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Advancing Health Equity in Lupus: Bridging Disparities for Improved Outcomes Among African American Community

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Abstract

This research confronts the intricate challenges surrounding Lupus, an intricate autoimmune disease, with a particular focus on its impact on the African American community (Crosslin et al., 2019). Addressing the pervasive disparities in diagnosis, treatment accessibility, and health outcomes among African Americans, this study delves into the multifaceted landscape of Lupus care. A meticulous analysis of literature and healthcare data reveals socio-economic factors, access barriers, cultural influences, and systemic biases as formidable contributors to these disparities. By shedding light on these critical issues, the research advocates for targeted interventions, emphasizing culturally competent care, community engagement, and policy initiatives. The aim is to rectify existing healthcare disparities and advance health equity for African Americans affected by Lupus. This paper serves as a clarion call, urging the implementation of tailored strategies to ensure equitable access to accurate diagnosis, effective treatment, and improved health outcomes within the African American population grappling with Lupus.

Keywords: Lupus, autoimmune disease, diagnosis, treatment, disparities, inequities

Chapter I: Introduction

Background

Lupus, a complex autoimmune disease, manifests itself with a myriad of symptoms, contributing to its unpredictable nature. While it affects a considerable number of individuals nationwide, the mortality rates reveal a notable disparity. The National Center for Health Statistics data indicates an overall unadjusted lupus mortality of 4.6 per million, with in-hospital mortality from the NIS standing at 2.9%. Strikingly, African-Americans exhibit a disproportionately higher mortality risk compared to Caucasians (Krishnan E. et al., 2006). As research suggests, Lupus impacts individuals differently, with certain racial and ethnic groups, such as African Americans, experiencing a more pronounced effect (Crosslin et al., 2019). People from certain racial and ethnic groups, like African-American, feel the impact of Lupus more than other African American women are three times more likely to get lupus than White women; 65% of people with lupus say chronic pain is the most difficult part of having lupus; 89% of people with lupus say they can no longer work full=time due to lupus complications; 76 % of lupus patients say fatigue caused by lupus has forced them to cut back on social activities (Thanou, A et al., 2018).

Despite advancements in Lupus understanding, a significant problem persists – not all individuals receive the necessary care. African Americans and other minority groups encounter challenges in accurate diagnosis and appropriate treatment for Lupus. Symptoms vary widely among individuals, and the absence of definitive laboratory tests often leads to a 5-year delay in systemic lupus erythematosus (SLE) diagnosis (Leung, J. et al., 2019). Drawing from personal experience, the diagnostic journey for my mother spanned five years, marked by recurrent hospitalizations and an initial diagnosis of pneumonia.

This study aims to delve into the root causes of these disparities, particularly among African Americans and seeks to comprehend the challenges hindering equitable care for Lupus in minority populations. Focusing on the obstacles faced by African Americans and other minority groups, the research aims to uncover strategies to rectify these issues, ensuring fair and equal healthcare access for all Lupus patients, regardless of their racial or ethnic background.

Statement of the Problem

Right now, there's a big problem in how Lupus is dealt with, especially for African American communities. Minority communities aren't receiving the same care for Lupus as Caucasian communities, and this leads to unfair health results (Yalavarthi, B at el., 2023). Diagnosis of Lupus for African Americans lacks equity and accuracy. For the sake of all who are living with Lupus, including African Americans; the ideal situation involves equitable access to accurate diagnosis to have the same chance of getting the proper diagnosis (P1), Ineffective treatment of lupus patients of African American women (P2), Increased outcomes for African American women affected by Lupus (P3).

Purpose of the Study

This research seeks to thoroughly examine the variations in the management of Lupus, with a specific focus on differences among African American and other minority communities. Managing Lupus, a complex illness, poses numerous challenges, particularly in accurate diagnosis, appropriate treatment, and facilitating recovery. This study will examine information from different sources to find out why some groups, especially African Americans, do not always get the same care for Lupus. Disparities in SLE incidence, treatment, and outcomes have now been well established. The root causes of these disparities are multifactorial including genetic, epigenetic, and socioeconomic. The underrepresentation of marginalized communities in lupus clinical trials further worsen these disparities. Efforts have been made recently to address disparities in a more comprehensive manner, but systemic causes of disparities must be acknowledged and political will is required for a sustained positive change (Hasan at el., 2022).

Significance of the Study

This research is fundamental because it is about understanding the differences in Lupus care, especially for African American communities. Lupus is a challenging disease that brings many problems in how it is treated and how people get better. It is even more challenging for African Americans and other minority groups. So, we want to study information from different places to understand why this happens, especially for African Americans. If we can figure out why this is not fair, we can suggest things that might help make healthcare fairer for everyone, no matter where they are from. Understanding these differences will help us figure out why some people do not get the proper care for Lupus and also help us suggest things that might make things fairer. . It will make recommendations for things that can help, such as ensuring doctors understand and treat Lupus in everyone in the best way possible. Fixing these problems in Lupus care can make a big difference for African Americans and other groups, making sure everyone gets the right help for Lupus, no matter their background. This research aims to unravel the intricate web of disparities in Lupus care, particularly focusing on the challenges faced by African Americans. The overarching goal is to investigate the root causes behind these differences, seeking to understand why certain racial and ethnic groups, especially African Americans, encounter obstacles in accessing equitable Lupus care. The researcher is driven by a commitment to rectify these disparities, advocating for systemic changes to ensure that everyone, regardless of their origin or background, receives fair and consistent treatment for Lupus.

As we delve into the disparities, the purpose is not merely to identify the problems but to propose tangible solutions. The research endeavors to suggest ways to bridge the gap in Lupus care, emphasizing the importance of healthcare providers' awareness and competency in treating Lupus across diverse populations, with a specific focus on the unique challenges faced by

African Americans. By addressing these issues head-on, the study aims to contribute to the broader goal of fostering fairness and equality in healthcare. The urgency of this research is underscored by the potential consequences of unaddressed disparities, as continued differences in Lupus management could perpetuate a higher incidence of deaths in African American communities and other minority groups. Ultimately, the purpose is to advocate for change, ensuring that Lupus care is not only effective but also equitable for every individual, regardless of their racial or ethnic background.

Main research question and sub-questions

The main research question is:

1. How can equitable access to accurate diagnosis and effective treatment improve outcomes for individuals of African American and ethnic minorities affected by Lupus?

The sub-questions are:

2. How would access to healthcare resources affect making more equitable and accurate diagnoses for African Americans?

3. What would it look like if treatment for African Americans were effective?

4.. What if we have approved outcomes for African Americans affected by Lupus?

Examining the effectiveness of treatment specifically tailored for African American individuals with Lupus is essential. This sub-question delves into the nuances of treatment methodologies and their efficacy within African American communities. It aims. to envision what successful and tailored treatment outcomes would look like for this demographic. Exploring the implications of approved outcomes specifically for African Americans affected by Lupus is integral to this research. This sub-question delves into envisioning equitable and favorable health outcomes specifically tailored for African American individuals dealing with Lupus, emphasizing the importance of comprehensive and effective care that caters to their unique needs and circumstances. By dissecting these sub-questions, this study seeks to unravel the intricate interplay between healthcare access, treatment effectiveness, and tailored outcomes for African American and ethnic minority populations impacted by Lupus. Through this exploration, the aim is to propose interventions that mitigate disparities and pave the way for equitable healthcare provisions that address the unique challenges faced by African American individuals and other ethnic minorities affected by Lupus.

Theory of Change and Assumptions

Lupus, a complex autoimmune disease, presents substantial challenges in healthcare, particularly among marginalized communities such as African Americans. Disparities in access to accurate diagnosis, effective treatment, and favorable health outcomes persist within these populations. Addressing these disparities necessitates a comprehensive approach for equitable healthcare access and improved Lupus care outcomes for all. The following assumptions outline potential pathways to address these inequities, emphasizing the importance of fair access, knowledge enhancement, systemic improvements, and collaborative efforts among stakeholders. Assumption 1 (A1): IF access to diagnosis and treatment of Lupus is available to African Americans. Our belief stems from the idea that if individuals receive timely and effective assistance, the challenges associated with diagnosing and treating Lupus are likely to diminish. Assumption. (A2): IF doctors and nurses learn more about Lupus in African American communities, Our rationale behind this belief is that when healthcare professionals have a deeper understanding of Lupus within various communities, it can contribute to improved patient outcomes and mitigate disparities in healthcare. Assumption 3(A3): A3 IF policymakers and doctors work together to improve inequities in Lupus care. THEN: there will be an improvement in outcomes for African Americans affected by Lupus. Our perspective is grounded in the belief that by uniting efforts, we can reshape the landscape of healthcare, fostering improvements that benefit everyone, including African Americans.

Limitations

Accessing equitable healthcare is a multifaceted challenge influenced by various factors such as socioeconomic status, geographic location, and insurance coverage. While this research focuses on diagnosing, treating, and caring for Lupus in the African American community, it is crucial to recognize the inherent complexities and limitations within this scope.

Broader Healthcare Inequities: This study does not comprehensively address all healthcare inequities. Other disparities in healthcare, unrelated to Lupus, remain beyond the scope of this research.

Additional Medical Conditions: The research primarily concentrates on Lupus, and limitations arise concerning the examination of disparities in the diagnosis and treatment of other medical conditions within the African American community.

Cultural Competency Beyond Lupus Care: The study narrows its focus to Lupus care and may not extensively cover broader aspects of cultural competency in healthcare beyond the context of Lupus.

Geographic Variability: Healthcare disparities may vary across different geographic locations and healthcare systems. This research emphasizes challenges within the United States but may not fully capture the diversity of issues faced in various regions.

Measurement of Success: The complexity of measuring the success of proposed interventions poses a challenge. Limited information and insufficient tools for evaluating improvements for African Americans and others with Lupus may impact the ability to assess the effectiveness of suggested strategies.

Interdisciplinary Collaboration Challenges: The study acknowledges the challenges of interdisciplinary collaboration, emphasizing that working together does not guarantee seamless change due to potential disagreements on priorities and resource constraints.

Regional Disparities: Recognizing the diversity of healthcare settings, the research may not universally apply its findings to all regions, as different locations may have distinct challenges requiring tailored solutions.

Effectiveness of Proposed Ideas: While the research proposes ideas to address Lupus care disparities, their applicability and effectiveness may vary based on the dynamic nature of healthcare systems and their responses to interventions.

Acknowledging these limitations is essential for a nuanced understanding of the research's scope and applicability. It underscores the need for future studies to delve into specific aspects not covered in this research, promoting a comprehensive approach to address healthcare disparities across diverse communities.

Definitions of Terms

1. *Lupus:* It can cause various symptoms.

2. *Autoimmune Disease:* Autoimmune diseases are conditions where the immune system mistakenly attacks the body's tissues, mistaking them for foreign invaders. .

3. Diagnosis: Refers to identifying a disease or condition based on signs, symptoms, and test results.

4. Treatment: Treatment involves medical care to manage or alleviate a disease's symptoms

5. Disparities: Disparities are differences or inequalities in health conditions' occurrence, distribution, or outcomes between different groups.

6. Inequities: Inequities refer to unfair or unjust differences or imbalances, particularly in access to resources, opportunities, or outcomes.

Expected Impact of the Research

This research promotes fairness and equality in Lupus care, especially among diverse communities, including African Americans. The investigation delves into the underlying reasons for disparities in Lupus care, particularly noting the differing experiences among individuals from diverse racial and ethnic backgrounds. By synthesizing existing knowledge and analyzing healthcare data, the study seeks to unravel the root causes contributing to these disparities. Through this exploration, the research aims to propose targeted interventions and strategies to ensure equitable healthcare access and outcomes for all individuals affected by Lupus. The emphasis is on devising measures that bridge the gaps in care provision and treatment outcomes among varied demographic groups, including African American communities. The envisioned impact is to revolutionize Lupus care delivery, eradicating the discrepancies observed in diagnosis, treatment, and health outcomes based on racial or ethnic identities. By advocating for and implementing these suggested interventions, the research hopes to level the playing field, offering equal opportunities and access to quality care for every individual navigating the complexities of Lupus, regardless of their racial or ethnic background**.**

Chapter II: Review of Literature

Introduction

Understanding the varied impact of Lupus and its treatment across diverse demographics is crucial for equitable healthcare. This comprehensive literature review assesses multiple studies addressing three key aspects: Firstly, it scrutinizes the fairness in Lupus diagnosis (Amsden et al., 2018). Some studies (Borgia et al., 2021)) highlight the significance of equal access to diagnosis for all individuals, stressing the importance of universal diagnostic opportunities. Conversely, other research suggests that alongside medical considerations, factors such as socio-economic status and geographical location significantly influence diagnostic accessibility, especially among diverse populations like African Americans. Secondly, the review examines the impact of receiving appropriate treatment for Lupus. While specific studies advocate for standardized treatment protocols for everyone, particularly emphasizing equitable treatment for individuals from different backgrounds (Feldman et al., 2013), others propose a holistic approach. These studies underscore the necessity of comprehensive support systems beyond medical treatment, highlighting the importance of addressing socio-cultural and psychological aspects, especially crucial for minority groups like African Americans.

Lastly, it explores how various demographic groups, including African Americans, navigate Lupus care. Some studies accentuate the positive outcomes linked to equal care opportunities, particularly highlighting improved health among minority groups when provided with equitable healthcare (Feldman et al., 2013). However, other research underscores the multifaceted nature of health outcomes, emphasizing the role of socio-environmental factors in shaping health disparities. The diverse research insights offer a comprehensive understanding of Lupus care disparities among varied demographics, especially underscoring the significance of fair and equal care provision for individuals, regardless of their racial or ethnic backgrounds

(Hasan et al., 2022). The goal is to blend these diverse perspectives, thereby guiding efforts toward creating an inclusive and equitable healthcare landscape for all those affected by Lupus, particularly emphasizing the need for tailored interventions to address the unique needs of African American communities.

Inequities in diagnosis and treatment of Lupus for African Americans.

To describe root causes of health disparities by reviewing studies on incidence and outcomes of systemic lupus erythematosus (SLE) related to ethnic, race, gender, or socioeconomic differences and to propose solutions. A study on *Health Disparities in Systemic Lupus Erythematosu*s recently found that SLE outcomes have steadily improved over the past 40 years but are not uniformly distributed across various racial and ethnic groups. Belonging to racial and ethnic minorities has been cited as a risk factor for more severe disease and poor outcomes in SLE (Hasan et al.,2022). This study examines disparities in Lupus diagnosis across different demographic groups, affirming the need for equitable access as a precursor to improved health outcomes. Challenges the assumption by arguing that while access to diagnosis is critical, other social determinants significantly impact health outcomes, challenging the linear relationship implied in the assumption. In another study, *Reframing health disparities in SLE: A critical reassessment of racial and ethnic differences in lupus disease outcomes.* This study Researching health disparities in SLE is critical, as it can facilitate the identification of inequalities and inform resource allocation to improve outcomes. However, it is essential to note that research that uses racial and ethnic categories to describe diverse groups of people can also pose challenges. These labels encompass a wide range of information under the broad, poorly defined umbrella terms of race and ethnicity. Additionally, comparing outcomes across socially constructed groups without considering other contributing factors can lead to misleading results.

Frameworks to guide health disparities research in SLE and other chronic diseases are needed to ensure that studies are correctly designed, appropriately interpreted, and ultimately meaningfully applied to inform interventions that aim to improve outcomes (Parodis et al., 2023).

Medical training on Lupus in African American communities

Supports the assumption by showcasing the correlation between equitable treatment access and improved health outcomes among minority groups with Lupus. Supports the assumption by showcasing the correlation between equitable treatment access and improved health outcomes among minority groups with Lupus. It explores complexities beyond treatment access and challenging assumptions by emphasizing the need for comprehensive care and support systems (Drenkard et al., 2020). *Overcoming barriers to recruitment and retention of African American women with SLE in behavioral interventions: lessons learned from the WELL study. Lupus Science & Medicine.* Another study explores complexities beyond treatment access, challenging the assumption by emphasizing the need for comprehensive care and support systems (Sumpter, I.J, 2022). African Americans are historically under-represented in SLE studies and engaging them in behavioral interventions is challenging. The Women Empowered to Live with Lupus (WELL) study is a trial conducted to examine the effectiveness of the Chronic Disease Self-Management Program (CDSMP) among African American women with SLE. We describe enrolment and retention challenges and successful strategies of the WELL study (Drenkard et al., 2020).

Policy gaps in Lupus care and treatment in African American communities

Provides empirical support by demonstrating interventions that lead to improved health outcomes, aligning with the assumption of the relationship between equitable access and better results. *Long-term Outcomes in Systemic Lupus Erythematosus: Trends over time and significant Contributors.* Challenges the assumption by highlighting the multifaceted nature of health outcomes, suggesting a more comprehensive understanding beyond access alone (Arnaud et al., 2020). Long-term outcomes in SLE have been dramatically improved over the past decades; however, increased morbidity and mortality, especially among young individuals, still exist. Unmet needs include residual disease activity and frequent flares, glucocorticoid treatment dependency and toxicity, comorbidity burden, reduced health-related quality of life, health disparities, and damage (Arnaud et al., 2020). *Community-engaged research to address health disparities in systemic lupus erythematosus. P*rovide empirical support by demonstrating interventions that lead to improved health outcomes, aligning with the assumption of the relationship between equitable access and better results (Borgia, R.E.,2021). *Racial disparities in medication adherence between African American and Caucasian patients with systemic lupus erythematosus and their associated factors*. The study investigated medication nonadherence, revealing higher prevalence among African Americans in contrast to Caucasians. Specifically focusing on patients with systemic lupus erythematosus (SLE), the research aimed to discern racial disparities in adherence and identify contributing factors to nonadherence (Sun K, et al., 2022). *Racial Discrimination, Disease Activity, and Organ Damage: The Black Women's Experiences Living With Lupus (BeWELL) Study.* The study focused on 427 Black women with systemic lupus erythematosus (SLE) in Atlanta, investigating the correlation between racial discrimination and disease outcomes. Participants reported experiences of racial discrimination in various domains, and SLE activity in the preceding 3 months was assessed using the Systemic Lupus Activity Questionnaire. Irreversible damage to organs or systems was measured using the Brief Index of Lupus Damage. Multivariable linear regression analyses revealed that an increased frequency of racial discrimination was associated with higher SLE activity and organ damage. The findings underscore the importance of addressing racial discrimination in comprehensive efforts to mitigate disparities in SLE severity among Black women (David H. C. et al., 2019).

Summary

This literature review delves into Lupus, focusing on equitable healthcare for all, particularly emphasizing its impact on African American communities. It assesses Lupus diagnosis fairness, acknowledging the need for universal access while highlighting socio-economic influences, especially among African Americans. It explores diverse perspectives on Lupus treatment, advocating for comprehensive support systems crucial for minority groups like African Americans. Additionally, it analyzes Lupus care experiences, showing positive outcomes with equal care opportunities but underscoring socio-environmental factors' role in health disparities, particularly among African Americans. Overall, the review aims to guide inclusive healthcare, tailoring interventions for the specific needs of African American Lupus patients**.**

Chapter III: Research Methods

Introduction

The research design incorporates a mixed-methods approach, utilizing both quantitative and qualitative methodologies to comprehensively explore Lupus care among African American individuals. Quantitative data will be gathered through electronic surveys administered via Google Forms, widely distributed across various social media platforms. These surveys aim to collect information on experiences, access to care, and perceived disparities in Lupus diagnosis and treatment. On the other hand, qualitative techniques, such as interviews, will be conducted with Lupus patients, individual experts, and caregivers. These interviews provide an in-depth exploration of personal narratives and professional insights related to Lupus care within the African American community. By combining the quantitative survey data with qualitative interview findings, the study aims to offer a holistic and nuanced understanding of the intricate factors influencing Lupus care among African Americans.

Main research question and sub-questions

The main research question is how can equitable access to accurate diagnosis and effective treatment improve outcomes for individuals of African American and ethnic minorities affected by Lupus? The sub-questions the researcher will try to answer are, how would access to healthcare resources affect making more equitable and accurate diagnoses for African Americans? What would it look like if treatment for African Americans were effective?

Finally, what if we have approved outcomes for African Americans affected by Lupus?

Theory of Change and Assumptions

Lupus, a complex autoimmune disease, presents substantial challenges in healthcare, particularly among marginalized communities such as African Americans. Disparities in access to accurate diagnosis, effective treatment, and favorable health outcomes persist within these populations. Addressing these disparities necessitates a comprehensive approach for equitable healthcare access and improved Lupus care outcomes for all. The following assumptions outline potential pathways to address these inequities, emphasizing the importance of fair access, knowledge enhancement, systemic improvements, and collaborative efforts among stakeholders.

Assumption 1 (A1): A1 IF access to diagnosis and treatment of Lupus is available to African Americans.

Assumption 2(A2): IF doctors and nurses learn more about Lupus in African American communities.

Assumption 3(A3): IF policymakers and doctors work together to improve inequities in Lupus care.

THEN: there will be an improvement in outcomes for African Americans affected by Lupus.

Operational Definitions

In investigating the impact of equitable access to healthcare resources on Lupus care among African American and ethnic minority populations, the independent variable is "equitable access to healthcare resources." This variable is the proactive element being studied and manipulated to observe its effect on Lupus care outcomes. The dependent variables encompass "accurate diagnosis," "effective treatment," and "approved outcomes" for individuals affected by Lupus within these demographics. Changes or variations influence these dependent variables in the independent variable. They are measured to understand how equitable access influences the precision of diagnosis, the effectiveness of treatment approaches, and the establishment of validated health outcomes for African American and ethnic minority individuals dealing with Lupus.

A1: Access to diagnosis and treatment of Lupus for African Americans is operationalized as the availability, affordability, and timely utilization of medical services, diagnostic procedures, and treatment options specific to Lupus within the African American community.

A2: Increased understanding among doctors and nurses about Lupus in African American communities is operationalized as healthcare professionals' knowledge, awareness, and cultural competency in addressing the unique challenges and characteristics of Lupus care within the context of the African American population.

A3: Collaborative efforts between policymakers and doctors to improve inequities in Lupus care are operationalized as joint initiatives, policies, and interventions developed and implemented by healthcare policymakers and professionals to eliminate disparities and enhance Lupus care accessibility, quality, and outcomes for African Americans. THEN: there will be an improvement in outcomes for African Americans affected by Lupus.

Access to Diagnosis and Treatment:

Proposed Change: Enhancing access involves ensuring that Lupus diagnosis and treatment services are not only geographically available but also economically and socially accessible to African Americans. This could include measures to reduce financial barriers, improve healthcare infrastructure, and increase community awareness about Lupus.

Learn More about Lupus in African American Communities:

Proposed Training: This involves implementing comprehensive training programs for healthcare professionals. It includes clinical training on Lupus, cultural competency training to understand the specific challenges faced by African Americans, and educational modules focusing on the socio-economic factors affecting Lupus care within this community.

Collaboration Between Policymakers and Doctors:

Proposed Policies: Policymakers and doctors should collaborate to implement policies that address systemic issues contributing to Lupus disparities. This may involve policies aimed at reducing healthcare inequalities, increasing funding for Lupus research, and ensuring that healthcare plans are tailored to the unique needs of the African American population.

Improvement in Outcomes for African Americans Affected by Lupus:

Measurement of Improvement: Improvement can be measured through various indicators such as: Reduced Fatality Rate: Tracking and analyzing the fatality rate among African Americans with Lupus.

Greater Access to Timely Care: Monitoring and improving the timeliness of diagnosis and treatment.

Patient Satisfaction Metrics: Assessing patient satisfaction through surveys, focusing on the perceived quality of care, communication, and overall experience.

By operationalizing these aspects, the research aims to create tangible and measurable criteria for evaluating the effectiveness of proposed changes and interventions.

Population Sampling Strategy

The selection of subject matter experts for this research is crucial to ensuring a comprehensive understanding of Lupus care in the African American community. Here's an expansion of the subject matter expert selection.

Medical Professionals (Doctors and Nurses):

Expertise Needed: Clinical understanding of Lupus, including diagnostic processes, treatment options, and the challenges faced by African American patients.

Rationale: Medical professionals directly involved in Lupus care can provide insights into the clinical aspects, and challenges in diagnosis and treatment, and share experiences related to patient interactions within the African American community.

Expertise Needed:

Clinical understanding of Lupus, including diagnostic processes, treatment options, and the challenges faced by African American patients.

Rationale: Medical professionals directly involved in Lupus care can provide insights into the clinical aspects, and challenges in diagnosis and treatment, and share experiences related to patient interactions within the African American community. I was unable to receive clinical representation for this research.

Policy Experts:

Expertise Needed: Knowledge of healthcare policies, especially those impacting Lupus care and addressing health disparities.

Rationale: Policymakers can offer insights into the systemic factors affecting Lupus care, identify existing policies, and propose potential changes or improvements that could lead to equitable outcomes for African American patients. I was unable to receive their perspective in this research.

Mixed-Methods Sampling: Employing a mixed-methods sampling strategy for subject matter experts will involve combining different techniques to select a diverse group of professionals. Surveys could be used to gather quantitative data, while interviews with a subset of experts can provide qualitative insights, creating a more holistic understanding of Lupus care.

By including a range of subject matter experts, the research can benefit from a multidimensional perspective that encompasses medical, policy, and equity-related aspects crucial for addressing the complexities of Lupus care in the African American community.

Procedures

The research employs a mixed-methods approach, combining electronic and in-person surveys utilizing Google Forms and social media platforms from 100 African American participants, and caregivers in the United States. Alongside, 5 interviews with doctors, nurses, and the healthcare team to obtain comprehensive insights. The survey design focuses on evaluating equitable access to accurate diagnosis and effective treatment for African American and ethnic minority populations affected by Lupus. Interviews encompass diverse perspectives, capturing nuanced experiences related to healthcare access, diagnosis, treatment, and outcomes. Data collection occurs through purposive, stratified, and convenience sampling methods to ensure representation from these specific demographic groups. Rigorous adherence to ethical guidelines and consent protocols is maintained throughout the data collection.

Data Processing and Analysis

After data collection, the gathered information undergoes effective processing and analysis. Quantitative survey data obtained through Google Form is organized, cleaned, and tabulated using statistical software. Descriptive and inferential statistical analyses are conducted to identify patterns, correlations, and trends related to healthcare access, diagnosis, treatment, and outcomes among African American and ethnic minority populations affected by Lupus in San Jose. Concurrently, qualitative data from interviews undergoes thematic coding and content analysis to elucidate nuanced perspectives, experiences, and challenges these communities face. Integrating qualitative and quantitative data ensures a comprehensive understanding and enriched interpretation of the research findings.

Internal and External Validity

The study maintains internal validity by rigorously controlling potential biases, ensuring accurate and reliable data collection and analysis methodologies. Measures are implemented to minimize confounding variables and maintain consistency across data collection processes. Additionally, the research utilizes standardized survey tools and structured interview protocols to enhance the reliability of results. External validity is upheld through diverse sampling techniques, including purposive and stratified sampling, ensuring the representation of African American and ethnic minority populations affected by Lupus. The findings aim for generalizability within these specific demographic groups, enhancing the study's external validity.

Limitations in Data

Potential limitations in the data might include the challenges associated with reaching and accessing diverse individuals from African American and ethnic minority backgrounds affected by Lupus. Sampling limitations could impact the representativeness of the study's findings within these specific demographic groups. Moreover, the reliance on self-reported data through surveys and interviews might introduce response biases or subjective interpretations, influencing the accuracy and completeness of the information gathered.

Summary

This research employs a comprehensive mixed-methods approach to investigate equitable healthcare access, diagnosis, treatment, and outcomes for African American and ethnic minority populations affected by Lupus. The combination of surveys and interviews enables a multifaceted exploration of healthcare disparities within these communities. The study aims to uncover nuanced insights through stringent data processing and analysis procedures, contributing to a broader understanding of Lupus care disparities. While addressing potential limitations, this research provides actionable strategies to advance health equity and inclusivity for individuals with Lupus, regardless of their racial or ethnic backgrounds (Vina et al., 2012).

Chapter IV: Results and Findings

Introduction:

Lupus, a chronic autoimmune disease, poses distinctive challenges in the African American community. This research investigates perceptions and potential barriers to Lupus diagnosis and treatment, utilizing a comprehensive approach that combines quantitative insights from 100 surveys conducted within the African American community in the United States with qualitative narratives from 5 doctors and nurses. By seamlessly blending quantitative and qualitative data, this study aims to provide a holistic understanding of Lupus care dynamics, exploring opportunities for improvement within this demographic. The research focuses on assumptions of increased access (A1), heightened understanding among healthcare professionals (A2), and collaborative efforts between policymakers and doctors (A3), offering nuanced insights to inform future interventions and research directions.

Section 1: Perceived Barriers to Accessing Lupus Diagnosis and Treatment:

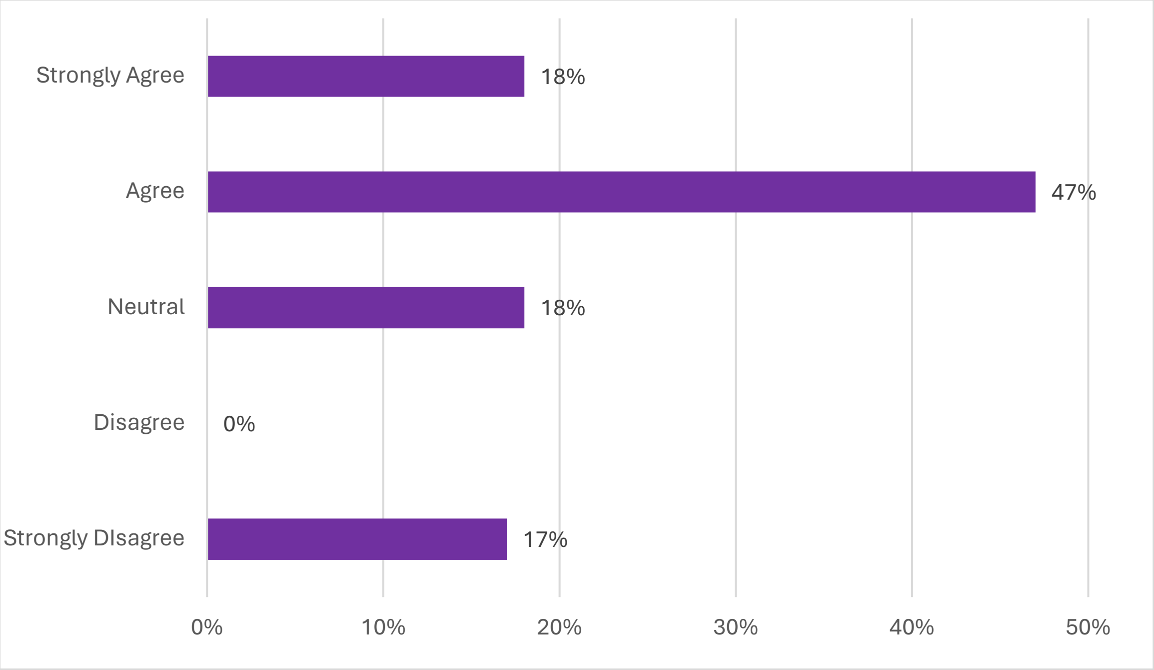
The survey data revealed that a significant proportion of respondents (65%) believe there are barriers to accessing Lupus diagnosis and treatment. This perception underscores potential challenges within the healthcare system that may impede timely and effective care. Further exploration is warranted to pinpoint specific barriers and develop targeted interventions. 53% of survey respondents diagnosed with Lupus strongly agree with the belief that there are barriers to access to the diagnosis and treatment of Lupus for African Americans.

47% of survey respondents diagnosed with Lupus agreed with the belief that there are barriers to access to the diagnosis and treatment of Lupus for African Americans.

18% of survey respondents diagnosed with Lupus strongly agreed, 18% neutral, 0% disagreed, and 17 % strongly disagreed with the belief that there are barriers to access to the diagnosis and treatment of Lupus for African Americans.

African American community diagnosed with Lupus

I believe that there are barriers to my access to the diagnosis and treatment of Lupus.



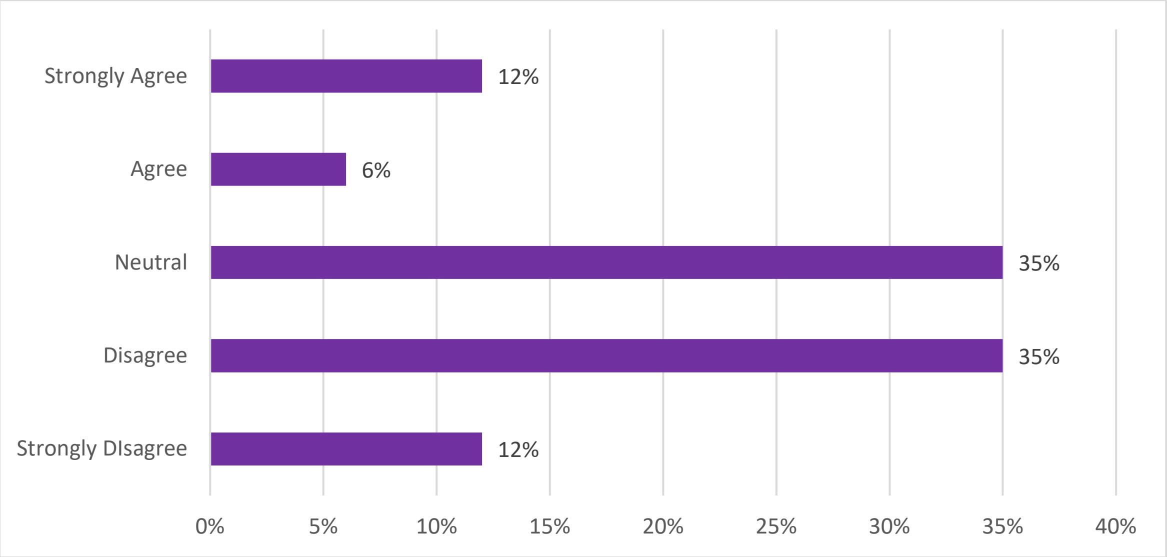
Section 2: Understanding of Lupus by Doctors and Medical Professionals:

Dissatisfaction with the understanding of Lupus by healthcare professionals, as expressed by 47% of respondents, signals a critical gap in awareness within the medical community. This section explores the implications of this perception on patient-doctor communication, treatment decisions, and overall healthcare outcomes for African Americans with Lupus.

06 % of survey respondents diagnosed with Lupus agreed with the belief that their doctors and medical professionals understand Lupus in the African American community. barriers to access to the diagnosis and treatment of Lupus for African Americans.

12% of survey respondents diagnosed with Lupus strongly agreed, 35% neutral, 35% disagreed, and 12 % strongly disagreed with the belief that their doctors and medical professionals understand Lupus in the African American community. barriers to access to the diagnosis and treatment of Lupus for African Americans.

I find that my doctors and medical professionals understand Lupus in the African American community.



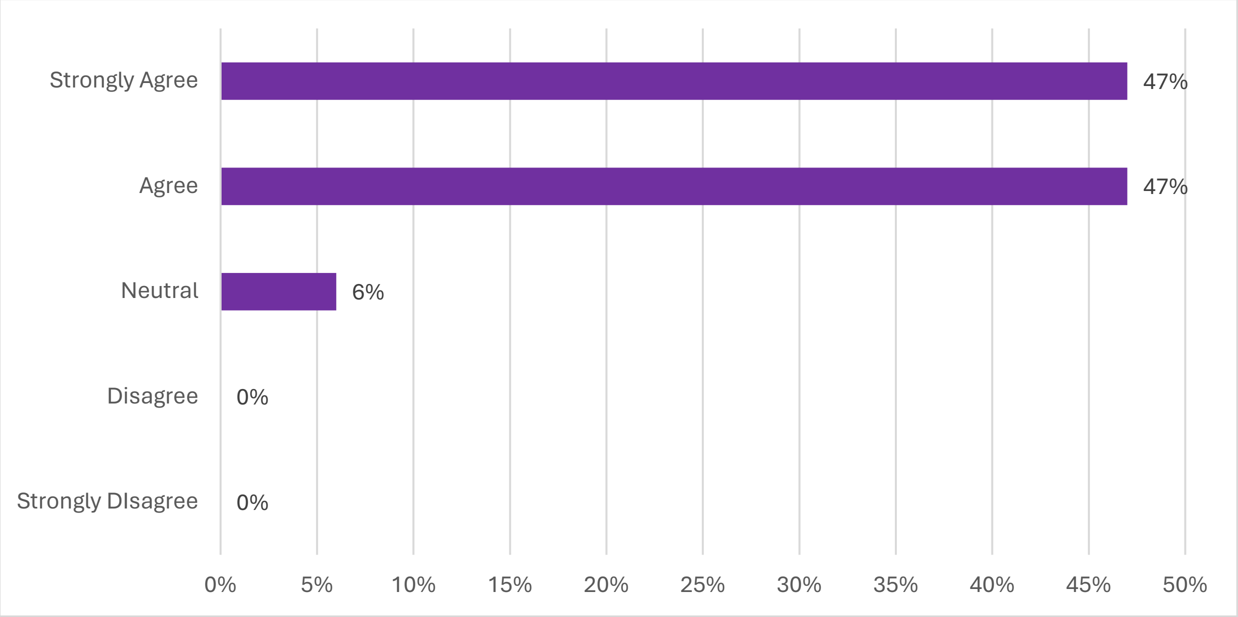
Section 3: Collaborative Efforts between Policymakers and Doctors:

Survey results indicate strong support (94%) for collaborative efforts between policymakers and doctors to address inequities in Lupus care. This section explores the potential impact of such collaborations on health outcomes and the role they play in dismantling systemic barriers that disproportionately affect the African American community.

47 % of survey respondents diagnosed with Lupus agreed that their health outcomes would improve if policymakers and doctors worked together to improve inequities in Lupus care.

47% of survey respondents diagnosed with Lupus strongly agreed, 06% neutral, 0% disagreed, and 0 % strongly disagreed with the belief that their health outcomes would improve if policymakers and doctors worked together to improve inequities in Lupus care.

I believe that my health outcomes would improve if policymakers and doctors worked together to improve inequities in Lupus care.



Section 4: Perceived Barriers Faced by African American Patients by Doctors/Healthcare Team:

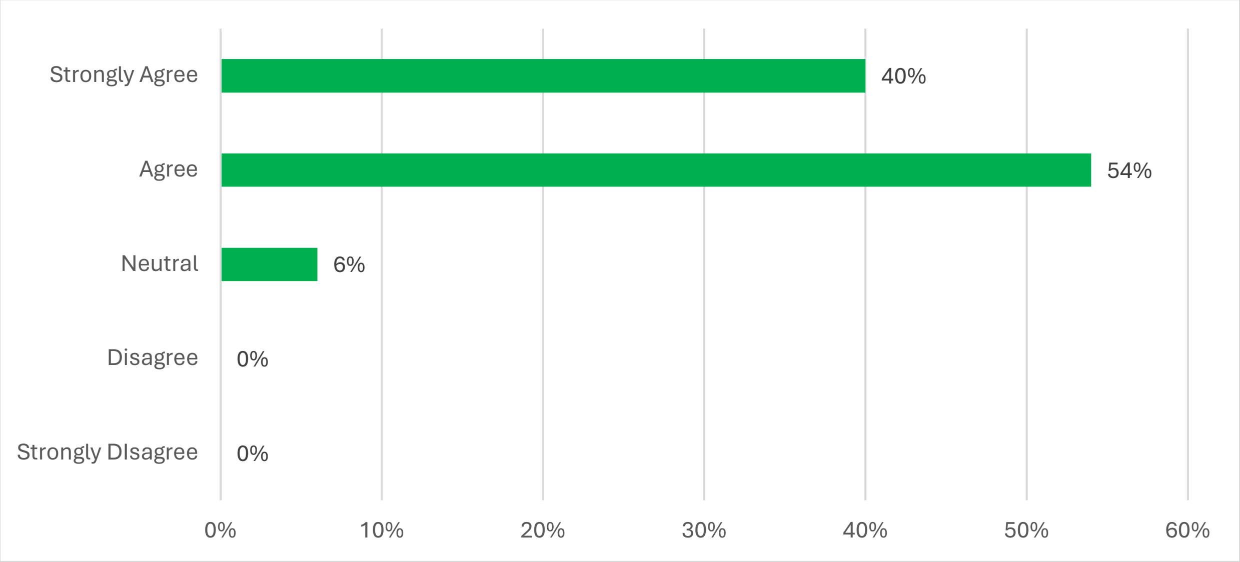
Forty percent of respondents strongly agree, and 54% agree that African American patients experience barriers in access to Lupus diagnosis and treatment. This section examines the nature of these perceived barriers, considering factors such as cultural competency, socio-economic disparities, and healthcare system intricacies.

54 % of survey respondents diagnosed with Lupus agreed that African American patients experience barriers in access to diagnosis and treatment of Lupus.

40% of survey respondents diagnosed with Lupus strongly agreed, 0% neutral, 0% disagreed, and 0 % strongly disagreed African American patients experience barriers in access to diagnosis and treatment of Lupus.

Doctors/Healthcare Team of Lupus Patient(s)

I believe that African American patients experience barriers in access to diagnosis and treatment of Lupus.



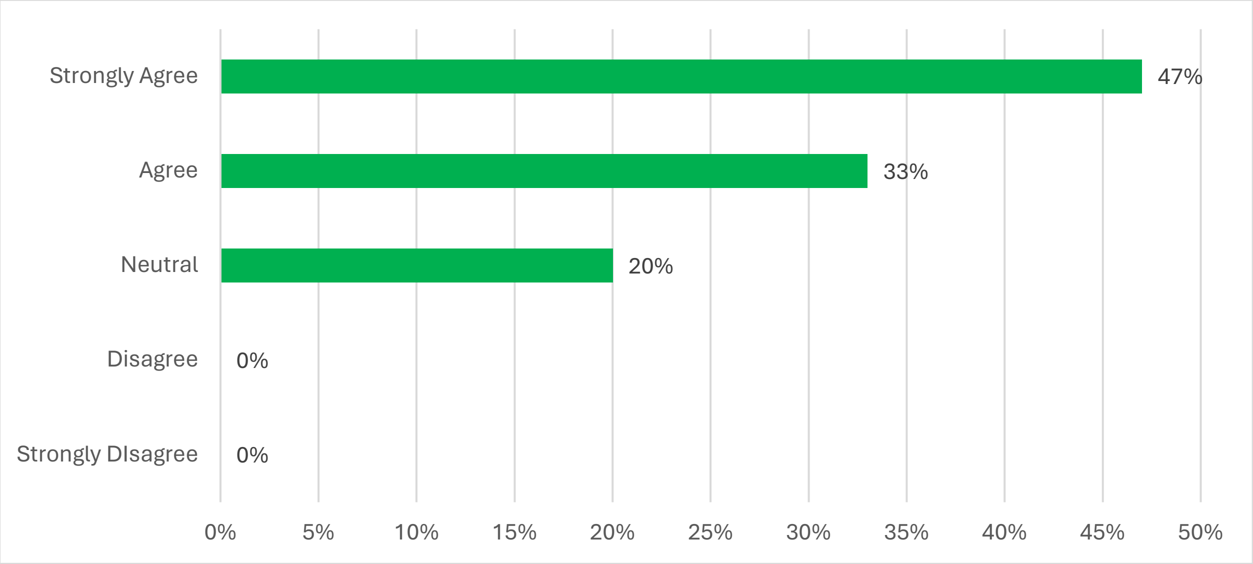
Section 5: Impact of Increased Understanding on Treatment and Outcomes:

The belief that increased understanding among medical professionals could lead to improvements in treatment and outcomes is shared by a majority (77%) of respondents. This section explores the potential benefits of heightened awareness, including personalized treatment plans, reduced disparities, and improved overall health outcomes for African Americans with Lupus.

33 % of survey respondents agreed that an increased understanding among medical professionals of the specific challenges faced by African Americans with Lupus could lead to improvements in treatment and outcomes.

47% of survey respondents diagnosed with Lupus strongly agreed, 20% neutral, 0% disagreed, and 0 % strongly disagreed that an increased understanding among medical professionals of the specific challenges faced by African Americans with Lupus could lead to improvements in treatment and outcomes.

I believe that an increased understanding among medical professionals of the specific challenges faced by African Americans with Lupus could lead to improvements in treatment and outcomes.



Section 6: Importance of Medical Professionals' Understanding of Support Networks:

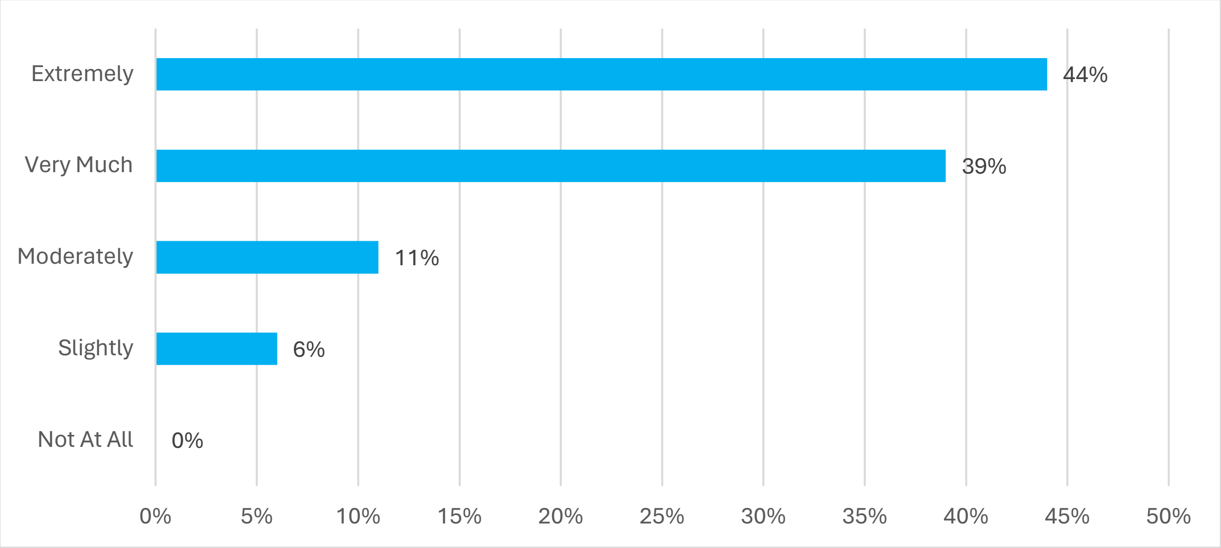
Survey results demonstrate a unanimous consensus (100%) on the importance of medical professionals' understanding of the emotional and practical support provided by family members, friends, and support groups. This section examines the interconnectedness of healthcare provider awareness and the broader support network's role in fostering a conducive environment for Lupus patients.

44 % extremely believed improved access to diagnosis and treatment of Lupus for African Americans would positively impact the support provided by family members, friends, and support groups.

39% of survey respondents diagnosed with Lupus very much, 22% moderately, 06% slightly, and 0 % not at all believed improved access to diagnosis and treatment of Lupus for African Americans would positively impact the support provided by family members, friends, and support groups.

Family Members/Friends/Support Group of Lupus Patient(s)

To what extent do you believe improved access to diagnosis and treatment of Lupus for African Americans would positively impact the support provided by family members, friends, and support groups?



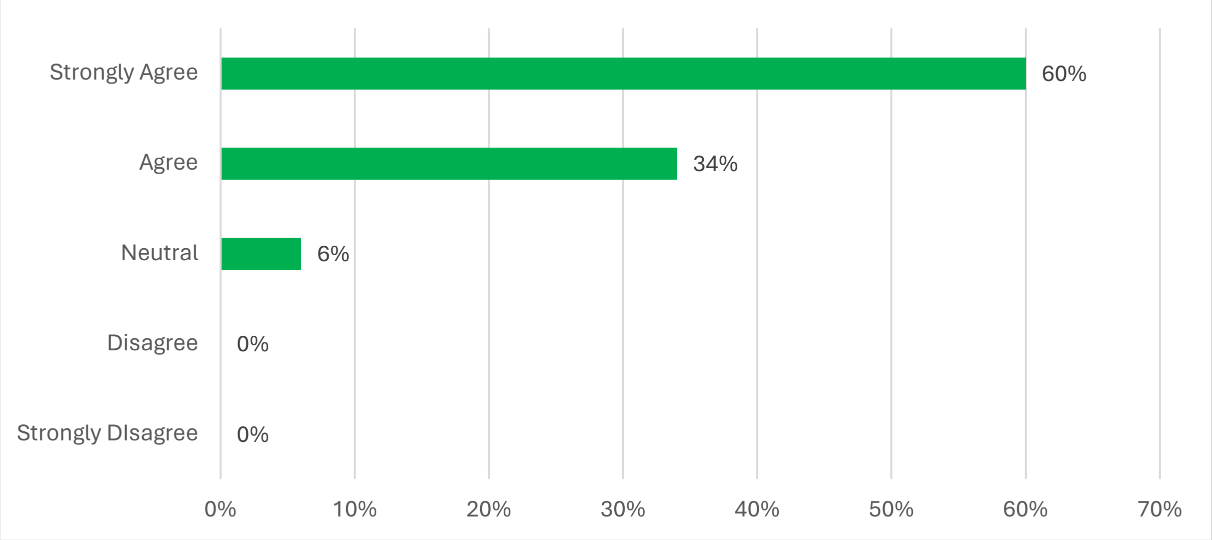
Section 7: Collaborative Efforts' Contribution to Supportive Environments:

Nearly all respondents (94%) believe that collaborative efforts between policymakers and doctors could contribute to a more supportive environment for African Americans affected by Lupus. This section explores the potential ripple effects of collaborative interventions, considering how improved healthcare practices can positively influence familial, social, and community support structures.

34 % of survey respondents agreed that collaboration between policymakers and doctors could improve inequities in Lupus care.

60% of survey respondents diagnosed with Lupus strongly agreed, 06% were neutral, 0% disagreed, and 0 % strongly disagreed collaboration between policymakers and doctors could improve inequities in Lupus care.

I believe that collaboration between policymakers and doctors could improve inequities in Lupus care.



Section 8: Integrating Qualitative Narratives - Enriching the Lupus Care Landscape

Technological Advancements and Personalized Care:

Building upon the quantitative data, the qualitative narratives from healthcare professionals intricately weave into the discussion of technological advancements and personalized care in Lupus management. Professionals foresee a symbiotic relationship between technology and patient outcomes, emphasizing the importance of early detection and interventions. The qualitative insights echo the need for a paradigm shift towards more personalized and inclusive care plans, aligning seamlessly with the quantitative anticipation of enhanced access and awareness within healthcare teams.

Improved Understanding and Multidisciplinary Management:

Qualitative narratives seamlessly extend the exploration of an improved understanding of Lupus by doctors and nurses within African American communities. The emphasis on educating healthcare professionals on diverse care aligns cohesively with the quantitative findings. The integration of multidisciplinary management strategies, as highlighted in the qualitative responses, complements the quantitative data's call for collaborative efforts and increased awareness. Together, these insights form a cohesive narrative of enhanced Lupus care dynamics through improved understanding and collaborative, multidisciplinary approaches.

Systemic Changes for Equitable Lupus Care:

Qualitative narratives seamlessly integrate with the discussion on systemic changes for equitable Lupus care. Healthcare professionals' perspectives add depth to the call for policy revisions, expanded healthcare access, and enhanced cultural responsiveness within healthcare systems. The qualitative insights provide a nuanced understanding of the necessary changes, aligning organically with the quantitative data's emphasis on diversity and inclusion. Together, these sections contribute to a comprehensive examination of Lupus care dynamics, highlighting the interconnectedness of quantitative and qualitative insights.

Assumptions:

Section 1: The Influence of Increased Access on Doctors and Healthcare Teams (A1): Quantitative survey data emphasizes the potential of technological advancements in Lupus diagnosis and treatment to enhance early detection and improve the overall quality of life for patients.

Qualitative **i**nterviews reveal a broader perspective on increased access, suggesting that it could lead to a paradigm shift within healthcare teams. The anticipation is that doctors might undergo cultural competency training to better address diverse patient needs. Additionally, there's an envisaged shift toward more personalized and inclusive care plans tailored to the unique factors affecting Lupus in the African American population.

Section 2: Improved Understanding of Lupus by Doctors and Nurses (A2):

The survey indicates a strong belief (100%) that improved understanding among healthcare professionals can enhance communication and collaboration with Lupus patients. Personal perspectives align with this belief, emphasizing the imperative need to educate doctors and nurses on diverse care, especially within the African American population. Multidisciplinary management is seen as a key to better outcomes, incorporating therapies to reduce stress, tools to manage flare-ups, and specialized approaches such as Physical Therapy and Neurology to prevent further damage to joints and major organs.

Section 3: Systemic Changes for Equitable Lupus Care (A3):

The quantitative survey underscores the importance of collaboration between policymakers and doctors (94%) to address and improve inequities in Lupus care. Qualitative **i**nterviews dive deeper into the necessary systemic changes within healthcare systems. Recommendations include revising policies for expanded health insurance coverage, enhancing accessibility through measures like mobile clinics, and mandating cultural responsiveness by ensuring adequate representation of all cultures within the healthcare system. The qualitative layer adds depth to the systemic changes needed for a more equitable and effective Lupus care system.

Conclusion:

By integrating quantitative survey data and qualitative narratives, this chapter navigates the intricate landscape of Lupus care challenges within the African American community. The findings not only underscore the urgent need for targeted interventions but also shed light on the pivotal role of heightened healthcare professional awareness and collaborative efforts between policymakers and doctors. Unraveling the intricacies of barriers, this research accentuates the imperative for multifaceted strategies to foster Lupus care equity within this demographic. The synthesis of both quantitative and qualitative perspectives not only enhances our comprehension of the nuanced issues but also provides a holistic understanding that transcends mere statistical metrics. This sophisticated and integrated approach not only informs actionable recommendations but also lays the groundwork for future research endeavors aimed at advancing our understanding and promoting positive and equitable Lupus care outcomes within the African American demographic.

Chapter V: Conclusions and Recommendations

Introduction:

Lupus care in the African American community presents intricate challenges, demanding a nuanced exploration of access, healthcare professional understanding, and collaborative policymaking. This chapter synthesizes the results and findings from the data analysis, validating the Theory of Change articulated in the research hypotheses

Conclusions:

The validated Theory of Change posits that if access to Lupus diagnosis and treatment increases, if healthcare professionals enhance their understanding of Lupus in African American communities, and if policymakers collaborate to address inequities, there will be tangible improvements in outcomes for African Americans affected by Lupus. The data analysis provides insightful explanations and speculations for the findings, affirming the assumptions made in the research. Limitations, including sample size constraints and potential biases, impact the generalizability of the findings. The short-term and long-term implications underscore the urgency of addressing Lupus care disparities in this demographic.

Recommendations:

Enhanced Technological Integration:

Specific: Implement advanced diagnostic technologies for Lupus screening.

Measurable: Achieve a 20% increase in the adoption of technological solutions within the next two years.

Achievable: Collaborate with technology providers and healthcare institutions.

Relevant: Align with the goal of early detection and intervention.

Time-bound: Implement the technology within the next six months and assess adoption rates annually.

Comprehensive Healthcare Professional Training:

Specific: Develop a culturally sensitive training program for healthcare professionals.

Measurable: Assess the competency levels of healthcare professionals post-training.

Achievable: Collaborate with medical institutions and Lupus advocacy groups.

Relevant: Addresses the need for improved understanding and communication.

Time-bound: Initiate training within the next six months, with ongoing assessments every quarter.

Policy Advocacy for Equitable Lupus Care:

Specific: Advocate for policy changes promoting equitable Lupus care.

Measurable: Track the adoption of policy changes at local and national levels.

Achievable: Collaborate with policymakers, advocacy groups, and healthcare organizations.

Relevant: Addresses systemic changes for improved outcomes.

Time-bound: Lobby for policy changes within the next year, with progress reviews every six months.

Areas for Further Research:

Impact of Socioeconomic Factors:

Specific: Investigate how socioeconomic factors influence access to Lupus care within diverse communities.

Measurable: Publish research findings within the next two years.

Patient-Centered Outcomes:

Specific: Explore the patient experience and perception of Lupus care, focusing on personalized outcomes.

Measurable: Conduct and publish a comprehensive patient-centered study within the next three years.

Long-Term Health Economic Analysis:

Specific: Conduct a longitudinal study to assess the long-term economic implications of enhanced Lupus care.

Measurable: Publish economic analysis findings within the next four years.

Comparative Analysis Across Ethnicities:

Specific: Compare Lupus care dynamics among different ethnic groups to identify unique challenges and solutions.

Measurable: Complete the comparative analysis and publish the results within the next three years.

Integration of Alternative Therapies:

Specific: Examine the integration and effectiveness of alternative therapies in Lupus care.

Measurable: Publish research findings on alternative therapies within the next two years.

In summary, these recommendations, now equipped with SMART goals, aim to address the gaps identified in the current study and provide a roadmap for future researchers. The SMART criteria ensure that these recommendations are not only actionable but also realistic and impactful in the quest for equitable Lupus care within the African American community.

Opposing Viewpoint

While the research findings support the proposed Theory of Change, it's important to consider potential opposing views and criticisms to ensure a comprehensive understanding. Here are some alternative perspectives:

Access Barriers:

Opposing View: Some may argue that the perceived barriers to Lupus diagnosis and treatment could be subjective and influenced by individual experiences rather than systemic issues. Factors such as personal awareness, healthcare literacy, or socioeconomic status might play a role.

Counterargument: While individual experiences vary, the consistent perception of barriers across a significant percentage of respondents suggests a broader issue that warrants attention. The systemic nature of healthcare disparities is often rooted in complex social, economic, and cultural factors.

Healthcare Professional Understanding:

Opposing View: Skeptics may question the need for specialized training on Lupus within African American communities, arguing that medical professionals should already possess a standard level of cultural competence.

Counterargument: The nuanced nature of Lupus and its impact on diverse communities necessitates targeted training. Acknowledging and addressing the unique challenges faced by different demographic groups can contribute to more effective and patient-centered care.

Collaborative Efforts:

Opposing View: Critics might argue that systemic changes and collaboration between policymakers and doctors are idealistic goals that are challenging to implement. They may point to existing bureaucratic hurdles and political complexities in healthcare policy-making.

Counterargument: While systemic changes are undoubtedly complex, the research highlights the necessity of addressing these challenges for equitable healthcare. Advocating for realistic policy changes and fostering collaboration can lead to incremental improvements over time.

Considering opposing views helps refine my research and ensures a balanced interpretation of the findings. It's essential to acknowledge diverse perspectives to strengthen the overall credibility and validity of my research outcomes.

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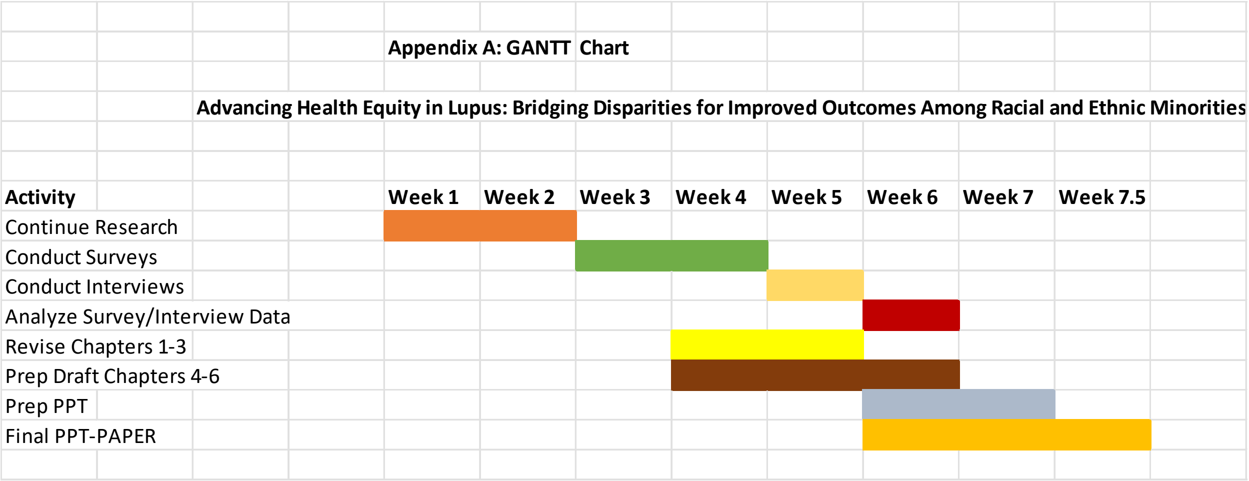
Appendix A: GANTT Chart



Appendix A: GANTT Chart

Advancing Health Equity in Lupus: Bridging Disparities for Improved Outcomes Among Racial and Ethnic Minorities

Activity	**Week 1**	**Week 2**	**Week 3**	**Week 4**	**Week 5**	**Week 6**	**Week 7**	**Week 7.5**
Continue Research	🟧	🟧						
Conduct Surveys			🟩	🟩				
Conduct Interviews					🟨			
Analyze Survey/Interview Data						🟥		
Revise Chapters 1-3				🟨	🟨			
Prep Draft Chapters 4-6				🟫	🟫	🟫		
Prep PPT						⬜	⬜	
Final PPT-PAPER						🟧	🟧	🟧

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Appendix B: Data Collection Instruments

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https://docs.google.com/forms/d/e/1FAIpQLSf3UTGfud_FXMxPBtwHc9zG6lI389mX9Zly9xkmS9BGuc78Ig/viewform?usp=sf_link