Distribution Agreement

Signature:

________________________________ _______________
Melanie Dakwa **Date**

'It’s Like Your Body is Fighting Against You’: Perceptions and Experiences Regarding Quality of Life in Black Women Diagnosed with Endometriosis

By

Melanie Dakwa
Master of Public Health

Behavioral, Social, and Health Education Sciences

____
Whitney S. Rice, DrPH, MPH
Committee Chair

____
Subasri Narasimhan, PhD, MPH
Committee Member

____
Cam Escoffery, PhD, MPH, CHES
Department Chair

'It's Like Your Body is Fighting Against You"

Perceptions and Experiences Regarding Quality of Life in Black Women Diagnosed with Endometriosis

By

Melanie Dakwa

B.S. Exercise Science, Towson University, 2018

Thesis Committee Chair: Whitney S. Rice DrPH., M.P.H

Thesis Committee Member: Subasri Narasimhan, PhD, M.P.H

An abstract of A thesis submitted to the faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in the Department of Behavioral, Social, and Health Education Sciences
2022

Abstract

‘It’s Like Your Body is Fighting Against You”

Perceptions and Experiences Regarding Quality of Life in Black Women Diagnosed with Endometriosis

By

Melanie Dakwa

Endometriosis impacts an estimated 10% - 15% of women of reproductive. The condition is characterized by the presence of endometrial tissue outside of the uterine cavity and can lead to symptoms that result in an overall lowered quality of life. Research on the experiences of women diagnosed with endometriosis historically focused on White middle-class women. There has been a disregard for Black women’s pain within research. As a result, there is a need to explore the impact of endometriosis on quality of life, particularly for US-born Black women. This study will aim to fill this gap by exploring the experiences of Black women diagnosed with endometriosis. Data were collected through semi structured in depth interviews with Black women between the ages 18-45, living in the United States, and diagnosed with endometriosis. Interviews were video and audio recorded on Zoom and then transcribed. A thematic analysis approach was then used to generate themes. A total of 18 Black women were interviewed for this study. Four themes emerged from the data: The psychosocial impact of endometriosis on quality of life; navigating healthcare experiences; resiliency and self-advocacy by any means necessary; the need to know: lessons learned and a call to action. When caring for Black women who are presenting symptoms of pain and lowered quality of life, it is important for healthcare professionals to be intentional about recognizing their own bias and acknowledging the historical context behind the dismissal of pain in Black women in the United States. This can be done through engaging in cultural sensitivity training and pursuing an individualized approach to care. Furthermore, healthcare professionals can also leverage support for women by identifying and including social networks to mitigate the burden of endometriosis to improve overall quality of life.

‘It’s Like Your Body is Fighting Against You”

Perceptions and Experiences Regarding Quality of Life in Black Women Diagnosed with Endometriosis

By

Melanie Dakwa

Bachelor of Science
Towson University
2018
Thesis Committee Chair: Whitney S. Rice DrPH., M.P.H
Thesis Committee Member: Subasri Narasimhan, PhD, M.P.H

A thesis submitted to the Faculty of the Rollins School of
Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in the Department of Behavioral, Social, and Health Education Sciences
2022

Acknowledgements

I would like to express a sincere gratitude to my thesis committee. I want to first thank Dr. Whitney Rice, my thesis committee chair, for her mentorship and constant support throughout this thesis process. I would like to also thank Dr. Subasri Narasimhan, my thesis committee member for taking on this project with me and providing feedback. I thank them both for empowering me in this process as someone with limited research experience. I also want to thank the BSHES department providing the space to be able to explore the option of research. I would like to thank Dr. Elizabeth Walker, my qualitative methods professor, for encouraging me to move what started off as a qualitative class project to a full thesis. I am appreciative of the Emory RISE center for their support in financial assistance for recruitment and compensation to participants. Additionally, I am thankful for their support in presenting these results at the Annual Association for Maternal and Child Health Programs conference. I would like to grant a special thanks to the study participants for sharing this space and their stories with me. Finally, I would like to thank my family and friends for the support and prayers as I have pushed through this research.

Table of Contents

CHAPTER I. INTRODUCTION

1.1 Problem Statement

Endometriosis impacts an estimated 10% - 15% of women of reproductive age (Denny 2007; Bertero and Grundstrom, 2017; Shafrir et al., 2018), which extrapolates to about 190 million women worldwide according to population estimates in 2017 (The World Bank 2017) . The condition is characterized by the presence of endometrial tissue outside of the uterine cavity and leads to symptoms that can lower overall quality of life (Denny, 2009; Young et al., 2014; Cox 2003).

Endometriosis can affect all areas of a woman's life, not just the physical and psychological components. The presence of pain can also be pervasive in intimate relationships, social functioning, and work life (Della Corte 2020; DiBenedetti 2020). The World Health Organization defines Quality of Life as "'individuals' perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns' (WHO, 2012). Signs and symptoms of endometriosis include, but are not limited to, heavy menstrual bleeding, chronic pelvic pain, dysmenorrhea, and pain during sexual intercourse, which can have significant impacts on emotional well-being (Moradi et al., 2014). The signs and symptoms of endometriosis are known well enough by medical professionals to prompt further investigation that leads to a diagnosis. However, because signs and symptoms of endometriosis can be linked to various gynecological issues in women, healthcare workers may struggle to easily diagnose this disease. This truth, coupled with the fact that individuals suffering from the disease are often not aware of the condition, can cause a delay between onset of symptoms and diagnosis (Agarwal et al., 2019). To this day, the exact etiology of endometriosis is not clear, thus pushing a lot of women to become expert patients in the self-management of their pain (Seear 2009). While self-management of pain is empowering for some women, it can also be seen as emotionally taxing to many women (Seear, 2009).

Although endometriosis is one of leading causes of infertility in women over 25 and is one of the most common gynecological diseases, it has been routinely underdiagnosed, underreported and under researched. Additionally, little published research examines how endometriosis impacts an individual's life beyond their physical symptoms. An overabundance of endometriosis research focuses on the physical symptoms of the disease (Cole et al., 2021). Therefore, understanding of the lived experience of people diagnosed with endometriosis, including management of non-physical symptoms and changes to their identity or other parts of their lives, could be useful. Further, although a large body of research on the experiences of women diagnosed with endometriosis exists, the historical focus on the condition was initially only in White middle-class women (Bougie, 2019). As a result, there is a need to explore the impact of endometriosis on quality of life, particularly for US-born Black cis-gender women, specifically considering the historical inattention and disregard for Black women’s pain within research. Informed by the intersectionality framework, this study aims to fill this need by examining quality of life perceptions in Black women diagnosed with and living with endometriosis. I also explore patient- provider relationships Black women discuss as they manage their endometrial symptoms and treatments, and the roles of resiliency and self-advocacy in their management of pain.

1.2 Purpose Statement

The purpose of this study is to explore experiences and perceptions of life quality among Black women with endometriosis. Additionally, the study will aim to explore the navigation of Black cis-gender women with endometriosis through the health care system and how they exemplify resiliency and self-advocacy in these experiences. The implications of this study may contribute to improved patient care and an increase in cultural humility among providers when dealing with this specific condition. Additionally, study findings could then help reduce misconceptions regarding this condition amongst Black women and rates of misdiagnoses.

I acknowledge that the experiences of Black women may be varied and different. They may have unique personal experiences to share considering the historical context behind pain assessment in the Black community and the sociodemographic factors that may contribute to a delay in diagnosis. It is important to understand Black women's diverse experiences in navigating through the healthcare system. Additionally, instances of self-advocacy and resiliency may be displayed in these experiences as it relates to pursuing quality care in the diagnosis and treatment of endometriosis. Although self-advocacy and resiliency may have positive connotations as it relates to ensuring quality of care, exploring both positive and negative experiences may shed light on the barriers to self-advocacy individuals may face as well as the mental impacts of resiliency.

1.3 Research question

This study is a qualitative preliminary analysis to explore the experiences of Black women diagnosed with endometriosis and to understand how their experiences shape their quality of life: Informed by the intersectionality framework, this study will:

- Explore how endometriosis diagnosis and subsequent management of symptoms affects Black women's life quality.
- Describe the experiences of patient-provider communication and health system navigation by Black women with endometriosis.

- Assess instances of resiliency and self-advocacy used by Black women with endometriosis as they cope with the condition.

1.4 Significance Statement

The myth of biological differences between Blacks and Whites has been historically perpetuated in the United States (Hoffman et al., 2016; Jones 2000; Jones 2014; Phelan & Link,2015). These ideas were pushed not only by laypeople but by physicians, scientists, and slave owners to justify the inhumane treatment of Black people during slavery in the 19th century (Hoffman et al., 2016). These historical beliefs continue to be observed among scientists and physicians today and have impacted specific populations suffering from disease. Research findings in a study done by Hoffman et al. (2016) concluded that those who hold some medical experience believe that there are racial differences in pain between Blacks and Whites, thus contributing to racial disparities in assessment and treatment of pain. Accordingly, Black Americans, specifically Black women, are systemically undertreated for pain compared to their White counterparts (Hoffman et al., 2016).

Jason A. Sampson, an American gynecologist published his first article on the condition of endometriosis in 1921. Although reports of endometrial tissue could be traced as far back as 1860, Dr. Sampson was the first one to coin this term to describe the growth of endometrial tissue outside of the uterus. Additionally, in 1938, Joseph Vincent Meigs, a Boston based gynecologist wrote on a piece that linked endometriosis and delays in childbearing. (Bougie 2019). The central aim to this theory was that incidences of endometriosis were higher among his private patients than the ward patients he encountered, and in the United States, the labelling of private vs ward patients carried implications in both race and socioeconomic status. From this claim that endometriosis is a disease of White middle-class women, the implication could be drawn that endometriosis is rare in those who do not identify with this population (Bougie 2019). Theories from Dr. Meigs did not go unchallenged. In 1976, Dr. Donald L Chatman, an African American gynecologist, noted that 1 in 5 of his African American private patients displayed laparoscopic evidence of endometriosis. However, 40% of these women had been misdiagnosed with pelvic inflammatory disease (Bougie 2019). Although more studies started to show evidence of similar rates of endometriosis in both Black and White patients, these assumptions and racialized theories persisted well into the 2000s. Compared to White women, Black women are less likely to be diagnosed with endometriosis and rather misdiagnosed with pelvic inflammatory disease, which is generally seen as a sexually transmitted disease (Bougie et al. 2019).

Stigmas behind pain assessment and treatment in Black women are not only rooted in unethical practices that disregarded the bodies of Black and brown people but are also rooted in biases that African American women possessed higher rates of promiscuity compared to their White peers (Bougie 2019). Additionally, slave era beliefs that Black women were hypersexual and less intelligent furthered ideas that they were incapable of pain and thus incapable of advocating for themselves (Bougie 2019; Trawalter 2015).

While public health has made tremendous strides in the fight for health equity and in bridging the gap in health disparities, there are still holes in the healthcare system that disproportionately affect Black Women to this day. Due to the intersections of race, gender, and chronic disease that may be experienced by the women in this study, the intersectionality framework will inform this study as a means of interpretation and discussion to further suggest the unique experiences of Black women. Additionally, it is significant for contextualizing how these identities may impact lived experiences including health and wellbeing. I will be interested in how race and other intersections of experience with gender and chronic disease may uniquely impact the findings surrounding the quality of care that Black women receive and how they perceive to exemplify resiliency and self-advocacy.

1.5 Theory

The intersectionality framework was initially used to contextualize the intersections of sex/gender and race/ethnicity in oppressed populations. However, this framework can extend to other domains as it has the potential to add improved validity to population health research. Additionally, intersectionality framework explores different intersections of identity, social position, processes of oppression or privilege, and policies that may have an impact on health and disease (Bauer, 2014). Although the term "Intersectionality" was first coined by Kimberle Crenshaw, an African American feminist legal scholar (Bowleg 2012, Bauer 2014) the idea of intersectionality can be traced as far back as 1851 (Bowleg 2012). Sojourner Truth, a freed slave, challenged the truth behind the intersections of race and gender in her famous *"Aint I a Woman"* speech. This is said to be one of the earliest recorded mentions of an intersectionality perspective as she challenged the idea that being a Woman and Black are mutually exclusive (Bowleg. 2012).

According to Bowleg (2012), there are 3 core tenets of intersectionality that can be most relevant to the work being done in public health. These core tenets are defined as (1) social identities are not mutually exclusive and unidimensional, but they are multiple and intersecting, (2) individuals from multiple historically oppressed groups are the focal or starting point and (3) intersections of race, gender and SES can intersect with macrolevel structures such as racism, poverty, etc.; and this can produce disparities in health outcomes (Bowleg, 2012).

Because this study aims to examine experiences and perceptions regarding quality of life in Black women who have been diagnosed with endometriosis, the utilization of this theoretical framework is appropriate for the study as it will aim to examine the multiple intersecting identities (e.g., race, gender, and chronic condition) and how it may impact their quality of care. Grounding this study in a framework such as intersectionality will also allow for the exploration of multiple intersecting levels of influence in the overall experience of quality of life and quality of care in the study population. At the intrapersonal level of influence, the study will aim to contextualize the identities of the participants as well as explore the knowledge, attitudes, and beliefs of individuals in their self-management of endometriosis. At the interpersonal level of influence, this study may examine familial relationships and other social networks and their role in the diagnosis, treatment, and management of endometriosis. Lastly, intersectionality theory may be utilized to examine experiences in quality of life and quality of care at an organizational level by exploring patient-provider relationships and journey to diagnosis.

1.6 Definition of Terms

Endometriosis: “A chronic inflammatory disease characterized by the presence of endometrial tissue outside the uterine cavity” (Facchin et al., 2015)

Quality of Life: "Abroad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life”. (Centers for disease Control and Prevention, 2018)

Resiliency: Psychologists define resilience as the process of adapting well in the face of adversity, trauma, tragedy, threats, or significant sources of stress—such as family and relationship problems, serious health problems, or workplace and financial stressors (American Psychological Association, 2012)

CHAPTER II. REVIEW OF LITERATURE

The purpose of chapter two is to review principal areas of background information about endometriosis relevant to this thesis. This chapter starts with a review of literature surrounding the topic of quality of life and endometriosis. Then it focuses on the topic of delay in diagnosis and how it may impact those with endometriosis. The chapter then concludes with an examination of the historical contexts behind healthcare in the Black community and narrows in on reproductive health care in Black women and how it may impact experiences with endometriosis.

2.1 Impacts on Quality of Life

Endometriosis produces lesions that are typically found in the pelvis, but they can occur in extra- pelvic sites that include the abdominal wall, upper abdomen, diaphragm, bowel, and lungs (Kim and Han, 2018). The lesions can induce an inflammatory response that can have a significant impact on a woman's quality of life as they often cause pelvic pain. This inflammation can cause a range of symptoms such as dysmenorrhea, abnormal bleeding, chronic pelvic pain, fatigue, and infertility (Simoens, Dunselman et al. 2012,). Research shows that these symptoms can lower the quality of life of women suffering from diagnosis and have a significant impact on different areas of life such as social relationships, sexuality, and mental health (Marinho et al.,2018; Yoldermir et al, 2018; Della Corte 2020). Several studies have examined the lived experiences of women living with endometriosis.

A study by Moradi et al. (2014) aimed to explore the impact of endometriosis on lives of women and looked at the differences across three different age groups. Semi-structured qualitative focus group discussions were conducted with 35 Australian women with endometriosis. Two main themes emerged: experiences living with endometriosis and the impact of endometriosis on women's lives. The theme "experiences of living with endometriosis" contained 5 categories, including: symptoms related to endometriosis, delayed diagnosis, treatment of endometriosis, experience with healthcare providers and lack information. Conversely, the theme "Impact of endometriosis on women's lives" contained 9 categories including: physical impact, psychological impact, marital/sexual relationship impact, social life impact, impact on education, impact on employment, financial impact, impact on life opportunities and impact on lifestyle (Moradi et al., 2014).

Upon exploration of the different impacts of endometriosis, researchers also found that the categories identified within the themes differed across the three age groups. Researchers ranked the most highlighted impact areas in each age group and found that women who fell into the 16-24 age group identified their social life as the most prominent area of impact. The research article states that women reported a reduction in their social life activities, and pain, stress, and mood swings caused by endometriosis impacted their relationships, leaving them more likely to distance themselves from any social gatherings (Moradi et al., 2014). In the 25-34 age group, marital/sexual relationships were most highlighted amongst the 9 distinct categories. Evidence shows that endometriosis can have a significant impact on penetrative sex due to the lesions caused by endometriosis. In the study, participants reported negative impacts of endometriosis on both their marital and sexual relationships. The pain caused by endometriosis decreased the frequency of intercourse thus putting a strain on their relationships. Infertility was also a topic of discussion within this category as it was seen as a cause of concern for women that had an impact on their marital relationships (Moradi et al., 2014). Lastly, the 35 and above group indicated that the physical impact of endometriosis was a top concern for them. Symptoms, treatment side-effects and changes in physical appearance were physical impacts of endometriosis experienced by participants in the study. Additionally, participants reported that their pain limited normal daily physical activities such as walking and exercise (Moradi et al., 2014).

The results from this study reaffirm the negative impacts that endometriosis can have on daily life while highlighting similarities and differences between 3 different age groups. Researchers highlight that across the 3 age groups, the impacts of endometriosis were also worsened by a lack of understanding as many participants reported no knowledge of endometriosis before their diagnosis and a lack of information among their families and friends, at school and at the workplace (Moradi et al., 2014). Increasing knowledge on an individual, societal, and organizational level were suggestions made by participants to help mitigate the negative impacts of endometriosis on daily lives. Conversely, researchers suggest that a better understanding of the long-term impacts of endometriosis at different life stages could help policy makers, health care professionals and the lay population improve the lives of women through reducing the negative impacts of endometriosis (Moradi et al., 2014).

Rea et al., (2020) aimed to explore and understand the lived experiences of women suffering from endometriosis. The study sample consisted of 25 women between the ages of 18 and 54 who were identified and enrolled by healthcare providers at a specialist center for the treatment of endometriosis. Through qualitative in-depth interviews and data analysis, four main themes and two sub themes were identified (Rea et al., 2020). The main themes of the study included “nobody believed me” with a subtheme of the women not understanding their condition; worsening of women’s lives with a sub theme of painful lives; disastrous intimate lives with their partners; and uncertainty about fertility (Rea et al., 2020). The study states that within the results, participants described the negative impacts of endometriosis on quality of life.

For example, participants discussed the impact on lives with their partners as painful sex is typically experienced by individuals with endometriosis (Rea et al., 2020).

Endometriosis has a significant impact on work productivity in women diagnosed with it (DiBenedetti, Soliman et al., 2020; Kim and Han, 2018). A study examining impacts of endometriosis on quality of life aimed to evaluate diagnosis, comorbidities, healthcare resource use, treatment patterns, costs, and quality of life of women with endometriosis (Klein et al., 2014). The questionnaire-based study included a sample of 134 patients who were diagnosed with endometriosis and recruited from the Leuven University Fertility Center in Belgium, a tertiary referral center for endometriosis. For a 2-month period, information was collected on the volume of healthcare resource use and health related quality of life related to endometriosis and the symptoms associated with endometriosis (Klein et al., 2014). Patients in the study were asked to report information on direct healthcare cost (e.g., outpatient physician visits, medication with trade name, number and duration of hospitalizations, etc.); non direct healthcare costs (e.g., transportation costs to healthcare providers and costs to receive additional support with household activities); indirect non healthcare costs (e.g., productivity loss related to work impairment) and quality of life, which was measured with an instrument that covered the five dimensions of health-related quality of life (e.g., mobility, selfcare, daily activities, pain/discomfort and anxiety/depression). Descriptive statistics were done to describe the demographic information, clinical variables, and healthcare resource use within the study sample. The study concluded that endometriosis can not only have significant impact on the individual but also have an impact on society as endometriosis may contribute to increased hospitalizations, surgeries, emergency room visits, infertility treatments and loss of productivity due to missed days at work (Klein et al., 2014). The authors suggest that earlier diagnosis of endometriosis and appropriate treatments may have a significant impact on productivity loss and healthcare consumption that could eventually reduce total costs at both an individual and societal level (Klein et al., 2014).

2.2 Delay in Diagnosis

To date, the exact etiology of endometriosis is not known, contributing to delay in diagnosis. The North American Endometriosis Association Survey of 4000 members reported that there was an average delay in diagnosis of 9.28 years. In like manner, an Australian Survey of 750 women found an average delay in diagnosis over 6 years (Cox, Henderson et al., 2003). According to Cox, Henderson et al., both survey results indicate that delay in diagnosis was attributed to the difficulties associated with diagnosis, and provider disregard of women's complaints. Several studies discuss factors surrounding delays in diagnosis of endometriosis.

A study by Ballard et al. (2006) aimed to investigate the reasons why women experience delays in the diagnosis of endometriosis and the impacts this delay may have on their lives. Their qualitative study employed semi-structured interviews and results concluded that delays in diagnosis occurred at both the individual patient level and the organizational (medical) level (Ballard et al., 2006). The study goes into depth about individual patient experiences, beliefs and attitudes that contribute to a delay in diagnosis. For example, although women recognized their periods as problematic and disruptive to their life, the difficulty in making clear distinctions between "normal" and "abnormal" menstrual experiences contributed to delays at the individual level (Ballard et al., 2006). Additionally, at the medical level, women reported feeling dismissed by provers and being told that their period pains were "normal". Because endometriosis can only be officially diagnosed though a surgical laparoscopy procedure, there may also be a significant delay due to that as well (Ballard et al., 2006). The study results revealed that delay on the medical level was due to the delay in the referral from primary care to secondary care. Participants reported that there were multiple visits to their primary doctor before they were referred to a specialist (Ballard et al., 2006).

Among those who suffer from endometriosis, feelings of fear, anger and depression are common as women report feeling isolated and alienated throughout their experience (Seear, 2009). Feelings are reported to be due to both delay in diagnosis and treatment by medical professionals, where their symptoms were not taken seriously. Emphasis on the pre-diagnostic period of endometriosis is essential to understanding the significant delays in diagnosis. Therefore, examining the formative experiences of women diagnosed with endometriosis may offer more insight on factors contributing to this delay and how this may translate to the self-management of their chronic condition.

A study by Seear, 2009 explored the experiences of women in Australia with endometriosis and examined how women become experts in their own care and the ramifications of these processes for women. The study sample consisted of 20 women between the ages of 24 and 55 and diagnosed with endometriosis and across all participants, there was an average delay in diagnosis of 9 years (Seear, 2009). Participants were recruited through a snowball sampling method and advertisements of the study were also place in the newsletter of an Australian endometriosis support group for women who were suffering from the chronic condition. The researchers conducted qualitative in-depth interviews that explored: diagnosis, treatment, patient-provider relationships, self-help, causation, and reflections on the illness experience (Seear, 2009). Three themes emerged from the interviews: the work involved in being an expert patient; and the positive and negative aspects of this role on women (Seear, 2009). The central argument of the research is that the responsibilities attached to being an expert patient can both increase (managing their health and the responsibility of risk management regarding diet) and decrease (listening to their body) the existing stresses of the women who are suffering from this disease. Additionally, it also adds to the literature that there is considerable work involved in self-management of this chronic condition with both positive and negative experiences described by the women (Seear, 2009).

Seear goes on to expand on this study by introducing a discussion on stigmatization, menstrual concealment, and the diagnostic delay of endometriosis (Seear, 2009b). Seear concludes that avoidance and minimization of stigma was a huge contributor to delay of diagnosis. Additionally, Seear concludes that this delay in diagnosis has a significant impact on the lives of women suffering from endometriosis. Women do not disclose information about their menstrual problems to doctors and even family. Women often choose not to disclose because they feared that their pain would be trivialized.

2.3 Black Women, Endometriosis, and Implicit Bias

According to the CDC (Centers for Disease Control), racism is defined as a system consisting of structures, policies, practices, and norms that assigns value and determines opportunity based on the way people look or the color of their skin. This system can place an unfair advantage on some people and disadvantage others throughout society (CDC, 2021). Additionally, the American Public Health Association also affirms racism as a public health crisis as it can have an impact on the health outcomes of disadvantaged groups (APHA, 2020).

Racism is a major contributor to the disparities in health outcomes amongst African American Women when compared to their White counterparts, even in sexual and reproductive health (Prather, Fuller et al. 2018). Prather, Fuller et al. 2018 state that the historical context behind racial inferiority is reflected through discriminatory healthcare practices that may have a significant impact in the quality of care that African American women receive from healthcare providers. Additionally, multiple experiences of racism tend to compromise the sexual and reproductive health of African American women. Although efforts have been made to move towards equitable healthcare, the historical influences of slavery, Jim Crow laws and racism cannot be ignored as instances of implicit bias persist in the medical system.

Because chronic pelvic pain is a common symptom experienced by women with endometriosis, it is important to explore how the historical underpinnings of implicit bias may affect pain assessment in this specific population. According to Hoffman et al. 2016, Black Americans are often undertreated for pain compared to White Americans. In this article the authors aim to examine whether racial bias is related to false beliefs about biological differences between Blacks and Whites such as the belief the Black people have “thicker skin” than White people (Hoffman et al. 2016). The authors employ two studies that look at White individuals with no medical training and White medical students to examine implicit bias. In study 1, conducted among White lay persons, the authors found that the study participants had endorsed at least one belief regarding the biological differences between Blacks and Whites (Hoffman et al. 2016). Additionally, medical students and residents were also studied to examine racial bias in the context of medicine, and Hoffman et al. 2016 confirmed that, just like the white lay persons, medical students held some concerning beliefs about the biological differences between Blacks and Whites. Thus, informing a downstream outcome regarding racial bias in pain treatment recommendations (Hoffman, 2016).

The journey to diagnosis is not an easy task. As mentioned before, due to perceived barriers on both an individual and organizational level, women with endometriosis may experience a delay diagnosis. Black women are less likely to be diagnosed with endometriosis overall and this is not necessarily because the incidence is low within this population but because of possible social factors such as implicit bias and racism (Bougie et al. 2019). Black women may have trouble getting necessary treatment, even if they are exemplifying the same symptoms as their White counterparts. Endometriosis was previously considered a disease of affluent White women and up until recently, Black women's pelvic pain was often attributed to pelvic inflammatory disease, an infection of the reproductive organs caused by an STD/STI (Bougie et al., 2019). This ideology could further the implicit bias and institutional racism and is possibly one of the many factors as to why Black women go misdiagnosed or underdiagnosed.

Socioeconomic status can also be a barrier to diagnosis and treatment within this population. Because endometriosis is only officially diagnosed through a surgical laparoscopy, there may be financial barriers for individuals with lower income. According to a survey done on Endometriosis in America, it was found that the average out of pocket expense for a laparoscopy was $4,923 (Editorial Team, 2020). There is no doubt that financial barriers may cause this population to be discouraged from seeking care. The enactment of the Affordable Care Act (ACA) helped to ensure that millions of Americans could receive health care coverage and because of this, the rate of uninsurance among Black Americans declined. Out of the 20 million people who gained coverage under the ACA, 2.8 million of them identified as African American (Taylor, 2019). However, the disparities in uninsurance persist~~s~~ as African Americans are still more likely to be uninsured than their White counterparts (Taylor, 2019). Although the insurance coverage expansions under the ACA have made progress towards universal coverage, there are still high costs attached to many coverage options- meaning that access to care that is affordable still poses as a challenge for many Americans- particularly African Americans.

2.4 Conclusion

Endometriosis clinics tend to focus on improving physical well-being with medical or surgical treatment. However, there is need to understand the degree to which transition into care addresses overall health related quality of life in an individual. According to Geukens, Apers et al. 2018, health related quality of life is being recognized as the ultimate outcome measure of quality health care. Moreover, the Institute of Medicine recognizes patient centered care as care that is “respectful of and responsive to individual patient preferences, needs, and values and guided by patients’ values” (Geukens, Apers et al., 2018).

Although there is extensive literature on endometriosis, to our knowledge, there are only two articles that explicitly explore endometriosis and the Black woman. Both articles were written by Donald L. Chatman, an American OB-GYN, and aimed to provide evidence of the existence of endometriosis in African American and provide evidence counter to previous theories that endometriosis was a condition only faced by middle class White women (Shade, Lane et al. 2011; Bougie, Healey et al., 2019). Additionally, while there are articles that look at endometriosis and the impact on quality of life, there is a lack diversity amongst study samples. This study will aim to fill this gap by examining the experiences of Black women between the ages of 18 - 45, diagnosed with endometriosis and living in the United States. This will help add to the scientific literature on this topic

CHAPTER III. STUDENT CONTRIBUTION

3.1 Description of student contribution

Melanie Dakwa's contribution to this study began in February 2021. During their qualitative methods course, she centered her class project on quality of life and Black women diagnosed with endometriosis and conducted 3 interviews for the project. Next, she had an initial discussion with thesis committee member, Dr. Subasri Narasimhan, in March 2021 about research interests and expanding the qualitative methods project into a thesis. In April 2021, the student then approached Dr. Whitney Rice, the Thesis Chair, about support on their proposed research topic. With the support and guidance from Dr. Rice, Melanie developed their research topic, recruitment materials, and data collection tools such as an interview guide. Additionally, they prepared a protocol for submission to Emory Institutional Review Board (IRB).

Conceptualization

This research topic was conceptualized based on the student's positionality/identity as a Black woman with negative experiences in quality of life and healthcare navigation, because of difficult menstrual experiences. Additionally, understanding the varied experiences of Black women in the United States, the student conceptualized this project as a means of exploring the lived experiences in Black women diagnosed with a chronic condition. Further, the exploration of topics such as intersectionality and medical mistrust in communities of color at the Rollins School of Public Health and how this may have an impact on health outcomes were key factors in informing the student's project. This student is currently pursuing a certificate in maternal and child health.

Planning

In May 2021, the student began drafting the study protocol for IRB submission. The study protocol was submitted June 2021 and Emory IRB approval was received in July 2021. With the support of Dr. Rice and RISE at Emory, the student was able to provide incentives for participants, employ paid Facebook ads as a form of recruitment, and use REDCap to assess eligibility of participants. Upon IRB approval, the student recruited participants.

Recruitment and Data Collection

Prior to recruitment, the student developed an eligibility questionnaire through RED-Cap to assess eligibility of participants and to collect demographic information that would be used later to assess the diversity of the study sample. With the support of The Center for Reproductive Health Research in the Southeast (RISE) at Emory, the student was able to develop and post Facebook ads as a form of recruitment. Additionally, the student set up an account on Research Match, an online research recruitment platform, and posted their study to recruit eligible participants. Facebook Ads were employed for one week that included a description of the study, a link to the questionnaire, and a recruitment flyer with additional details. Participants were also recruited and contacted to fill out the eligibility questionnaire through Research Match. The student assessed eligibility based on answers from surveys. Eligible participants were then contacted through their preferred contact method (email/phone) about scheduling interviews. Participants also had the option of scheduling a pre-interview call if they had any questions/concerns. If an individual agreed to scheduling, the student scheduled an online Zoom meeting and sent an invite to participant. The student used an interview guide and probes to collect perspectives on experiences and perceptions on quality of life and diagnosis of endometriosis.

Analysis

Once the data was collected and transcribed by Landmark Associates, Inc., the student developed a codebook using a thematic approach. The student then conducted a preliminary analysis and identified emerging codes throughout the data and then used the codes to develop themes to help inform the thesis. After identifying these themes, the student presented the results with their thesis chair and discussed any other emerging themes. The student then identified a potential journal for submission.

Deliverables

Ms. Dakwa will publish a manuscript in a peer-reviewed reproductive health journal with guidance from Drs. Rice and Narasimhan. The manuscript will contribute to the scant research on the experiences in living with endometriosis and the impacts on quality of life among Black women living in the United States, in hopes of increasing awareness of this condition.

CHAPTER IV. JOURNAL ARTICLE

HSC Qualitative Article Guidelines

"It's Like Your Body is Fighting Against You...": Perceptions and Experiences Regarding Quality of Life in Black Women Diagnosed with Endometriosis

Melanie Dakwa [a], Suba Narasimhan [b], Whitney Rice [a]

[a]*Department of Behavioral Social and Health Education Sciences, Rollins School of Public Health, Emory University, Atlanta, USA.*

[b]*Department of Global Health, Rollins School of Public Health, Emory University, Atlanta, USA.*

*Whitney Rice DrPH, MPH whitney.s.rice@emory.edu *corresponding author*

Abstract

Endometriosis impacts an estimated 10% - 15% of women of reproductive. The condition is characterized by the presence of endometrial tissue outside of the uterine cavity and can lead to symptoms that result in an overall lowered quality of life. Research on the experiences of women diagnosed with endometriosis historically focused on White middle-class women. There has been a disregard for Black women's pain within research. As a result, there is a need to explore the impact of endometriosis on quality of life, particularly for US-born Black women. This study will aim to fill this gap by exploring the experiences of Black women diagnosed with endometriosis. Data were collected through semi structured in depth interviews with Black women between the ages 18-45, living in the United States, and diagnosed with endometriosis. Interviews were video and audio recorded on Zoom and then transcribed. A thematic analysis approach was then used to generate themes. A total of 18 Black women were interviewed for this study. Four themes emerged from the data: The psychosocial impact of endometriosis on quality of life; navigating healthcare experiences; resiliency and self-advocacy by any means necessary; the need to know: lessons learned and a call to action. When caring for Black women who are presenting symptoms of pain and lowered quality of life, it is important for healthcare professionals to be intentional about recognizing their own bias and acknowledging the historical context behind the dismissal of pain in Black women in the United States. This can be done through engaging in cultural sensitivity training and pursuing an individualized approach to care. Furthermore, healthcare professionals can also leverage support for women by identifying and including social networks to mitigate the burden of endometriosis to improve overall quality of life.

What is known

- The presence of pain from endometriosis can be pervasive in intimate relationships, social functioning, and work life
- Endometriosis was originally considered as a condition impacting white middle class women
- Endometriosis is one of leading causes of infertility in women over 25

What is Added

- Black women express resiliency and self-advocacy as a necessity in managing their endometriosis
- Black women expressed disappointment and dissatisfaction in their quality of care
- Support from the close networks in the management of their endometriosis increased their quality

Introduction

Endometriosis impacts an estimated 10% - 15% of women of reproductive age (Denny 2007; Bertero and Grundstrom, 2017; Shafrir et al., 2018) which extrapolates to about 190 million women worldwide according to population estimates in 2017 (The World Bank 2017) . The condition is characterized by the presence of endometrial tissue outside of the uterine cavity and leads to symptoms that can lower overall quality of life (Denny, 2009; Young et al., 2014; Cox 2003).

Endometriosis can affect all areas of a woman's life, not just the physical and psychological components. The presence of pain can also be pervasive in intimate relationships, social functioning, and work life (Della Corte 2020; DiBenedetti 2020). The World Health Organization defines quality of life as "'individuals' perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns' (WHO, 2012). Signs and symptoms of endometriosis include, but are not limited to, heavy menstrual bleeding, chronic pelvic pain, dysmenorrhea, and pain during sexual intercourse, which can have significant impacts on emotional well-being (Moradi et al., 2014). The signs and symptoms of endometriosis are known well enough by medical professionals to prompt further investigation that leads to a diagnosis. However, because signs and symptoms of endometriosis can be linked to various gynecological issues in women, healthcare workers may struggle to easily diagnose this disease. This truth, coupled with the fact that individuals suffering from the disease are often not aware of the condition, can cause a delay between onset of symptoms and diagnosis (Agarwal et al., 2019). To this day, the exact etiology of endometriosis is not clear, thus pushing a lot of women to become expert patients in the self-management of their pain (Seear 2009). While self-management of pain is empowering for some women, it can also be seen as emotionally taxing to many women (Seear, 2009).

Although endometriosis is one of leading causes of infertility in women over 25 and is one of the most common gynecological diseases, it has been routinely underdiagnosed, underreported and under researched. Additionally, little published research examines how endometriosis impacts an individual's life beyond their physical symptoms. An overabundance of endometriosis research focuses on the physical symptoms of the disease (Cole et al., 2021). Therefore, understanding of the lived experience of people diagnosed with endometriosis including management of non-physical symptoms, and impacts on their perception of self or other parts of their lives could be useful. Further, although a large body of research on the experiences of women diagnosed with endometriosis exists, the historical focus on the condition was initially only in White middle-class women (Bougie, 2019). Racism is a major contributor to the disparities in health outcomes amongst African American Women when compared to their White counterparts, even in sexual and reproductive health (Prather, Fuller et al. 2018). Prather, Fuller et al. 2018 state that the historical context behind racial inferiority is reflected in discriminatory healthcare practices that may have a significant impact on the quality of care that African American women receive from healthcare providers. Additionally, multiple experiences of racism tend to compromise the sexual and reproductive health of African American women. Although efforts have been made to move towards equitable healthcare, the historical influences of slavery, Jim Crow laws and racism cannot be ignored as instances of implicit bias persist in the medical system.

Because chronic pelvic pain is a common symptom experienced by women with endometriosis, it is important to explore how the historical underpinnings of implicit bias may affect pain assessment in this specific population. According to Hoffman et al. 2016, Black Americans are often undertreated for pain compared to White Americans. In this article the authors aim to examine whether racial bias is related to false beliefs about biological differences between Blacks and Whites such as the belief the Black people have “thicker skin” than White people (Hoffman et al. 2016). The authors employ two studies that look at White individuals with no medical training and White medical students to examine implicit bias. In study 1, conducted among White lay persons, the authors found that the study participants had endorsed at least one belief regarding the biological differences between Black and White people (Hoffman et al. 2016). Additionally, medical students and residents were also studied to examine racial bias in the context of medicine, and Hoffman et al. 2016 confirmed that, just like the white lay persons, medical students held some beliefs about the biological differences between Black and White people.

Informed by the intersectionality framework, this study aims to fill this need by examining quality of life perceptions in Black women diagnosed with and living with endometriosis. I also explore patient-provider relationships Black women discuss as they manage their endometrial symptoms and treatments, and the roles of resiliency and self-advocacy in their management of pain.

Methods

Design

For this study, qualitative methodology was utilized to understand perceptions regarding quality of life among Black women diagnosed with endometriosis. Additionally, this approach was used to further explore their experiences with navigation through the healthcare system and how they exemplify self-advocacy and resiliency in these experiences. In-depth interviews were conducted to discuss these topics.

Recruitment

Study participants were eligible based on the following criteria: 1) Black woman; 2) between the ages of 18 and 45; 3) living in the United States and 4) diagnosed with endometriosis. With support from the Emory Center for Reproductive Health Research in the Southeast (RISE), the researcher conducted a mixture of a purposive and snowball recruitment method to recruit a minimum of 16 participants. Participants were recruited through Facebook ads and Research Match, an IRB approved recruitment website. Interested individuals were directed to a RED Cap survey link to assess eligibility for the study. Those who met the criteria were contacted by the researcher to schedule a phone call if they had any questions about the study and they were given the option to schedule the interview. Verbal consent was given by every participant before the interview. Recruitment resulted in a total of 18 interviews.

Setting

The study was conducted in a private Zoom meeting room at times convenient for the participants. All interviews lasted between 20 and 75 minutes. Participants were given the option of conducting the interview over the phone if there were technical issues with Zoom.

Data Collection

In-depth interviews were conducted between the months of September and October 2021. Through the eligibility survey on RedCap, basic demographics were collected from each participant. The in-depth interview guide focused on five areas as follows: 1) knowledge of endometriosis; 2) impacts on quality of life; 3) navigation and experience in the healthcare system; 4) patient-provider interactions; and 5) perceptions on self-advocacy and resiliency. The interview guide also contained probing questions to inquire further about participants' experiences. Interviews were both audio and video recorded with verbal consent of the participant and then transcribed by Landmark Associates, Inc.. Upon completion of the interview, a $30 electronic visa gift card was provided to each participant. Due to indication of participant ineligibility during the interviews, two interviews were removed from the final analytic sample resulting in 16 total interviews.

Data Analysis

All transcripts were uploaded into *MAXQDA 2022*, a qualitative data analysis software used for data management and coding. Using the Braun and Clarke analysis framework for thematic analysis, data was analyzed in 6 different stages. Initially, transcript data was reviewed by the researcher for familiarization . Next, a preliminary codebook was developed and reviewed by the research team with deductive codes developed from the interview guide and inductive codes developed through open coding. Transcripts were coded line by line and at the completion of coding, themes were generated by collapsing codes that were similar and discarding codes that were not relevant to the goals of the research.

After, the emerging themes generated a summary of the themes were presented to the research team for validation. Upon validation, themes were then defined, and a report was produced by the researcher.

Findings

Sixteen participants met the study eligibility criteria. Participants resided in different regions of the United States: Northeast (n = 3), West (n = 3), Midwest (n = 3), and South (n = 7). Additionally, participants identified different forms of diagnosis: clinical diagnosis by a medical professional (n = 11), laparoscopy (n = 6), ultrasound (n = 4), MRI (n = 2), and other (n = 2). Table 1 provides further description of the participant demographics.

When asked about the physical symptoms they experienced, the symptoms widely described across the sample included: vomiting, pelvic pain, headaches, pain during sex, heavy bleeding, constipation, rectal pain, and blood clots.

- *...I mean, imagine your cramps times about 20. That's what endometriosis feels like. Um, you lay down. It doesn't help. You sit up on your knees. It doesn't help. It's just-it's just one of the—and not only does it hurt in your uterus, it hurts in your top of your stomach too. - Aliya, 36 to 45*
- *I started having this, like, intense, like, pressure where I felt like my stomach was gonna explode, and it was, like, so painful I could barely talk sometimes. I couldn't, like, stand up straight. - Andy, 26 to 35*
- *The physical would be a stabbing pain in my uterus that wouldn't go away. I felt like—that's how I could describe it—like someone was taking a knife and stabbing me in my uterus over, and over, and over again. - Casey, 26 to 35*

Description of themes

During analysis four main themes were identified: (1) psychosocial impacts of endometriosis on quality of life (2) navigating healthcare experiences (3) self-advocacy and resiliency by any means necessary (4) the need to know: lessons learned and a call to action.

The Psychosocial Impacts of Endometriosis on Quality of Life

The psychosocial impacts of endometriosis on quality of life are a salient theme throughout all 16 interviews. Psychosocial well-being encompasses mental, social, emotional, and spiritual dimensions of what it means to be healthy. Participants mentioned a range of impacts of endometriosis such as impact on their social life, mental/emotional health, intimate relationships, and their perceptions of themselves.

Impact on Social Life

Many participants described the impact of endometriosis on their social life. Many went into detail about cancelling plans and important events, having to adjust their day-to-day life and routines, and the burden of social networks not understanding what they're going through.

- *I could remember times when I would stay home, um, because my periods were just so heavy. Um, and just, uh, at the end of the day, um, d-during-during that-the-the week of knowing that I'm on my period, just making sure that okay, am I prepared to-to be out in public, you know? - Mandy, 36 to 45*
- *Um, also, I like to be a pretty active person. Like, I like to be social and interact with people and also be out in nature. And so I felt as if, like, once those flares happened, I feel as if, like—I feel like a decent amount of my day is kinda taken away, or at least-or at least, like, I'll be having a fun time, then it'll be like, "Surprise, endometriosis." - Angie, 18 to 25*

One participant described their frustrations with having to plan their life around their period, even feeling envious at those who do not have to deal with the same burden

- *definitely frustrated and sometimes even depressed because I'll, like—I'll sit there and be like why is it happening to me or, like, why is it that I'm the one that has the-the horrible periods and, like, everybody, they're like they're fine. They're going to the beach. They're doing whatever. And, like, for me, it's like when is-when is my period coming? Oh no, I'm* *not gonna be available that day. Like, you'll find me—I'm on the couch or in my bed with a heating pad for the whole day. - Ike, 26 to 35*

Impact on Intimate Relationships

Many participants describe painful sex as something that has impacted their intimate relationships in marriage/committed relationships and casual sexual relationships.

- *Yeah. Intimately definitely. Um, with-with my husband, I mean, I'm-I'm thankful that he's patient, but just it-it-it could be-there were times when it could be pretty painful, um, just intimately. And so, um, not being able to have those experiences, uh, sometimes just I-I may have wanted to... it kinda can put a damper on-on your relationship. - Mandy,36 to 45*

Some participants even described their experience of having to communicate these issues with their romantic partners and how in some instances they received support and understanding.

- *it's been, like, a year since my diagnosis, I'm a lot more communicative with my partner, and he's very understanding of, um, what's going on and is very respectful. He knows what consent is, which awesome. Um, so I think that that's helped a little bit with this self-perception, but when I first started out, there was that insecurity - Angie, 18 to 25*

Impact on Emotional/Mental Health

The emotional and mental impact of endometriosis was salient throughout interviews as participants described experiences with anxiety, depression, fear and hopelessness. One participant goes into detail about the impact of her symptoms of heavy bleeding on their emotional health.

- *So it was like I'd hafta make what I call super pads just to get through a period, then run to the bathroom, hope I had enough time. It was-it was just that-that made me really kinda depressed, and I'd wanna stay home from school 'cause it's like, what's the point of, like, hoping I make it to the bathroom. And, and then at nighttime, I'd make like those super pads, where it'd be like eight pads put together. - Toya, 26 to 35*

Although the term "silent killer" was only used by one participant to describe how endometriosis symptoms cannot be seen on the outside, this related closely to the notion that "nobody understands"; which is a term frequently used by participants. This socially isolating experience was also emotionally and mentally burdensome for participants.

- *it hurts you psychologically because you're in constant pain, and nobody understands it. Um, you know, they'll ju—"Oh, you just got cramps." No, these aren't cramps. These are somethin' else, you know. - Aliya, 36 to 45*

Perceptions of Self and Womanhood

Many participants discussed the impacts of endometriosis on their perceptions of self, going into detail about feelings of frustration related to how they feel endometriosis has impacted their body and self-image.

- *I used to think I was invincible. And, like I said, I was in, like, phenomenal health, and, um, I was invincible. And now I'm like I get a little bit scared of my body sometimes because, you know, while I think it's still great, I feel like it could fail me, and I never know what's gonna happen next. And so that kind of bugs me, um, because, like, you wanna check that box of excellent health. And I don't. I'm like, oh, it's in good health - Rica, 36 to 45*

- *And then the other thing I would say in terms of like body perception is I get very, very frustrated because—I know this might sound-this might sound bad. But it gets to the point where, like, I think to myself, I'm doing everything that they're telling me to do. I'm eating healthy. I'm eating this. I'm not eating this or whatever, and then like the endometriosis is still there thriving, right? And it's like nothing I'm doing is working, but then, like, a friend of mine eats like trash. You know like, she eats whatever she wants. Pizza, all of this stuff, and she's like totally fine. So it makes me get like upset with my own body because it's like why aren't you doing what we need you to do, you know? - Ike, 26 to 35*

Regarding their perceptions of self, some participants mentioned the perceptions on how endometriosis has impacted their feelings as a woman in relation to phenomena of sex, fertility and overall feelings about their menstrual cycles.

- *And-and tellin' myself that, of course, I'm not less of a woman if I can't reprodu-reproduce. Right? But it still stinks. - Phylicia, 36 to 45*
- *just it makes you kinda resent your body ... Um, uh, it makes you—like I said, it makes you question yourself as a woman. - Talia, 26 to 35*
- *I just felt really like I hated bein' a woman. Like I hated havin' my period. Like why is this happening to me? So it was like kind of feeling disadvantaged and not being able to get somethin' that would just stop the symptoms completely— - Toya, 26 to 35*

Navigating Healthcare Experiences

Many participants discussed early experiences with symptoms in their teen years that were later related to endometriosis. Symptoms were normalized by not only close networks but by the healthcare professionals they went to see as “something women just go through”. Many participants went into detail about the experience in their younger years with symptoms that were not initially recognized as endometriosis:

- *Yeah, around 13 or so, like heavy bleeding, like rectal pain, like stabbing rectal pain, abdominal pain. Like not bein' able to stay in school 'cause I was in so much pain. - Toya, 26 to 35*
- *I just thought I had really bad periods. Now that—well, now that I know that that was a huge sign. I just had horrific periods since the time that I was 12, which is when I got my first menstrual. - Casey, 26 to 35*

Interactions with Healthcare Providers

Regarding the diagnosis and management of their endometriosis, participants were asked about their experiences with healthcare providers and their perceptions on the interactions. A myriad of experiences was described by participants regarding interactions with providers. Some participants made sure to shine light on the positive interactions with their doctors. Answering questions, feeling cared for and doctors that went the extra mile were some attributes of these positive experiences.

- *Uh, I-I felt listened to. I felt heard. Um, there-there were a few appointments that I can remember still feeling like okay, well, that didn't, you know—may not have—get caught. The answer that moment that I-that I was looking for, or I don't even know what answer I was looking for. But like n-sometimes there wasn't always an i-an immediate solution, you know. But-but at least I-I knew that okay, well maybe there'll-there'll be some resolution. Maybe, you know, something will be done. I'll find out something. Um, and* *just having to be pa-patient. That much—you know, playing the waiting game a little bit longer. But feeling like there was a path, as opposed to just— Mandy, 36 to 45*

- *But, like, this is the person who actually listened to me, so like, I literally sat on the phone with him for, like, I think 30 minutes 'cause he does, like, tele-telemedicine. So I literally sat on there for, like, 30 minutes to an hour. He answered all—I remember I made a list of 36 questions. He literally answered every single one of them for me. - Ike, 26 to 35*
- *Yeah, I receive, um, adequate care, and then finances wasn't a issue. Everything was bein' sorted out. - Rose, 26 to 35*

On the opposing side, there were overwhelming comments regarding the negative experiences of Black women with their health care providers. Many participants felt dismissed, misunderstood, and went into detail about insensitive comments that were made by providers.

- *So I felt, um, ignored when I was explaining my pain and my situation. And I felt they could've done something sooner, but on the flipside, I'm not a medical professional, but, you know, could they have saved my ovary if they would've acted faster? Maybe, maybe not. I'll never know. - Rica, 36 to 45*
- *But I saw a male doctor, and he was just, like, um, you know, "You're only experiencing, like, this pain during your period." "If you're fine elsewhere we don't have to do anything about it." And I was like, that doesn't seem right to me 'cause if my endometriosis is so bad, like, I don't wanna wait until I'm doubled-over in pain in an emergency situation— - Dina, 36 to 45*
- *And so he's going through all the symptoms that I have. And he's like, 'Wow okay, so you have pain,' um, 'you have all this pain, blah, blah, blah.' And he says to me, 'Oh, you're married,' you know, all these regular questions. And he's like, you know, he was like,*

'Wow, you're really damaged. Your husband needs to put you back on the shelf.' And he had a intern in there and she was like—yeah, I-I think an intern. She was, like, learning, you know. And she was like—she mouthed to me when he turned around, she said, 'I'm so sorry.' - Casey, 26 to 35

Feelings After Diagnosis

There was clearly a delay in diagnosis for many participants as they described experiences with symptoms in younger years and the final diagnosis at an older age. Many participants described two different feelings when they were finally diagnosed by a healthcare professional. As far as the negative feelings, participants described feeling concerned, defeated and angry.

- *I was not sad. I was just concern 'bout my health because I got three kid. And the problem bein' with me, like, all this real early. I thought because I was gainin' weight or all that, so I'm finally glad that I find out what it is so I know now. - Kia, 26 to 35*
- *But, um, I felt angry at-at all the doctors that I've seen up to that point who had missed it because then, like, if somebody had realized what was going on, maybe I would still have my fallopian tubes. - Andy, 26 to 35*

While others felt feelings of relief and validation after their diagnosis.

- *I was happy that they had something called, um, endometriosis because I was just in a lot of pain and I just, I heard about it before, and I knew it wasn't really—real bad. I thought it maybe had been cancer or something like that. And I was just happy that it wasn't cancer basically and that I-I was gonna live, and I wasn't gonna die, and it was something that was treatable - Didi, 36 to 45*
- *So it felt like a relief, like now I know this is what it is. - Toya, 26 to 35*

Perceptions on Quality of Care

When asked about their feelings regarding their overall quality of care, many participants described dissatisfaction with the care they received while trying to manage their condition. Two participants who described their experience with symptoms as a teen went into detail about what it looked to like to trust your healthcare providers:

- *"Um, I just felt like really at that time my trust was in the doctors because I didn't know anything. - Casey, 26 to 35*
- *...my mom had no idea what was causing this pain, so she just thought it was like the doctor said. You know, 'cause we're-we're brought up to kinda, like, trust your medical professionals, right? 'Cause, like, we're not-we're not doctors, so we go to them looking for, you know, the ideas and the cures and whatnot. - Ike, 26 to 35*

Regarding their diagnosis, participants described disappointment in the time to took to reach a diagnosis. Many reiterated the dismissiveness of healthcare professionals which may have led to a diagnosis well beyond when they first started to experience symptoms, and this played into their dissatisfaction with care.

- *You know, like, I could've gotten the proper intervention early on, who would have known what to do. I would've known what the problem was my whole life. And so then I wouldn't have had all this agony of, like, trying to have a baby and, like, the misery that comes with infertility and, like, and not knowing what's wrong, and, like, why it's not working. Um, like, I could've saved years of pain and, like-like, all the weeks of my life that have been l—all the time that I've lost, like, all the things that I couldn't do because I was in pain, like, could've been avoided. - Andy, 26 to 35*

- *It was very, like, dismissive, dismissive. Come back when you're ready to have kids and if you're struggling. You know what I'm saying? Like if you-if you conceive with no problem, cool. It's great. But if you have a problem conceiving, come back and then we'll worry about it at that point. - Ike, 26 to 35*
- *Um, but I just felt like I was, like, a number, like I did not matter. She didn't care to investigate or find out for me or say, "Hey. Here's this test," or anything like that. You know? I did—I did have conversations with her. But eventually, I left because I realized I wasn't going to get the care that I needed. - Phylicia, 35 to 45*

One participant goes into more detail about having somewhat of a positive experience but perceiving it being attributed to their profession.

- *And I will say this, I-I do notice that I'm treated differently once people learn what my profession is. I think that makes a difference. But when people don't know what I do, if they think that I'm just, like, the average person who walks in, I do get treated differently. And I think it's compounded by race. If that makes sense?... So previously, uh, I was a researcher. And currently, I'm an epidemiologist. And so when they see that in my chart, they talk to me differently. They have different questions for me. They wanna engage me about the nature of my work. You know what I mean? They feel—it seems as if we are all on the same playing field. But if I-if I were, say, for instance, maybe just a clerk or a case manager, because previously I was a case manager, I'd never felt like I was getting the attention that I needed or that I deserved or even respect. - Phylicia, 36 to 45*

Birth control is a form of treatment salient throughout the interviews. While some participants heeded to prescriptions of birth control as a form of treatment for their symptoms, there was a general understanding that did nothing but mask the pain. Additionally, some participants felt as if doctors don’t look deeply into additional forms of treatment, seeing birth control as an “easy fix”.

- *And they're so quick to throw the birth control pill at you and say here you go. Oh, it's just here you go. Here's the birth control pill. And I'm like, well, this isn't working. - Rica, 35 to 45*

The desire for doctors to investigate their condition in detail was something attributed to quality of care in participants. One participant described their dissatisfaction with the care they received in which a doctor made it known that it worked for someone else:

- *That’s what I wished the doctors would have listened to me and not told me, oh well this is what worked for somebody else. Well, I'm not somebody else. I'm me, and this is the symptom that I'm having. Maybe you never heard of it. Well, just say that but don’t tell me that it's impossible. Don't tell me that 'cause I know the pain that I have. - Casey, 26 to 35*

Resiliency and Self Advocacy by Any Means Necessary

Resilience Defined

Participants were asked how they perceived themselves to be resilient throughout the process of living and managing their endometriosis. The perceptions of resiliency amongst the participants varied, with some participants discussing the difficulties of resilience but the necessity of it.

- *And so now I’m kind of trying to keep the mindset that-that’s what I need to do, um, but it’s hard, right, ’cause there are days where I just wanna just give up and not pursue anything. But I-but I keep thinking, like, I can’t do that because I don’t wanna be put in a* *situation where one day it gets really bad, and I'm, you know, I can't work or whatever. - Dina, 36 to 45*

- *Um, I felt weak. I didn't. I-I-I felt like the world was on top of my shoulders, and I didn't understand, like, the why. Like, oh gosh, no. You know, like, I went from being strong to being weak. Um, it was, you know, I can look back, and say, wow, I was strong, but I didn't feel that way. Um, no, I felt very out-out of control. Like, I wasn't in control of anything. - Rica, 36 to 45*

Other participants go into more detail about their perception of resilience in relation to strength and being motivated by loved ones and also being motivated by their personal motto that they must be the one to fight for themselves.

- *So I don't look at it as why me. You know what, I do believe that it has made me stronger. - Casey, 26 to 35*
- *I wanna have a good quality of life in between that. And I-I didn't-I didn't stop fighting to find something. - Toya, 26 to 35*
- *I feel like-I feel like I'm resilient because I didn't give up. - Nia, 26 to 35*

Experiences and Perceptions on Self Advocacy

Participants were asked to describe their experiences with self-advocacy regarding the management of their endometriosis. The women had varying experiences with this, however, staying organized, speaking up for yourself, finding the right doctor and doing personal research were similar things participants brought up that were done to take care of their health.

- *I have to stay, like, super organized. So I ended up making um, I ended up making, like, a Google Drive folder with like everything. So every-every time I speak with a doctor, every* *time I speak with the insurance company, all of that, it's like—you kinda have to because at this point you've gone on, like, hundreds of doctor's appointments, hundreds of consultations, hundreds of phone calls with insurance company. And, like, it's impossible to remember every, you know, like everything. - Ike, 26 to 35)*

- *So, I use that system for everything. For my job, if I feel like my job doesn't value me, then I look for somethin' elsewhere. If I feel like, um, y-y-you know, m-my doctor doesn't care about my needs or i-is-or is not-is not listening to my needs, then I have to go some elsewhere. So, um, always be your biggest advocate, um, and once you do that, you will find your right fit. And your right fit will work for you. They will be for you. Um, so, and if you have those three things, you will be successful, and you will find the right treatment plan for you. You will find, um, the right answers for whatever that is that you're trying to do. Um, but you have to do your work for yourself as well. - Talia, 26 to 35*

Self-advocacy was perceived as a double-edged sword amongst participants, with some describing positive emotions towards self-advocacy such feeling empowered in having agency over their body and how advocating for themselves may be better for the long run.

- *It make me feel, like, good, like, I'm doin' somethin' right – for myself (Kia, 26 to 35)*
- *it makes me feel empowered. It makes me feel like this thing that I have—I have at least a little bit of control over this thing that I have no control over. (Angie, 18 to 25)*

Others described negative emotions attached to having to advocate for themselves such as frustration due to the complexity of managing the condition and feeling tired.

- *It’s tiring... ’cause you put forth a lotta effort. Like, in every time I see a doctor even though they have my records I have to explain everything again. And I have to go back 20 years. - Dina, 36 to 45*
- *I would say frustrated because, like you know, it's-it's like you always keep getting into these hurdles. Like just-just when you think that you fixed something, it's like something else comes up in-in-in the mix. Um, but at the same time, it's also-it's also empowering because you know that it's like, alright, I gotta get it done. Nobody else is gonna do it for me. And, you know, just-just go out and do it, basically, you know? - Ike, 26 to 35*

One participant went into detail about regret towards advocating for themselves and speaking up.

- *And I knew I wasn’t stupid. Like, but I felt stupid, like, and I felt like I should never have brought it up. Like, I regret it. I’m seriously, and maybe even still do, regret bringing it up because bringing it up did nothing but, like, make me feel horrible. - Andy, 26 to 35*

The Need to Know, Lessons Learned and Call to Action

Lessons Learned About Themselves

When asked about lessons they learned about themselves in the management of endometriosis, many participants reiterated resiliency as a lesson learned. Describing that although living with endometriosis has put a damper on their quality of life, their tolerance for pain is higher than they expected. Additionally, as endometriosis was described as a “silent killer” by one participant, it has taught some to not judge people by their appearance. Although endometriosis has had an impact on body image for many participants, it has also rendered an appreciation in the strength of their body. One participant describes:

- *And I feel like being a woman who has endometriosis is kinda like my body is still a marvel. Like I've learned to still be amazed at all that my body does, even with the issues and the problems. Like, I can still probably have children. Like, I have learned to kind of respect my body more, even though it's doin' this thing to me every month, I-I'm still very amazed, like, at what a woman's body can do. Like, a lot of respect for my body has been earned. - Toya, 26 to 35*

Call To Action

To close the interview, participants were asked to describe what advice they would give to those who don't know much about endometriosis; and this included healthcare professionals and Black women who also find themselves in the same position. Advice to Healthcare professionals was salient throughout all interviews with participants describing the importance of believing and listening to your patients, understanding that their pain is real, and pursuing treatment that is holistic and culturally sensitive.

- *I know that they know about science and what they learned about in school. But that has nothing to do with what they're going through in their body. - Casey, 26 to 35*
- *just to-to listen and not sort of be dismissive of women or—and-and girls who—to-to people with a uterus who say that they are in pain. Um, like, I mean, I can't count how many, like, different doctors, I told I was having, like, terrible pain and, like, nothing happened. The only reason anybody noticed is because, in the course of treatment for infertility, that was presumed to be caused by something else - Andy, 26 to 35*
- *Don't-don't say it's-it's-it's in their head. Um, you know, just listen because what-what-what harm is it gonna do to listen and look into it? Even if it's only, um-even if it's one*

doctor's appointment, that could make a difference. You know, listen and-and-and don't disregard a person ever. - Mandy, 36 to 45

One participant even suggested collaboration between those in the endometriosis community and healthcare professionals.

- *So what they need is someone from the endo community to get in contact with the people doing the conferences so they can have a little conference, you know, presentation or seminar at these medical things, so that the OBGYNs and even the hematologist and the PCPs are more aware of endo. Because it's not—I've talked to a lot of doctors, you know, in other specialties. - Jo, 36 to 45*

To Black Women who find themselves in the same position as participants once did, participants went into detail about advice which included: advocating for yourself, listening to your body, education, and the importance of finding the right doctor.

- *fight for what you believe in—basically, because doctors can be wrong. They're people too. - Nia, 26 to 35*
- *Listen to your body. Don't let anyone, not even a doctor tell you what you know - Casey, 26 to 35*
- *Um, so, do your own research. Um, and then, not only that, to do, you know—uh, find your fit with your doctor. Um, the first doctor, you know, you meet, you don't always have to go to. It—you know, sh-, —you have to shop around for them too. They-they are also—they're—you are hiring them as well. You know what I'm sayin'? So-so, never forget that. You never have to just settle with some-, —with a doctor either, um, because that's a relationship that you buildin' as well. So, if you feel like that—In a relationship—*

> *that's just like I treat-I treat everything, every big thing in my life like a relationship, including jobs, doctors, um, anything. Um, if you don't treat me right, if you don't listen to me, if-if I feel like you don't have my best interests, if you don't value me, we can't work. - Talia, 26 to 35*

Discussion

The research study utilized qualitative methods and aimed to explore the perceptions and experiences regarding quality of life in Black women diagnosed with endometriosis and living in the United States. Additionally, it sought to explore their experience in navigating the healthcare systema and how they have perceived to exemplify self-advocacy and resiliency in the management of their endometriosis.

The data from the themes address the main research questions as it suggests that endometriosis is seen to have a significant impact on the quality-of-life participants. Additionally, participants go into depth about their complex experiences in navigating through the healthcare system through their interactions with providers, perceptions on quality of care and distinct feelings after diagnosis. Furthermore, this study confirms that participants have had unique experiences in how they perceive themselves to be resilient and how they may exemplify self-advocacy in the management of their endometriosis.

Implications

The analysis of these aims identified for themes: (1) the psychosocial impact of endometriosis on quality of life, (2) navigating healthcare experiences (3) resiliency and self-advocacy by any means necessary and (4) The need to know: lessons learned and a call to action. The psychosocial impacts of endometriosis on quality life are a theme that was salient throughout all 16 interviews as participants described how it has impacted various aspects of their lives, thus impacting their perceptions on quality of life. The different psychosocial impacts included social life, emotional/mental health, intimate relationships, and their perceptions of themselves. This result aligned with broad evidence of literature as it showed the impact that endometriosis can have on quality of life. (Moradi et al.,2014; Rea et al., 2020; Kelin et al., 2014)

Participants expressed their perceptions on interactions with providers and their overall experience with the healthcare system regarding their diagnosis, treatment, and management of endometriosis. While some participants shined a light on their positive experiences, most expressed dissatisfaction with their quality of care and even endured insensitive comments made by healthcare professionals regarding their symptoms. A delay in diagnosis was typically due to their symptoms being normalized and dismissed by healthcare professionals so feelings towards a final diagnosis varied among participants. While some felt relieved to put a name to their pain, others felt frustrations towards the complexities of getting to a diagnosis and all they had to endure.

Addressing the organizational level of influence, it can be implied from the study results on quality of life and navigating healthcare experiences that there is a need for sensitivity training for doctors who are met with patients who may present symptoms related to endometriosis. Additionally, although women who may be suffering from endometriosis may present similar symptoms, an individualized approach to care is necessary to assess the needs and desires of the patients that align with their idea of a “good” quality of life. Implications may also be drawn to leverage the support for women with this condition by identifying their close social networks and using this to mitigate the burden endometriosis may cause. A study by Moradi et al., 2014 reaffirms this by stating the need for increased knowledge on an individual, societal and organizational level as suggestions made by participants to mitigate the negative impacts endometriosis may have on daily lives.

As reported in the study findings, Black women perceived resilience and self-advocacy to be challenging but essential when it comes to caring for themselves and their condition. There are pros and cons to being an expert in your condition. While some participants describe how it may be empowering to have agency over your body, challenges rest in having to always speak up for yourself to be heard. This finding aligns with previous literature that explored the experiences of women in Australia regarding their experiences with endometriosis. The central argument revealed the responsibilities of being an expert patient and how that may both increase and decrease the existing stresses women may endure related to this condition (Seear, 2009). Implications can be drawn that it takes significant work to manage a condition like endometriosis, and on an individual level, while it may be proven essential to increase knowledge on self-advocacy for women who may be suffering, it is important for there to be a healthy balance between practicing self-advocacy and seeking a care team that can work best with the patient.

Resiliency was reiterated as a lesson learned for participants. Additionally, a call to action to both healthcare providers and Black women who may in the same position was brought up. Advice given to healthcare providers included listening to their patients, acknowledging that their pain is real, and approaching care in a way that is holistic and culturally sensitive. Participants also reiterated the importance of self-advocacy as advice to Black women who may find themselves in the same position thus implying the complexities of the diagnostic journey of endometriosis. Additionally, findings suggest that doctors play a significant role in the diagnosis and successful management of endometriosis. Thus, healthcare professionals should be encouraged to research more about this condition and consider possible implicit bias.

Healthcare professionals must consider a culturally sensitive approach when dealing with women of color in the diagnosis and treatment of endometriosis. It is important to understand how intersecting oppressed identities such as being Black, being a woman and being diagnosed with a chronic condition may add to the stress that leave Black women underdiagnosed for this condition, thus lowering their quality of life. Additionally, considering and acknowledging the historical context behind the mistreatment and dismissal of a Black women's pain could help present a more sensitive approach to women who present symptoms that may be related to this condition.

Limitations

Due to the design of this qualitative study, such as the sample size, the findings are not generalizable to all Black women with endometriosis in the United States. In depth interviews were conducted on zoom and over the phone, while this was convenient considering the study population, this limited engagement in some instances as some participants chose to not have their cameras on. Reliance on self-reported endometriosis diagnosis by a healthcare professional also posed a limitation in determining eligibility. Due to IRB constraints, the researcher could not ask for medical record information to confirm this diagnosis. Lastly, eligibility did not ask participants whether they were born in the United States, it sought experiences from Black women who were living in the country. This presents as a limitation as experiences in US born Black women vs immigrant Black women may differ.

Strengths

Regardless of the limitations, the study posed various strengths. Because the study sought to explore the experiences of Black women living in the United States, the zoom format provided a convenient way to reach participants who were not local. Additionally, the individual in-depth interviews allowed for a comfortable space for participants to share their story, considering that this is a sensitive topic. Lastly, the researcher conducting the interviews had relevant lived experiences that allowed them to empathize with participants while also understanding the terminology surrounding this condition. Furthermore, this study explored the experiences of Black women and created a space for them to tell their story, as they are often misrepresented or underrepresented in research concerning reproductive health.

In conclusion, this study provided insight into the experiences regarding quality of life in Black women diagnosed with endometriosis. This study also provides a call to action for both healthcare professionals and Black women who may be struggling with the same condition, thus revealing the vital role of an individual in caring for themselves but the role doctors also play in moving things forward. When caring for women of color who are presenting symptoms that may be like other conditions, it is important for healthcare professionals to be intentional about recognizing their own bias and acknowledging the historical context behind the dismissal of pain in Black women in the United States.

Future Directions

Because this study did not ask about ethnicity, future research should consider exploring the difference in the experience of US born Black women and immigrant-born Black women by considering culture as a determinant of health. Additionally, future research may consider perspectives from healthcare providers and the role they play in the diagnostic journey and their perceptions on quality of life for women who are living with endometriosis. Lastly, while in-depth one on one interviews were used for this study, other qualitative methodologies may be considered such as mixed methods or focus groups.

CHAPTER V. PUBLIC HEALTH IMPLICATIONS

Healthcare professionals must consider a culturally sensitive approach when dealing with women of color in the diagnosis and treatment of endometriosis. It is important to understand how intersecting oppressed identities such as being Black, being a woman and being diagnosed with a chronic condition may add to the stress that leaves Black women underdiagnosed for this condition, thus lowering their quality of life. Additionally, considering and acknowledging the historical context behind the mistreatment and dismissal of a Black women's pain could help present a more sensitive approach to women who present symptoms that may be related to this condition. The study utilized qualitative methods to explore the perceptions regarding quality of life in Black women diagnosed with endometriosis living in the United States.

The analysis of these aims identified four themes: (1) the psychosocial impact of endometriosis on quality of life, (2) navigating healthcare experiences (3) resiliency and self-advocacy by any means necessary and (4) the need to know: lessons learned and a call to action.

The psychosocial impact of endometriosis on quality of life

The psychosocial impacts of endometriosis on quality life is a theme that was salient throughout all 16 interviews as participants described how it has impacted various aspects of their lives, thus impacting their perceptions on quality of life. The different psychosocial impacts included social life, emotional/mental health, intimate relationships, and their perceptions of themselves. This result aligned with broad evidence of literature as it showed the impact that endometriosis can have on quality of life. (Moradi et al.,2014; Rea et al., 2020; Klein et al., 2014)

Navigating healthcare experiences

Participants expressed their perceptions on interactions with providers and their overall experience with the healthcare system regarding their diagnosis, treatment, and management of endometriosis. While some participants shined a light on their positive experiences, most expressed dissatisfaction with their quality of care and even endured insensitive comments made by healthcare professionals regarding their symptoms. A delay in diagnosis was typically due to their symptoms being normalized and dismissed by healthcare professionals so feelings towards a final diagnosis varied among participants. While some felt relieved to put a name to their pain, others felt frustrations towards the complexities of getting to a diagnosis and all they had to endure.

Addressing the organizational level of influence, it can be implied from the study results on quality of life and navigating healthcare experiences that there is a need for sensitivity training for doctors who are met with patients who may present symptoms related to endometriosis. A study by Mujumdar et al., 2004 explored the effects of cultural sensitivity on health care provider attitudes and patient outcomes with a purpose of determining the effectiveness of cultural sensitivity training on the knowledge and attitudes of health care providers. Additionally, they sought to assess the satisfaction and health outcomes of groups of minority patients with health care providers who received training (Mujumdar et al., 2004). Study results found that cultural sensitivity training increased open-mindedness and cultural awareness. It also improved how multiculturalism was understood and how to improve communication with minority populations thus concluding that cultural sensitivity not only improves the knowledge and attitudes of healthcare providers but also is shown to improve patient outcomes (Mujumdar et al., 2004).

Although women who may be suffering from endometriosis may present similar symptoms, an individualized approach to care is necessary to assess the needs and desires of the patients that align with their idea of a “good” quality of life. Implications may also be drawn to leverage the support for women with this condition by identifying their close social networks and using this to mitigate the burden endometriosis may cause. A study by Moradi et al., 2014 reaffirms this by stating the need for increased knowledge on an individual, societal and organizational level as suggestions made by participants to mitigate the negative impacts endometriosis may have on daily lives.

Resiliency and self-advocacy by any means necessary

As reported in the study findings, Black women perceived resilience and self-advocacy to be challenging but essential when it comes to caring for themselves and their condition. There are pros and cons to being an expert in your condition. While some participants describe how it may be empowering to have agency over your body, challenges rest in having to always speak up for yourself to be heard. This finding aligns with previous literature that explored the experiences of women in Australia regarding their experiences with endometriosis. The study revealed that the responsibilities of being an expert patient and how that may both increase and decrease the existing stresses women may endure related to this condition (Seear, 2009). Implications can be drawn that it takes significant work to manage a condition like endometriosis, and on an individual level, while it may be proven essential to increase knowledge on self-advocacy for women who may be suffering, it is important for there to be a healthy balance between practicing self-advocacy and seeking a care team that can work best with the patient.

The need to know lessons learned and a call to action

Resiliency was reiterated as a lesson learned for participants. Additionally, a call to action to both healthcare providers and Black women who may in the same position was brought up. Advice given to healthcare providers included listening to their patients, acknowledging that their pain is real, and approaching care in a way that is holistic and culturally sensitive. Participants also reiterated the importance of self-advocacy as advice to Black women who may find themselves in the same position thus implying the complexities of the diagnostic journey of endometriosis. Additionally, findings suggest that doctors play a significant role in the diagnosis and successful management of endometriosis. Thus, healthcare professionals should be encouraged to research more about this condition and consider possible implicit bias.

Healthcare professionals must consider a culturally sensitive approach when dealing with women of color in the diagnosis and treatment of endometriosis. It is important to understand how intersecting oppressed identities such as being Black, being a woman and being diagnosed with a chronic condition may add to the stress that leave Black women underdiagnosed for this condition, thus lowering their quality of life. Additionally, considering and acknowledging the historical context behind the mistreatment and dismissal of a Black women's pain could help present a more sensitive approach to women who present symptoms that may be related to this condition.

Future Directions

Because this study did not ask about ethnicity, future research should consider exploring the difference in the experience of US born Black women and immigrant-born Black women by considering culture as a determinant of health. Additionally, future research may consider perspectives from healthcare providers and the role they play in the diagnostic journey and their perceptions on quality of life for women who are living with endometriosis. Lastly, while in-depth one on one interviews were used for this study, other qualitative methodologies may be considered such as mixed methods or focus groups.

Conclusion

In conclusion, this study provided insight into the experiences regarding quality of life in Black women diagnosed with endometriosis. This study also provides a call to action for both healthcare professionals and Black women who may be struggling with the same condition, thus revealing the vital role of an individual in caring for themselves but the role doctors also play in moving things forward. When caring for Black women who are presenting symptoms of pain and lowered quality of life, it is important for healthcare professionals to be intentional about recognizing their own bias and acknowledging the historical context behind the dismissal of pain in Black women in the United States. These approaches should also be applied for immigrant Black women as well considering the cultural differences they may display. Thus, future research should consider exploring the difference in these experiences between US-born Black women and immigrant-born Black women concerning their experience in quality of life considering cultural differences.

References

Agarwal, S. K., Chapron, C., Giudice, L. C., Laufer, M. R., Leyland, N., Missmer, S. A., Singh, S. S., & Taylor, H. S. (2019). Clinical diagnosis of endometriosis: A call to action. *American Journal of Obstetrics and Gynecology*, *220*(4). https://doi.org/10.1016/j.ajog.2018.12.039

American Psychological Association. (n.d.). *Building your resilience*. American Psychological Association. https://www.apa.org/topics/resilience.

APHA. (2020). Structural Racism is a Public Health Crisis: Impact on the Black Community. AMERICAN PUBLIC HEALTH ASSOCIATION. Retrieved October 4, 2021, from https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2021/01/13/structural-racism-is-a-public-health-crisis

Ballard, K., Lowton, K., & Wright, J. (2006). What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertility and sterility*, *86*(5), 1296–1301. https://doi.org/10.1016/j.fertnstert.2006.04.054

Bauer, G. R. (2014). Incorporating intersectionality theory into population health research methodology: Challenges and the potential to advance health equity. *Social Science & Medicine*, *110*, 10–17. https://doi.org/10.1016/j.socscimed.2014.03.022

Bougie, O., Healey, J., & Singh, S. S. (2019). Behind the times: Revisiting endometriosis and race. *American Journal of Obstetrics and Gynecology*, *221*(1). https://doi.org/10.1016/j.ajog.2019.01.238

Bougie, O., et al. (2019). "Influence of race/ethnicity on prevalence and presentation of endometriosis: a systematic review and meta-analysis." BJOG **126**(9): 1104-1115.

Bowleg, L., “The Problem With the Phrase *Women and Minorities:* Intersectionality—an Important Theoretical Framework for Public Health”, *American Journal of Public Health* 102, no. 7 (July 1, 2012): pp. 1267-1273.

Centers for Disease Control and Prevention. (2018, October 31). *HRQOL concepts*. Centers for Disease Control and Prevention. https://www.cdc.gov/hrqol/concept.htm.

Centers for Disease Control and Prevention. (2021, July 8). *Racism and health*. Centers for Disease Control and Prevention. Retrieved October 4, 2021, from https://www.cdc.gov/healthequity/racism-disparities/index.html.

Cole, J. M., Grogan, S., & Turley, E. (2020). “The most lonely condition I can imagine”: Psychosocial impacts of endometriosis on women’s identity. *Feminism & Psychology*, *31*(2), 171–191. https://doi.org/10.1177/0959353520930602

Cox, H., Henderson, L., Wood, R., & Cagliarini, G. (2003). Learning to take charge: Women's experiences of living with endometriosis. *Complementary Therapies in Nursing and Midwifery*, *9*(2), 62–68. https://doi.org/10.1016/s1353-6117(02)00138-5

Della Corte, L., et al. (2020). "The Burden of Endometriosis on Women's Lifespan: A Narrative Overview on Quality of Life and Psychosocial Wellbeing." Int J Environ Res Public Health **17**(13).

Denny, E., & Mann, C. H. (2007). Endometriosis-associated dyspareunia: The impact on women's lives. *Journal of Family Planning and Reproductive Health Care*, *33*(3), 189–193. https://doi.org/10.1783/147118907781004831

DiBenedetti, D., et al. (2020). "Patients' perspectives of endometriosis-related fatigue: qualitative interviews." J Patient Rep Outcomes **4**(1): 33.

Editorial Team, 2020. (2020, July 9). *Out-of-Pocket Costs: Laparoscopic Surgery for Endometriosis*. Endometriosis.net. Retrieved October 4, 2021, from https://endometriosis.net/clinical/cost-laparoscopy-surgery.

Facchin, F., Barbara, G., Saita, E., Mosconi, P., Roberto, A., Fedele, L., & Vercellini, P. (2015). Impact of endometriosis on quality of life and Mental Health: Pelvic Pain makes the difference. *Journal of Psychosomatic Obstetrics & Gynecology*, *36*(4), 135–141. https://doi.org/10.3109/0167482x.2015.1074173

Geukens, E. I., et al. (2018). "Patient-centeredness and endometriosis: Definition, measurement, and current status." Best Pract Res Clin Obstet Gynaecol **50**: 11-17.

Grundström, H., Alehagen, S., Kjølhede, P., & Berterö, C. (2017). The double-edged experience of healthcare encounters among women with endometriosis: A qualitative study. *Journal of Clinical Nursing*, *27*(1-2), 205–211. https://doi.org/10.1111/jocn.13872

Hoffman, K. M., Trawalter, S., Axt, J. R., & Oliver, M. N. (2016). Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proceedings of the National Academy of Sciences*, *113*(16), 4296–4301. https://doi.org/10.1073/pnas.1516047113

Jones, C. P. (2000). Levels of racism: a theoretic framework and a gardener's tale. *American journal of public health*, *90*(8), 1212.

Jones, C. P. (2014). Systems of power, axes of inequity: parallels, intersections, braiding the strands. *Medical Care*, S71-S75.

Kim, J. H. and E. Han (2018). "Endometriosis and Female Pelvic Pain." Semin Reprod Med **36**(2): 143-151.

Klein, S., D'Hooghe, T., Meuleman, C., Dirksen, C., Dunselman, G., & Simoens, S. (2014). What is the societal burden of endometriosis-associated symptoms? a prospective Belgian study. *Reproductive biomedicine online*, *28*(1), 116–124. https://doi.org/10.1016/j.rbmo.2013.09.020

Marinho, M. C. P., et al. (2018). "Quality of Life in Women with Endometriosis: An Integrative Review." J Womens Health (Larchmt) **27**(3): 399-408.

Moradi, M., Parker, M., Sneddon, A., Lopez, V., & Ellwood, D. (2014). Impact of endometriosis on women’s lives: A qualitative study. *BMC Women's Health*, *14*(1). https://doi.org/10.1186/1472-6874-14-123

Majumdar, B., Browne, G., Roberts, J., & Carpio, B. (2004). Effects of cultural sensitivity training on health care provider attitudes and patient outcomes. *Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing*, *36*(2), 161–166. https://doi.org/10.1111/j.1547-5069.2004.04029.x

Nnoaham, K. E., Hummelshoj, L., Webster, P., d'Hooghe, T., de Cicco Nardone, F., de Cicco Nardone, C., Jenkinson, C., Kennedy, S. H., & Zondervan, K. T. (2019). Reprint of:

Impact of endometriosis on quality of life and work productivity: A Multicenter study across ten countries. *Fertility and Sterility*, *112*(4). https://doi.org/10.1016/j.fertnstert.2019.08.082

Rea, T., et al. (2020). "Living with endometriosis: a phenomenological study." Int J Qual Stud Health Well-being **15**(1): 1822621.

Seear, K. (2009). The third shift: Health, work and expertise among women with endometriosis. *Health Sociology Review*, *18*(2), 194–206. https://doi.org/10.5172/hesr.18.2.194

Seear K. (2009). The etiquette of endometriosis: stigmatisation, menstrual concealment and the diagnostic delay. *Social science & medicine (1982)*, *69*(8), 1220–1227. https://doi.org/10.1016/j.socscimed.2009.07.023

Shade, G. H., et al. (2011). "Endometriosis in the African American woman—racially, a different entity?" Gynecological Surgery **9**(1): 59-62.

Shafrir, A. L., Farland, L. V., Shah, D. K., Harris, H. R., Kvaskoff, M., Zondervan, K., & Missmer, S. A. (2018). Risk for and consequences of endometriosis: A critical epidemiologic review. *Best Practice & Research Clinical Obstetrics & Gynaecology*, *51*, 1–15. https://doi.org/10.1016/j.bpobgyn.2018.06.001

Simoens, S., et al. (2012). "The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres." Hum Reprod **27**(5): 1292-1299.

Taylor, — J. (2019, December 19). *Racism, inequality, and health care for African Americans*. Retrieved November 3, 2021, from https://tcf.org/content/report/racism-inequality-health-care-african-americans/.

The World Bank. Population ages 15-64 (% of population). 2017 (https://data-worldbank-org.proxy.library.emory.edu/indicator/SP.POP.1564.TO.ZS. opens in new tab).

TodayShow. (2020, June 30). *How this black doctor is exposing the racist history of gynecology*. TODAY.com. https://www.today.com/health/racism-gynecology-dr-james-marion-sims-t185269.

Trawalter, S., & Hoffman, K. M. (2015). Got pain? racial bias in perceptions of pain. *Social and Personality Psychology Compass*, *9*(3), 146–157. https://doi.org/10.1111/spc3.12161

World Health Organization. (1998). Programme on Mental Health WHOQOL User Manuel.

Yoldemir, T. (2018). "Quality of life for women with endometriosis: premenopausal and postmenopausal perspectives." Climacteric **21**(5): 411-412.

Young, K., Fisher, J., & Kirkman, M. (2014). Women's experiences of endometriosis: A systematic review and synthesis of qualitative research. *Journal of Family Planning and Reproductive Health Care*, *41*(3), 225–234. https://doi.org/10.1136/jfprhc-2013-100853

APPENDIX

Appendix A.

Table 1. Emerging Themes and Codes

Theme	***Codes informing themes***					
The psychosocial impacts of endometriosis on quality of life	*Social life*	*Mental/Emotional health*	*Intimate relationships*	*Perceptions of self*	*Womanhood*	*Physical Symptoms*
Navigating healthcare experiences	*Patient-provider interaction*	*Perceptions on quality of care*				
Experience with self-advocacy and resiliency	*Resiliency*	*Perceptions of self-advocacy*	*Experiences with self-advocacy*			
The need to know: Lessons learned and a call to actions	*Lessons learned about self*	*Advice*				

Appendix B

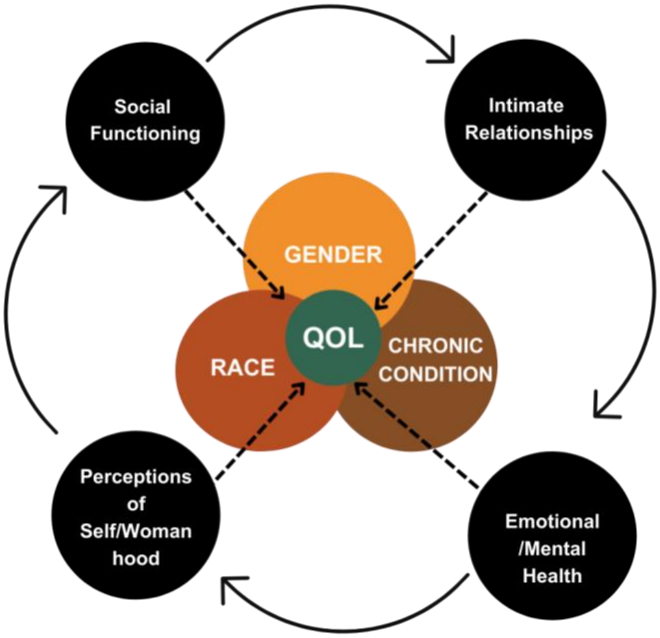
Table 2. Study Participant Demographics

Table 2. Study Participant Demographics

Characteristic		Total Participants N (%)
Age		
	18 to 25	1 (6.25)
	26 to 35	7 (43.75)
	36 to 45	8 (50)
Age of Diagnosis		
	18 to 25	6 (37.5)
	26 to 35	7 (43.75)
	26 to 45	3 (18.75)
Region of Residence		
	Northeast	3 (18.75)
	West	3 (18.75)
	Midwest	3 (18.75)
	South	7 (43.75)
Completed Level of Education		
	High School	1 (6.25)
	Some College	6 (37.5)
	Graduated College	3 (18.75)
	Graduate Degree	6 (37.5)
Method of Diagnosis		
	Clinical	11 (62.5)
	Laparoscopy	6 (37.5)
	Ultrasound	4 (25)
	MRI	2 (12.50)
	Other	2 (12.50)

Appendix C

Figure 1. Conceptual framework of themes regarding quality of life and study participants' intersecting identities



Appendix D

Interview Guide

KNOWLEDGE OF ENDOMETRIOSIS

1. **To what extent were you aware of any of the signs or symptoms of endometriosis before your diagnosis?**
    - What were your perceptions of endometriosis pre diagnosis?
    - Were you aware of anyone who was diagnosed with endometriosis?

INITIAL EXPERIENCE WITH ENDOMETRIOSIS SYMPTOMS

1. **Can you tell me around what time did you first start experiencing symptoms of endometriosis?**
    - What were your reactions to these symptoms?

2. **Can you describe, in detail, your symptoms before you were diagnosed with endometriosis?**
    - What did your physical symptoms consist of?
    - What did your psychological symptoms consist of?
    - What did your emotional symptoms consist of?

3. **What were your pain management strategies before you received an official diagnosis?**
    - If they changed after receiving a diagnosis, can you describe how they changed?

QUALITY OF CARE/NAVIGATION THROUGH THE HEALTHCARE SYSTEM

1. **What prompted you to go to the doctor about endometriosis signs or symptoms?**
2. **What did your initial conversations with the doctor look like? Regarding your symptoms.**
    - How did you describe your concerns with the doctor?
    - What was their response?
    - How did you feel after these interactions?
    - What was the process like of finally getting to a diagnosis?
    - What were your thoughts, feelings and emotions after receiving a diagnosis?
3. **What types of treatment for endometriosis were offered by the provider/specialist/clinician?**
    - Can you describe, in detail, your thoughts after treatment was discussed?

IMPACT ON QUALITY OF LIFE

1. **What areas of your day-to-day life were impacted by endometriosis?**
2. **Has endometriosis impacted any intimate relationships with your partner?**
    - Positive and negative

3. **Has endometriosis impacted the relationship with your family?**
    - Positive and negative

4. **Has endometriosis impacted the relationship with your friends?**
    - Positive and negative

5. **Has endometriosis impacted your professional life? (work and/or school)**
    - Positive and Negative

6. **Can you describe any transitions/adjustments you have had to make in your life living with endometriosis?**
7. **<u>Has</u> living with endometriosis impacted the way you perceive yourself and your body?**
    - If yes, please explain how. If no, please explain why

8. **Is there anything else you would like to share regarding your experience with living with endometriosis?**

<u>SELF ADVOCACY/ RESILIENCY</u>

1. **Can you describe, in detail, if you have had difficult experiences in navigating through the healthcare system?**
    - What were your feelings, thoughts and emotions?
    - Can you describe how you perceive to have bounced back from those experiences?

2. **How do you advocate for yourself in managing your endometriosis?**
3. **Were there any perceived barriers to advocating for yourself in the diagnosis and treatment of your endometriosis?**
    - How did you respond?

4. **How did self-advocacy make you feel in your endometriosis management?**
    - Can you give both positive and negative examples?

<u>CLOSE/WRAP UP QUESTIONS</u>

1. **What have you learned about yourself in living with endometriosis?**
    - What has been most helpful aspect?
    - What has been the least helpful?

2. **For those who don’t know much about endometriosis (family, friends, and even doctors), what advice would you give them to better support their loved ones who are currently battling with this chronic disease?**