theories: Historical particularism, Social learning theory, and The socialization model. All three theories inform the need for an understanding and openness among health care providers to improve health outcomes for African American women in the lupus community.

Historical Particularism

Marvin Harris (1968) gave the term historical particularism, but he was closely aligned with Boas' theory of cultural relativism. His theory is rooted in the idea that every person comes with their unique cultural history and experiences and that one must suspend judgment best to understand each client/patient within this context. Historical particularism holds that each culture and society should be described and understood on its own terms; each culture and person comes from their unique historical and cultural experience. As such, medical professionals must understand the root of the mistrust that has been established between African American women with lupus and the greater

medical community in America. An African American woman is not a cultureless individual who comes into a doctor's office but has been informed by cultural expectations based on historical experiences. According to historical particularism theory, this woman brings her traditions, circumstance, experiences, traumas, cultural trauma, and historical traumas. She brings everything with her that shapes who she is.

Social Learning Theory

Social learning theory, proposed by Albert Bandura (1977), emphasizes the importance of observing, modeling, and imitating behaviors, attitudes, and emotional reactions (McLeod, 2016). The theory's framework posits that people learn from one another through observation and imitation, and new behaviors may be reinforced through intervention. According to Irby (2013), Bandura's theory provides the basis for learning human behavior and outlining mentoring as a social function. Additionally, human behavior comprises three factors: cognitive, environmental, and behavioral. Cognitive factors are also called personal characteristics, including a person's knowledge, expectations, and attitudes. Ecological or environmental aspects comprise social norms, access to the community, and influence on others (ability to change their environment). Behavioral factors consist of skills, practice, and self-efficacy. In cultural humility training, the desired behavior is expressed and modeled. Once that pattern is established and learning occurs, improved health outcomes will follow. This theory suggests that people can learn new skills and behaviors by modeling and using them to change health outcomes for African American women with lupus. Thus, a new trend may emerge by teaching medical students, health care professionals, and educators cultural humility. The

knowledge of how to approach patients with cultural humility may be instilled more intentionally, and improved health outcomes will become apparent.

Socialization Model

The socialization model relates to social learning, which refers to processes where individuals are taught skills, behaviors, values, and motivations needed for functioning in a culture. Paramount among these are social skills, social understanding, and emotional maturity required for interaction. Socialization processes include those whereby culture is transmitted from each generation to the next, including training for specific roles and specific occupations (Maccoby, 2007). Health care has a culture just as every other occupation, and when that culture is not being entirely fair to those they serve, the power imbalance needs to be challenged. Socialization can be a tool that brings a positive change to the culture by spreading positive behavior among culturally sensitive peers and challenging the cultural norm. If socialization of cultural humility begins in medical schools with the students, then the culture of the health care system will start to change to an open and equitable system.

Chapter 5: Social Innovation

Cultural Humility Training

Based on the systematic review of Psychosocial Interventions that Improve Health Outcomes for African American Women with Lupus, the bases of the We are Lupus Strong cultural humility training were derived. The systematic review of research aimed to answer the following research question: what psychosocial interventions exist to improve health outcomes for African American women with lupus? Four eligible articles, such as interventions serving African American women with lupus, fit the criteria. Another is it was based in the United States, and the study aimed to improve health outcomes. The results showed improved health outcomes; however, there was no integration of physician involvement in the interventions. The leading indicator of improvement was peer support and self-management interaction. For example, self-management intervention is the patient taking their medication on a set schedule and meeting with a peer mentor for accountability. The systematic review informed the design for the innovation by highlighting the need for improved health outcomes, the mistrust between the African American community and the healthcare system, and non-culturally sensitive interventions, further invoking the need for culturally sensitive physician integration. Considering these needs, the Cultural Humility Training for Medical Professionals Serving African American Women with Lupus was created.

Research has indicated that negative bias has interfered with positive health outcomes for African Americans (Hall et al., 2015). This notion is not foreign to African American women with lupus. The interviews with community partners from the Lupus Howse Foundation and Cedar Sinai Medical Center confirmed the idea that African

Americans are disproportionately at a disadvantage in the healthcare system. This information from the community partners comes from their experience with the lupus community and research, which informed the decision to create cultural humility training for medical professionals.

To be humble and do nothing out of vain conceit and to not think of oneself above others is a biblical principle that guides this idea of working with others where there is a power imbalance.

Closing the health gap begins with healthcare providers, medical students, and medical professionals who service African American Women with lupus. According to Hall et al. (2015), this population experiences challenging gaps in care, particularly between themselves and their providers. The cultural humility training was developed to assist the individuals working in this system in understanding the dynamics of this marginalized population. African American women are three to four times more likely to develop the disease than their white female counterparts (Williams et al., 2018). African American women had the highest mortality rate due to lupus and were two to three times more likely to have premature deaths caused by lupus (Bartels et al., 2020). This is important to note that cultural humility training for the specific marginalized population was crucial to impact the health outcomes.

Target Population

The target population for the training is medical professionals, health care providers, and medical students who are directly working with African American women with lupus.

Modules

The cultural humility training consists of four 120-minute modules. Upon the initial meeting with the training request, the layout of the four modules is decided. The training can be divided into one module per day for four consecutive days, one module per week for four weeks, or compressed into a full day of training. However, further discussion with the training requester will determine the client's needs. The initial two-hour meeting with the requester will evaluate the needs and goals.

The facilitator will be a survivor of lupus or have a close personal connection with the lived experience of lupus. Physicians could also train and disseminate this training as a strategy to build rapport with participants. Having a physician train another physician would benefit the cultural humility training by adding credibility to a colleague delivering the information,

In sequence, the four modules are Lupus and Historical Interactions between African American Women and the Healthcare System, The Significance of Community Engagement, Cultural Humility, Defined and Implementation of Cultural Humility.

Two of the four modules are complete for this program and pass the innovation section of the Doctor of Social Work requirements. The four modules have been outlined in the training manual, and modules three and four development will take place soon before dissemination.

This cultural humility training is specific to African American women with lupus. Different cultural competence and cultural humility training are doing the work to promote racial justice across health care. The two training that was closely studied were

Georgetown University, National Center for Cultural Competence, and Kent State University, *Fostering Cultural Humility in the Classroom*. Both pieces of training yielded relevant information to guide and assist in building the *We Are Lupus Strong* curriculum for African American women with lupus. The unfavorable components of the studied training targeted a wide range of populations. Their focus is mental health, health care for children and families, infant death, classrooms, and teachers, which all are important topics to address. However, this project aims to directly impact the health outcomes for African American women with lupus.

Chapter 6: Evaluation. Methodology & Results Summary

Research Questions

This comprehensive project investigates the experiences of African American women diagnosed with lupus as they navigate the healthcare system while encountering the implicit bias that causes poorer health outcomes among African American women. The research questions guiding this study are: Can cultural humility training for physicians increase positive health outcomes and health care experiences for African American women with lupus? Can cultural humility training increase physicians' understanding of the needs of African American female patients with lupus?

Methods for Assessing the Project's Impact

The methods for assessing this project's impact include pre- and post-assessment in implicit bias and knowledge of biases towards African American women in health care.

Pre- Assessment

Implicit Bias pre-test for participating physicians will be administered directly after the speaker's introduction and training. The Ethnocentrism Scale will be used to capture the response of the participants to their implicit, explicit, or neutral answers. The scale measures the person's view of their own culture as the center of everything vs. other cultures as subprime. Sample questions include, "Most people would be happier if they lived like people in my culture?" and "I am very interested in the values and customs of other cultures?".

Current lupus patients will also be asked to complete a questionnaire that evaluates their experience in receiving treatment from their health care providers. These questions are aimed at locating similar experiences between patients. Sample questions include, "Does your provider listen to your concerns about your health?" and "Do you trust your provider is giving you the best treatment possible?". Using this data, the researcher will look for patterns and evaluate critical issues to address in the Lupus Strong curriculum to benefit health care providers. Treatment rating questionnaires for current patients will be given to the physician's office to be given to their patients who are willing to participate in the project. The questionnaire will evaluate the effectiveness of the provider's change in patient relationship with the patient after completing the cultural humility training.

Implement Project

The facilitator or physician will lead the four-part Cultural Humility training. Once the fourth module is completed, the participants must complete a post-survey. The physician survey response will act as an exit ticket to collect physician responses. The survey will evaluate the effectiveness of the information provided throughout the training and what the participants liked or would change/add. This will give the facilitator information to assess if the activity requires modification in future rollouts.

Post-Assessment (6 months- 1 year later)

The Implicit Bias scale for participating physicians will evaluate the change once the knowledge has been put into practice. A pattern of openness to equality of cultures

may emerge, and implicit bias will decrease. The electronic version will be sent to the participating physicians via email for easy access.

Treatment rating questionnaires for current patients will be sent to the physician's office following the training. The questionnaire will be administered to participating African American women with lupus patients. The questionnaire will assess the improvement of provider and patient relationships, treatment options, and outcomes. It will also guide any necessary adjustments to the training and information provided during the training.

Data Analysis Questions:

Once training is completed, and the follow-up has been conducted along with the assessments completed by the participating physician and the patients they serve, the data will be analyzed to answer the following questions. (a) are the implicit bias ratings for participating physicians reduced after training and the opportunity to implement the practices learned? (b) are treatment ratings higher for current patients with the same physician after the physician has participated in cultural humility training? The analysis of the questions will give an understanding of what to adjust, modify or keep in the cultural humility training.

Financial Plans and Project Accountability

Cultural Humility training will be packaged in the following ways:

The training is a for-profit model that the creator will teach and facilitate for a hired physician.

- Training packages with data analysis offered to hospitals with follow-up recommendations (Training \$8000, Pre & post testing & Analysis: \$ 700 per participant- 10 participant minimum)
- Training packages with data analysis offered to insurance companies with follow-up and recommendations (Training \$15000, Pre & post testing & Analysis: \$ 1200 per participant- 10 participant minimum)
- Guest Lectures at medical schools (\$2,000 per module)
- Follow-up consulting and coaching (\$500 per hour)
- All packages will include travel and accommodation expenses separate from the initial training cost. This consists of a facilitator and one staff member.

Project Accountability for Cultural Humility training

An initial meeting with the requester of the training will be conducted to establish mutual understanding and goals. The meeting will be a one, two-hour pre-training meeting to develop plans. After the training, a second meeting with the requestor will occur—a one, two-hour post-training session to review data analysis and recommendations with questions and answers. Lastly, an exit survey will be given to assess the services' satisfaction.

Data Collection methods, instrumentation (cultural humility training)

A soft roll-out of the We are Lupus Strong cultural humility training was conducted in two settings. The soft roll-out consisted of crucial information from each of the four modules, the definition of lupus and the experience of a lupus survivor, historical implication, the definition of cultural humility, and the implementation of cultural

humility. The rollout was conducted at the California Baptist University and the Medical University of South Carolina. The two groups were pre-nursing and pre-med students. Pre- and post-surveys were presented to the pre-nursing and pre-med students to understand the following subjects: lupus knowledge, implicit bias, healthcare bias, and African American women's experiences with the healthcare system.

Interviews with a physician treating African American women with lupus from Cedars Sinai Medical Center were insightful in gaining awareness from a provider's point of view and receiving validation from a physician working directly with African American women with lupus.

An interview with a lupus community partner of the Lupus Howse Foundation was to increase understanding of the lived experience of an African American lupus survivor from a leader in this community that has worked several years servicing lupus survivors.

Informal qualitative data collection was conducted by interacting and interviewing the African American women currently navigating the healthcare system to manage care for lupus. The interactions were during support groups, outings, and individual conversations.

Results of the Data Collection

Pre-Assessment Data

What was found from the two different classes from the universities was that there was minimal to no knowledge of lupus as a disease that affects African American

women. Most pre-med or pre-nursing students have minimal to no awareness of the impact of lupus on African American women. Further, most pre-med or pre-nursing students have some knowledge of the implicit biases within the healthcare system towards African American women. What was found was that there was a lack of knowledge thus far in their programs which addressed lupus, and there was an interest in learning more.

Post Assessment Data

After being provided a snippet of the entire curriculum, however, it was enough for the students to engage with the personal nature of the disease through someone's personal lived experience while also recognizing the research and need to develop a better understanding of lupus as a cultural humility. Most pre-med or pre-nursing students' knowledge of lupus as a disease affecting African American women was increased due to Cultural Humility training soft roll-out. Most pre-med or pre-nursing students experienced an increased awareness of the impact of lupus on African American women due to Cultural Humility training. Most pre-med or pre-nursing students experienced increased knowledge of the implicit biases within the healthcare system towards African American women.

It was found that there was an interest in learning additional information on the topic of lupus and cultural humility and its impact on the health outcome for this marginalized population.

Evidence of the actual or proposed impact of the project on the social problem and population identified.

As the training is completed by participating medical professionals or medical students end of training surveys will be conducted. This is to evaluate the effectiveness of the training and to collect data that will confirm the research. Evidence of the project's impact is a reduction in implicit bias ratings among physicians and health care professionals after experiencing We Are Lupus Strong cultural humility training. Further evidence of the project's impact is an increase in positive patient ratings by African American women treated by physicians who have experienced Cultural Humility training. The data results inform if there is a need to modify, adjust or live the movement.

Chapter 7: Conclusion and Implications

This project aims to provide compelling content about lupus and understanding cultural humility in delivering healthcare. Cultural humility training will support medical professionals in obtaining a sense of cultural factors that influence African Americans surrounding health and healing. Results from the soft roll-out, conducted at two universities among nursing-student and pre-med students, yielded vital data. The data indicated a lack of knowledge regarding lupus and bias against African American women among healthcare providers. Critical ethical consideration is the information disseminated will not be accepted by the medical community and will be pushed back. As well as, the participants may not use the material and information provided or not use it correctly. Future research will gather data and information about other racial, marginalized groups of chronic disease sufferers encountering similar health disparities. Further dissemination of the project is to complete the third and fourth modules, copyright the training, and propose the training to various medical universities for formal presentation and fees.

Appendices

For additional information on the, **We Are Lupus Strong Cultural Humility Training for Medical Professionals Serving African American Women with Lupus**, please get in touch with Tanisha Robinson at Info@gloriisme.com.

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