UTERINE FIBROIDS: A SILENT CRISIS

Diana Mwikisa

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UTERINE FIBROIDS: A SILENT CRISIS

A Thesis
Presented to the School of Communication
and the
Faculty of Graduate College
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Supervisory Committee:
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Dr. Cynthia Robinson
Black women in the United States are three times more likely to have uterine fibroids compared to any other ethnicity. Existing studies estimate that about 80 to 90 percent of Black women will develop fibroids by age 50. Uterine fibroids are “non-cancerous tumors found in the uterus” (Orellana et al., 2022, p.1184). The exact cause of uterine fibroids is not fully understood, and more research is needed to gain insight into the causes of this debilitating disease (Yu et al., 2018). The purpose of the study is to gain an in-depth understanding of the lived experiences of Black women with uterine fibroids in the United States through the lenses of the culture-centered approach (CCA) and the patient-centered communication model. This study investigated the following research questions: RQ1 How do Black females with uterine fibroids navigate diagnosis and management of their condition? RQ2 How has culture played a role in the way Black females with uterine fibroids manage their condition? RQ3 How do Black females with uterine fibroids characterize communication with their healthcare providers? Therefore, using a qualitative approach, semi-structured interviews were conducted with ten participants across the United States between August 2023 and September 2023. Data were coded and emerging themes identified. The main results revealed that most participants had been offered birth control to manage their uterine fibroid symptoms. Most participants felt that healthcare providers chose their fibroid treatment for them, and
they did not have a say in their treatment. Participants expressed that they needed more
information about access to advanced fibroid treatment and the freedom to make their
own informed decisions about their fibroid treatment.

*Keywords: Uterine fibroids, hysterectomy, myomectomy, Black women,
uterus, patient-centered communication model, culture-centered approach
theory (CCA).*
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2024
DEDICATION

This thesis is dedicated to every Black woman living with uterine fibroids, especially to the women who made this research possible.

You opened your hearts and courageously shared your stories.

I appreciate how real and authentic you were about your experiences.

I am forever grateful!
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Chapter I

Introduction

Over the years, uterine fibroids have become a topic of great importance and concern globally. Uterine fibroids, also known as uterine leiomyomas or myomas, are “non-cancerous tumors found in the uterus” (Orellana et al., 2022, p.1184). There are three major types of uterine fibroids classified by their location: intramural fibroids, which grow within the muscular uterine wall; submucosal fibroids, which grow in the uterine cavity; and subserosal fibroids, which project outside of the uterus (Mayo Clinic, 2022).

Symptoms of uterine fibroids range from heavy and prolonged periods (also referred to as heavy menstrual bleeding (HMB)), bleeding or spotting between periods, passing of clots during periods, anemia, pelvic pain, bloating, diarrhea, and pain during sexual intercourse. Due to unbearable symptom burden caused by uterine fibroids, some women have a hysterectomy (the surgical removal of the uterus) as treatment. Furthermore, uterine fibroids have become one of the leading causes for hysterectomy in America and around the world (Aninye & Laitner, 2021; Drayer & Catherino, 2015; Eltoukhi et al., 2014; Fuldeore & Soliman, 2017; Mutai et al., 2015; Yu et al., 2018).

Uterine fibroid disease is common and can develop in any woman of any race, who has a uterus, during childbearing years. Literature suggests that uterine fibroids tend to shrink after menopause due to the reduction of estrogen in the body. The exact cause of uterine fibroids is still not well understood, and more research is needed to gain insight into the causes of this disease (Yu et al., 2018).
The central research question this study sought to answer is as follows: How do self-identified Black females (aged 19-60) across the United States experience the process of living with uterine fibroids and seeking treatment? This question will be investigated through the lens of the Culture Centered Approach theory (CCA) and the patient-centered communication model.

It is estimated that about 70 percent of white women and 80 to 90 percent of Black women will develop fibroids by age 50 in their lifetime; however, not all women diagnosed with uterine fibroids will experience symptoms associated with fibroids and may not require treatment. Various treatments for fibroids exist, such as hysterectomy, medication for heavy menstrual bleeding, contraceptive pills, uterine artery embolization, myomectomy, and uterine fibroid embolization. However, with the exception of the hysterectomy procedure, these treatments do not prevent fibroids from growing back (Dillard, 2016; Eltoukhi et al., 2014; Mutai et al., 2015). A myomectomy is a surgical procedure which does not remove the entire uterus but “involves an abdominal incision through which fibroids are cut out of the uterus” (Myles, 2013, p.14).

Because Black women develop uterine fibroids two to three times more than white women and fibroid symptoms have been found to be more severe in Black women (Berman et al., 2022; Dillard, 2016; Henshaw et al., 2022), this study focuses on participants who self-identify as Black/African American women. In this study, the term Black woman will be used to refer to anyone who self-identifies as a Black African American person with a uterus (Wright & Dagan, 2020).
Background & Need

Black/ African American women experience greater prevalence of uterine fibroids compared to women of any other ethnic group in the U.S. Literature reveals that Black women in the United States face greater disease burden and low quality of life due to uterine fibroid diagnosis and burden. However, it is unclear why Black women are affected by fibroids to a greater extent compared to women of other ethnicities in the U.S. There is an assumption that African ancestry plays a major role in Black women developing fibroids. Literature reveals that in the United States, Black women in general tend to experience delays in timely diagnosis or treatment for various reasons such as historical medical mistrust, medical errors, culture, gender, and racial issues (Al-Hendy et al., 2017; Charifson et al., 2022; Eltoukhi et al., 2014; Orellana et al., 2022). There is limited research on uterine fibroids among Black women due to limited enrollment of Black participants on studies on uterine fibroids, which is rooted in historical medical issues of mistrust and unethical treatment of African American study participants (Eltoukhi et al., 2014). Literature suggests that there is a need to understand and raise awareness about fibroids, the impact of fibroids, and the magnitude of the problems they cause in the lives of Black women.

Purpose of the Research

Through the lenses of the culture-centered approach (CCA) and the patient-centered communication model, this qualitative study aims to gain an in-depth understanding of the lived experiences of Black women with uterine fibroids in America, including the cultural implications of seeking treatment for fibroids. The focus is on how Black women with uterine fibroids navigate their understanding and meanings of health
communication issues tied to their everyday lived experiences with uterine fibroids and their options for seeking healthy ways of managing their uterine fibroids. This thesis seeks to present Black women’s stories of their lived experiences with fibroids through their voices to raise awareness about the impact and the importance of seeking early diagnosis and treatment of fibroids.
Chapter II

Literature Review

Fibroids affect about 20 to 50 percent of women worldwide and account for about 67% of all hysterectomies performed in middle-aged women. Based on a survey of U.S. women (n= 59,411), that the prevalence of women with uterine fibroids increased with age, especially in women aged 50-54 (Fuldeore & Soliman, 2017).

Uterine fibroids and the associated symptoms affect women’s quality of life (Fuldeore & Soliman, 2017). Fibroids can grow very large, causing a woman’s belly to swell and appear pregnant. Due to their enlargement, fibroids can stretch the size of the uterus, press on other organs adjacent to the uterus, which can result in uncomfortable and painful pelvic pressure, frequent urination, constipation, infertility, difficulty conceiving, miscarriages, and complications during childbirth (Mayo Clinic, 2022). A larger percentage of women with fibroids experience heavier flow of blood during their menstruation compared to women without uterine fibroids. The heavy menstrual bleeding is accompanied by extremely bothersome symptoms, mainly, severe passing of clots, spotting/bleeding between periods, anemia, painful menstrual cramps, severe pelvic pressure, severe constipation/bloating and/or diarrhea (Charifson et al., 2022; Murji et al., 2020). The hysterectomy procedure is the most common intervention for uterine fibroids in the U.S. (Dillard, 2016; Fuldeore & Soliman, 2017).

In addition to severe symptoms, the quality of life of women living with fibroids can be reduced due to the high cost of medical care. In 2017, the annual cost spent on fibroids in the U.S. was about 34 billion dollars (Cardozo et al., 2012; Fuldeore & Soliman, 2017; Igboeli et al., 2019). A study which assessed socioeconomic factors and
life experiences in the context of uterine fibroids found that financial constraints, including income decline, excess transportation expenses, and low educational levels were linked to higher prevalence of uterine fibroids among Black women (Charifson et al., 2022).

Black women face greater disease burden and low quality of life due to uterine fibroid diagnosis and burden. The prevalence of uterine fibroids has been found to be higher in Black women in the United States, compared to white women in the United States. In the United States, Black women with uterine fibroids often go undiagnosed and untreated for lengthy periods of time and are prone to face greater symptom burden and pain compared to white women and women of other ethnicities (Al-Hendy et al., 2017; Eltoukhi et al., 2014; Mutai et al., 2015). It was found that white women and women of other ethnicities were more likely to have private insurance to help cover their healthcare for advanced procedures to treat fibroids while African American women and Hispanic women had Medicare which limited their access to advanced treatments for fibroids. In cases of women with equal access to health care, there were racial differences in the outcome and response to fibroid treatment. Black women’s bodies do not respond the same way to fibroid treatment as the bodies of white women or women of other ethnicities. The causal reasons for these racial differences in response to fibroid treatment is poorly understood (Eltoukhi et al., 2014).

**Black Women, Pain, and Patient-Provider Communication**

In this study, pain is defined as pelvic pain, which refers to any pain in the lower abdomen or pelvis area (Mayo Clinic, 2022). Physical pain in the lower abdomen and
lower back during periods and sexual intercourse, as well as pelvic pain, is one of the key indicators of the presence of fibroids.

Ineffective patient-provider communication poses a potential health risk to Black women if medical providers do not address their healthcare needs or concerns by dismissing their complaints about physical pain and its severity (Thorpe et al., 2022).

For example, a study found that when obstetricians and gynecologists (OB-GYNs) did not ask their Black female patients about sexual pain, it limited the women from disclosing their sexual pain (Thorpe et al., 2022).

Additionally, other studies found and confirmed that unmet clinical needs of uterine fibroid patients negatively affect the management of uterine fibroids, uterine fibroid pain, and the overall quality of life among Black women. An unmet clinical need is a medical requirement that could be a treatment or diagnosis not adequately addressed. For example, lack of consensus on how to report imaging findings for a fibroid abdominal exam using available diagnostic tools. Or how to categorize uterine fibroids not routinely reported in imaging reports, although it is vital to identify the type of fibroids a patient has. Other unmet needs could be reproductive disorders or unspecified pelvic pain, sometimes overlooked before beginning treatment for uterine fibroids. An unmet medical need can also comprise of lack of information or clarity on the possibility of the presence of cancer like uterine sarcoma, which could lead to treatment errors like the spread of cancer during surgical procedures to treat uterine fibroids (Al-Hendy et al., 2017).

In addition to unmet medical needs, it was found that racial biases play a key role in the way healthcare providers and patients perceived the expectations and management
of pain and disease across different ethnic groups, leading to delayed treatment of uterine fibroid disease (Al-Hendy et al., 2017; Aninye & Laitner, 2021).

Black women respond to pain differently compared to other ethnicities and are erroneously perceived to have the ability to bear greater levels of pain compared to other ethnic groups due to society’s narrative of the strong Black woman. A key reason for the undertreatment of pain is nurses underestimating the level of pain experienced by women (Davis, 2015; Hoffmann & Tarzian, 2001; Stalnikowicz et al., 2005; Thorpe et al., 2022; Watson-Singleton, 2017; Winfield, 2022).

Public Stigma

Public stigma also contributes to the disease burden and the cultural impact of uterine fibroids. Public stigma, also referred to as social stigma, refers to the social rejection of a person or group of people who are treated as dishonorable or often ignored. Public stigma involves overshadowing people’s individuality and humanity based on a particular characteristic such as but not limited to illness, physical appearance, race, or sexual orientation (du Pre & Overton, 2021). A study found that Sub-Saharan women with uterine fibroids and vitamin D deficiency may “not seek medical attention in an effort to hide their disease until marriage due to attached stigma” (Igboeli et al., 2019, p. 3). In addition to public stigma, research suggests that some women with fibroids suffer in silence due to the guilt, stigma, and shame associated with fibroid symptoms (Igboeli et al., 2019). Furthermore, health stigma may stem from structural or institutional forces which are closely linked to culture, such as unequal access to medical treatment, discriminatory laws, and unfair tax codes (Metzl & Hansen, 2014).
Cultural Impact of Uterine Fibroids

Cultural influences play a role in the delayed treatment for fibroids. Culture can be defined as “a set of beliefs, rules, and practices that are shared by a group of people” (du Pre & Overton, 2021, p.132). Culture is critical in understanding how communities think about and define health. Outside experts often exclude marginalized communities' contributions to their constructions of health when drafting health policies (Sastry et al., 2021).

Cultural beliefs and perceptions sometimes clash with health literacy efforts regarding fibroids and menstruation in some cultures where it is a taboo to speak about disease and menstruation or undergo certain medical procedures (Igboeli et al., 2019; Orellana et al., 2021). For example, it was found that instead of undergoing a hysterectomy to treat fibroids, some women would rather die and be buried with their uterus because of their cultural beliefs that they need their womb for childbearing in their afterlife (Igboeli et al., 2019, p.5). In a recent study, Orellana et al. (2022) attempted to understand the perceptions of ethnoracial factors in the diagnosis and treatment of uterine fibroids. They found that Black women reported that their work life and homelife were significantly disrupted by severe fibroid symptoms compared to women of other ethnic groups. Further, Black women’s perception on race/ethnicity and negative interpersonal healthcare provider-patient interactions affected their treatment for fibroids. It was concluded that both cultural and familial factors had a significant impact on fibroid diagnosis and management (Orellana et al., 2022). Further, cultural beliefs and their normalization can further prolong and complicate the process of seeking medical treatment for uterine fibroids (Aninye & Laitner, 2021).
Health Literacy

Lack of health literacy is a barrier to uterine fibroid treatment. In a study aimed at assessing awareness and knowledge of uterine fibroid symptoms and presentation among African American women, it was found although most participants knew what fibroids were and that they were common amongst African American women, most had a misconception that fibroids were cancerous and could be diagnosed through a blood test. Further, although the women were knowledgeable of the symptoms of uterine fibroids, they did not have much knowledge about the impact of fibroids. It was also found that participants’ internet usage and education had the highest correlations with fibroid awareness (Ekpo et al., 2014). Additionally, it is important to note that research has found that although “the term ‘fibroid’ is well-known, knowledge as to the causes, prevalence, symptoms, and treatment options are not” (Igboeli et al., 2019, p.2).

Because heavy menstrual bleeding (HMB) is a key indicator of the presence of uterine fibroids, Marsh et al. (2014) sought to understand and assess the knowledge of heavy menstrual bleeding in African American women of reproductive and postmenopausal ages (40-44 years) in the Midwestern region of U.S.A. It was found that more than 80 percent of the participants surveyed demonstrated adequate knowledge about the term fibroids in general; however, close to 90 percent incorrectly answered most of the specific questions about fibroids such as causes, symptoms, and treatment. The study also found that there was a gap in the knowledge of heavy menstrual bleeding and that the proportion of participants with heavy menstrual bleeding was higher than the nationwide prevalence of HMB (Marsh et al., 2014).
In another study on women’s experiences in seeking and obtaining knowledge about uterine fibroids, it was found that out of a total of 60 women, more than 70 percent were not satisfied with either the clarity, quality, or quantity of available information on fibroids. It was revealed that participants were of the view that if they had more knowledge about fibroids, they would have made different decisions on the choice of treatment sought. It was reported that participants felt that there was significant need for fibroid patients to have more knowledge about fibroids, to engage in self-education, and to have access to unbiased counselors and trustworthy physicians. A significant finding was that increasing knowledge about fibroids helped patients face diagnosis and improved their decisions on fibroid treatment options without regret (Ghant, 2015). More research on preventing fibroid development and education and increased awareness on the nature and symptoms of uterine fibroids could improve quality of life, remove negative social stigma, and even decrease mortality rates of women who have been diagnosed with advanced uterine fibroids and seek treatment” (Igboeli et al., 2019).

The lack of information about uterine fibroids in popular sources of health information in the United States is a major oversight. Despite the need for attention on uterine fibroids, this disease is often neglected by some health organizations in their agenda for interventions for women’s reproductive health research (Dillard, 2016). The lack of information about uterine fibroids affects health literacy about uterine fibroids among Black women.

Recent Efforts to Address Uterine Fibroid Challenges

It was reported that due to the high risk of reoccurring fibroids, in the past, after fibroid patients had a myomectomy, health insurance could deny fibroid treatment based
on recurring fibroids. However, a study (Eltoukhi et al., 2014) reported the benefits of new legislation on healthcare, which makes provision for more healthcare services for women’s health by all healthcare plans, through the Patient Protection and Affordable Care Act (ACA). Some of the key reported benefits of the ACA which improve availability of healthcare for African American women, include women’s direct access to obstetricians and gynecologists without referral; women’s access to contraceptive medications without copayments; and the elimination of insurance companies’ ability to deny coverage based on the reoccurring nature of fibroids. Most importantly, it was reported that research on fibroids was assigned as a high-priority area for target research by the Patient-Centered Outcomes Research Institute (Eltoukhi et al., 2014).

Recently, in 2015, efforts were being made to push a bill on funding for uterine fibroids disease and in 2020, Vice President Kamala Harris submitted a bill on uterine fibroids to The U.S. House of Representatives for the provision of funding for uterine fibroids research and education (Aninye & Laitner, 2021; Drayer & Catherino, 2015).

**Theoretical Framework**

The theoretical framework for this study is the collaboration of the culture-centered approach (CCA) and the patient-centered communication model. Stubbe (2020) proposed that both patient-centered care and cultural competence are vital for efforts to improve the overall quality of health care. In another study, Koenig (2014) revealed a relationship between communication and patient-centered care through broadening cultural understanding regarding health, although there isn't much research that examines this relationship. Therefore, the patient-centered communication model is a suitable framework for this thesis since clear communication and a trustworthy relationship
between a healthcare provider (such as a physician/nurse/counselor) and the patient are critical for fibroid diagnosis and treatment.

The patient-centered communication model has been applied in various studies. Firstly, a review of studies on patient-centered communication in the context of chronic pain found that positive interactions between clinicians and patients are crucial elements of patient-centered care, and that shared medical decision making between patients and clinicians consists of collaborative efforts to identify treatment options which align with the patient’s values and yields greater patient satisfaction (Basnyat, 2022).

Research has also revealed that contributors to “successful patient-centered communication include clinicians engaging with the patient in a nonjudgmental and non-stigmatizing way and practicing supportive listening; this in turn encourages patients to self-disclose and be open and forthcoming about their pain experiences” (Basnyat et al., 2022, p. 3).

Secondly, a study exploring provider-patient dialogue in the context of uterine fibroids, found that little research was focused on African American women’s experiences with uterine fibroid disease burden, and there has been little investigation on the impact of uterine fibroid disease burden on the quality of life of Black women (Dillard, 2016). Therefore, this thesis seeks to fill that gap by focusing on Black women’s experiences with fibroid disease burden.

While the patient-centered communication model is suitable for this thesis, the CCA is also suitable because its focus is on “understanding the meanings of health issues from a localized cultural lens” (Dillard, 2016, p.123). It is noteworthy to mention that
foundational knowledge and development of the culture-centered approach is attributed to Dutta (2007).

The CCA “emphasizes attempts at changing social structures surrounding health through dialogues with cultural members that create spaces for marginalized cultural voices” (Dutta, 2007, p.305). The culture-centered approach puts culture at the core of health communication practices.

In the past, cultural differences were conceptualized as hindrances to effective health communication efforts. Over the years, health communicators have joined efforts to address these barriers. In the culture-centered approach, culture is placed at the center of theorizing and application development and is not as an afterthought. Over the years, CCA has been developing and is described as dynamic and context based. The culture-centered approach draws its theoretical applications from critical theory, cultural studies, postcolonial theory, and subaltern studies. Key aspects of CCA include ideology, hegemony, and control, while serving marginalized groups (Dutta, 2008).

The culture-centered approach plays a significant role in redeeming cultural voices by actively engaging with these voices for dialogue and addressing the erasure of cultural voices in dominant discourses. CCA places emphasis on the need to develop communication frameworks grounded in the culture and context of those affected. The argument is that health is a cultural construct and must be rooted in cultural meanings and tied to values and that human beliefs and practices related to health are a central aspect of culture. Illness and how patients respond to it are attributed to sociocultural factors. There is an increase in the awareness of global cultural differences with more attention on culture in health communication (Dutta, 2008). Other scholars agreed that CCA is useful
for understanding health meanings and experiences through cultural voices in marginalized communities (Sastry et al., 2021).

While the CCA theory has been used by several scholars, this thesis investigates the works of scholars whose studies using CCA stood out. Firstly, Ephraim (2013) used the CCA theory in a study about African youths and the dangers of social networking and argued that the culture-centered approach incorporates the principle of information ethics and respect for the dignity and rights of individuals.

Secondly, Dutta (2014), applied the use of CCA in a study about a culture-centered approach to listening by focusing on voices of social change, to outline key principles of listening to address global inequities produced by neoliberal globalization. It was argued that exploitation is rooted in the denial of communicative capacity. Dutta (2014) stated that “listening offers an opening for interrogating the inequities in the global landscape of power distribution, by attending to unvoiced assumptions and principles” (Dutta, 2014, p. 68).

Thirdly, a study about decolonizing communication for social change applied the culture-centered approach as a theoretical approach to understanding how dialogues with marginalized communities resist dominant conceptual categories for development. The study showed that “the CCA picks up the cultural turn in development communication voiced by scholars such as Servaes (1999) to explore the possibilities of fostering multiple pathways of development rooted in culture” (Dutta, 2015, p. 131). Culture was described as a reflection of values, communication characteristics, a reflection of local beliefs, attitudes, and practices.
Lastly, in a more recent study, Dutta (2018) used the CCA theory to investigate how the culture-centered approach was applied in addressing health disparities and communication infrastructures for subaltern voices, with the goal of conceptualizing a framework for understanding how culture is theorized and applied in health communication. It was concluded that amid growing global health inequalities, CCA offers an anchor in addressing health inequalities. CCA allows an opportunity for the creation of communicative spaces and the participation of communities. Emphasis was placed on co-creation through local collaboration and communicative practices to build knowledge. It was highlighted that “CCA opens up the definition, meaning, and design of participation to community voices, with the goal of building theories from below” (Dutta, 2018, p. 240). Based on these findings, this 2018 study on the application of CCA was found to be most useful to inform this thesis.

Therefore, this study used both the patient-centered communication model and the culture-centered approach as a lens to explore the topic of Black women’s journey with uterine fibroids. This approach could be very helpful in addressing the accessibility of Black women’s voices who have been diagnosed with uterine fibroids in meaningful ways that provide solutions from the community; the CCA approach does not generalize cultural beliefs and practices but seeks to capture emerging cultural messages and everyday meanings from participants, through the co-construction of data by the research team and community members (Dutta, 2018).

It is also useful to examine studies on how CCA has been applied in the context of patient-provider communication. For example, a key study by Ross and Castle Bell (2017) advocates that the culture-centered approach improves healthy trans-patient-
provider communication and will be helpful in this thesis to demonstrate how CCA has been applied in a patient-provider communication context. The culture-centered approach was used as a tool to extract the voices of trans individuals as a pathway to legitimate spaces for marginalized group members to share their personal narratives within the context of their lived experiences. The argument was that trans individual health narratives are fundamental to understanding how to improve trans-patient-provider communication within a diverse cultural context (Ross & Castle Bell, 2017). The study explored the lived experiences of trans individuals with health practitioners. The study aimed to improve the overall trans-patient-provider relationship through health communication efforts to understand the trans population, meet trans patients’ needs, and provide recommendations to health providers in their communication with trans patients.

In the same study, two major emerging themes were 1) advice for practitioners to modify their behavior when communicating with trans patients, include preferred pronouns, and maintain professionalism by only asking health-related questions and 2) office visit procedures that are trans-inclusive by adjusting information on hospital intake forms and online content to be more trans-friendly or include trans-focused expertise. Data showed that trans individuals’ lived experiences in the healthcare context informed the types of care they had hoped to receive from health practitioners. Data from the study revealed that health practitioners need to make specific changes like modifying communication behavior by using a trans-friendly or inclusive approach that does not discriminate, using offensive or inappropriate comments about trans patients and their lifestyle choices, and avoiding mentioning a patient’s gender identity unless it is relevant for treatment purposes when communicating with trans patients and when caring for them.
(Ross & Castle Bell, 2017). It was found that participants who self-identified as trans agreed that changes in practitioners’ behavior during office visits, modifications to office logistics, and e-health particulars would contribute to a healthy communication environment (Ross & Castle Bell, 2017).

Another study that informs this thesis is one by Koenig et al. (2014), which also involves an application of CCA and patient-centered communication. The main objective of the study was to educate healthcare providers about culture-centered communication and its role in the readjustment of veterans returning to civilian life. It was concluded that to provide patient-centered care to returning veterans, healthcare providers must be attuned to the challenges of the readjustment experience, including culture shock. “Patient-centered care is premised on the ability of patients to be at the center of care, which requires that providers understand differences between military and civilian cultures, the readjustment process, and veterans’ cultural capacity for resilience” (Koenig et al., 2014, p. 419).

Based on literature reviewed for this study, it is evident that there is a need to investigate Black women’s experiences of living with uterine fibroids, given that they are disproportionately impacted by the disease compared to women of other ethnicities: They experience more pain as well as delayed access to treatment have more risk factors for physical pain compared to women of other ethnic groups in the United States. Literature demonstrated that the patient-centered communication approach has gained popularity over the past two decades and is deemed crucial for the delivery of high-quality healthcare by health providers. It was also evident that there is an extensive body of
research that advocates for the patient-centered approach to medical care (Mead & Bower, 2000).

**Purpose Statement & Research Questions**

By drawing on the culture-centered approach and the patient-centered communication approach, my study addressed a significant gap about how Black women experience living with uterine fibroids. This study contributes to the limited body of qualitative research on uterine fibroids in the United States (Dykstra et al., 2023). This study is significant because it seeks to understand how culture plays a role in how Black women’s lived experiences with fibroids, how they address stigma associated with fibroids, and how they communicate with their healthcare providers. Due to the need to raise awareness on fibroid education, this thesis also aims to gain insight on the dialogue and any misinformation that might exist on fibroids among Black women and how this impacts their lived experiences with fibroids.

The following are the study’s specific research questions:

**RQ1:** How do Black women with uterine fibroids face the diagnosis and management of fibroids and what influence do fibroids have on their quality of life?

**RQ2:** How has culture played a role in the way Black women with uterine fibroids seek information about and treatment options for fibroids?

**RQ3:** How do Black women with uterine fibroids characterize communication with their healthcare providers?
Chapter III
Methodology

My inquiry explored the impact of uterine fibroids on the quality of life of Black women by investigating their experiences of seeking treatment through the lenses of the culture-centered and patient-centered communication models. Creswell and Poth (2018) affirmed that qualitative research allows the researcher to conduct research in a natural setting, relies on the researcher as a key instrument in data collection, allows for the use of multiple methods, involves complex reasoning between inductive and deductive reasoning, focuses on participants’ multiple perspectives while providing meaning, involves emergent and evolving themes and designs, and provides detailed understanding of complex issues.

The culture-centered approach and the patient-centered communication models guided how questions were formulated for the semi-structured interview guide for the semi-structured interviews in this study. Please see Appendix for interview questions. Some questions came from interview conversations, but most questions were determined by the researcher. Semi-structured interviews were conducted to investigate meanings and experiences related to uterine fibroids (Dillard, 2016).

My interview protocol comprised of a detailed script for the introduction to my study through an introductory statement, a reminder to start recording on Zoom and enable audio transcriptions, a reminder to check that settings on Zoom were set to record to the cloud and a reminder to assign unique identifier codes to maintain the privacy and confidentiality of my participants. My interview protocol included a section for main questions and estimated time allocations to guide the interview duration. I ended off by including a section for the concluding statement which had a section to thank participants.
for responding to the interview questions and a reminder that their identities would remain confidential.

The interview protocol elements for this study included:

1. Introduction of the study
2. Explanation of the interview process
3. Explanation of participants rights and signing of consent forms and verbal consent
4. Ethical considerations, privacy, and confidentiality expectations
5. Survey questions inclusive of demographic and screening questions
6. Main interview questions with probing and follow-up questions
7. Conclusion remarks, request for member checking and follow-up questions

Participants for this study were self-identified Black African American women of reproductive age (19 - 60 years), who had lived experience of pelvic/reproductive pain, had been diagnosed with uterine fibroids, and live in the United States. After Institutional Review Board (IRB) approval was obtained, eligible participants were recruited. I recruited participants through the theoretical sampling method (Creswell & Poth, 2018). I sent out a digital flyer and a written introduction letter about my study and sent it to the Fibroid Foundation, which is a non-profit global community of fibroids patients, The We Can Wear White organization, and Fibroid Queen, a fibroid advocate and influencer on social media. Unfortunately, they were unable to help me recruit participants or post my flyer on their social media sites. I then posted a digital recruitment flyer on social media on Facebook and Instagram, which are popular social media platforms. Two weeks after posting my recruitment flyer, I still did not have a response from any participant.
Therefore, I changed the wording on my flyer from seeking participants from the Midwest, to seeking participants from the United States. I also changed the wording from seeking self-identified African American women, to self-identified Black or African American women, and I started receiving feedback from prospective participants who met the inclusion criteria. To ensure that these individuals met the inclusion criteria, I asked them the following screening questions: Have you been diagnosed with uterine fibroids?" “Do you self-identify as Black?” “Are you between 19 and 60 years old? I also used snowball sampling to recruit participants by asking each participant at the end of the interview to recommend anyone they knew who had been diagnosed with uterine fibroids and met the recruitment criteria (Creswell & Poth, 2018). Participants were recruited through theoretical sampling. Theoretical sampling allows the researcher to go back and forth between sampling, data collection and analysis until data saturation is reached and the researcher can no longer collect new information from the interviews (Charmaz, 2014; Creswell & Poth, 2018).

For each individual who met the study’s inclusion criteria, I sent out a study information and consent email, and read out the consent form for participants before each interview. I conducted face-to-face interviews as well as Zoom interviews for participants who were far to reach. Participants were informed that their participation was voluntary, and they could withdraw from the study at any time. Oral consent was obtained from each participant after they had gone over the introductory information about my study. A total of 11 female participants who self-identified as Black or African American and had received a fibroid diagnosis were interviewed for this research. Ten were included in the summary of findings. The first interviewee was a close acquaintance who met the
participant inclusion criterion; however, her interview was conducted as a pilot to test, modify, and strengthen the interview protocol. Face-to-face interviews, both in-person and Zoom, were conducted with 10 women, and each interview lasted about 30–60 minutes long. The reason Zoom interviews were used alongside face-to-face interviews was because I wanted to interview Black women living in the United States and because of distance, travel costs and the duration for this study, it was appropriate to conduct Zoom interviews which allow for real-time interviews virtually and allows for audio transcript recording, making it easier to capture data and analyze it. Transcribed audio recordings were given identifier codes to prevent revealing participants’ true identities.

Further, memoing was done. Memoing or memo-writing is a key qualitative technique which involves the researcher writing down insights, thoughts, and interpretations of data throughout the research process (Creswell & Poth, 2018). The memoing process added details of my insights and interpretations to participant responses and nonverbal communication throughout the research process for this thesis.

Data Analysis

Data were analyzed using open, axial, and selective coding (Creswell & Poth, 2018; Dillard, 2016). Another author Myles (2013) used qualitative interviews and grounded theory methodology in their study, which examined how Black women frame the condition of having uterine fibroids. Audio recordings from the Zoom interviews and memo-written notes were transcribed and then initial coding was used to categorize emerging themes from the data. The responses from my ten participants were categorized according to the research questions used in the interview guide. These will be explained in the discussion section using tables. The interview guide reflecting the questions which
participants answered and were analyzed is available in the appendices section at the end of this paper.

After conducting interviews, I thoroughly read through each transcript and systematically organized and prepared the data for analysis. Each transcript was formatted as a Word document, which allowed for highlighting and interpreting. The first stage of the data analysis began with data immersion. This process entails reading through the data several times over for the researcher to be immersed in the data (Creswell & Poth, 2018). The process of data immersion supported the first step of the coding process which was my initial/open coding. While working through my transcripts, I coded every sentence of my data line-by-line, and then I broke down my qualitative data into excerpts and created codes to label each participant’s excerpt. My initial codes ranged from descriptive codes to conceptual codes. This coding was quick and spontaneous and required little interpretation. The reason initial coding was used was because “when grounded theorists conduct initial coding, we remain open to exploring whatever theoretical possibilities we can discern in the data” (Charmaz 2014, p.116). For data analysis purposes, data from each participant was compared with data from the literature review as well as interview data from other participants. “Through comparing data with data, we learn what our research participants view as problematic and begin to treat it analytically” (Charmaz 2014, p. 116). While analyzing the data, I asked myself key questions about the data. These questions were informed by Charmaz (2014) who cautioned that initial coding should stick closely to the data and affirmed that “during initial coding, we ask what is this data a study of? what do the data suggest? from whose point of view? And what theoretical category does this specific datum indicate?”
The emerging themes were color coded in Word when the different emerging themes were being compared and categorized according to the research questions. I examined the data and assigned words and phrases that captured their essence (Creswell & Poth, 2018).

After initial coding, I further analyzed my data by delving deeper into the data using axial coding. This is where I identified larger themes, which were relevant to my research questions and drew connections between my codes. Then, using selective coding, I coded anything that was interesting or stood out to me in the data. Guided by my research questions, I grouped my codes into emerging themes and further collapsed several similar emerging themes into single themes. I ended up with ten key themes identified in the analysis: using birth control and surgical techniques; managing symptoms of excessive bleeding, pain (physical and emotional) and fatigue; incorporating fibroid management into prenatal care; adopting a healthier lifestyle; searching for accurate medical information; conservative cultural values regarding reproductive health; spirituality in seeking treatment; adopting high pain tolerance and delaying seeking treatment; doctors dismissing symptoms/not listening to patients and their needs, and racial bias during patient-provider consultations. These key themes were identified according to my research questions. After the coding phase was complete, a codebook was created on Excel using the words or phrases that represent the codes found in the data. The code book on Excel helped me clearly organize and differentiate between my codes and themes, and easily access my audio and transcripts whenever I needed to refer to them during the analysis. The codebook acts as “a data display that lists key codes, definitions, and examples” that are useful during analysis (Tracy, 2013, p. 191). In
the second phase of coding (axial coding), patterns, and cause-and-effect relationships began to emerge. Codes were developed in combination with the analysis.

During data collection and analysis, a separate codebook was kept where I took notes and wrote down my thoughts and ideas as they emerged during the analysis. Although the codebook was not a formal method of data analysis, it was extremely useful in recording areas of interest, concern, and curiosity. These notes are commonly known as analytic memos; they “help researchers figure out the fundamental stories in the data and serve as a key intermediary step between coding and writing a draft of the analysis” (Tracy, 2013, p. 196). My codebook contained code definitions and examples from the raw data that illustrated codes, relationships between codes, and what they meant in terms of the broader phenomenon under investigation. I also reflected on my researcher positioning during the data analysis, considering that I had been diagnosed with uterine fibroids while conducting this study. I ensured that I kept my own experiences of living with fibroids out of my study, and only reported my participants’ experiences.

I included member checking to go over the participants’ responses and codes to confirm accuracy of data captured. Seven out of ten participants responded to codes for member checking. Member checking is a process where transcripts and preliminary codes are shared with participants of a study to clarify if the researchers’ interpretations of participant responses are accurately recorded (Dillard, 2016). For example, some participants preferred to have their direct quotations included and not edited by the researcher. The member checking process enabled me to reduce instances of disagreements in the representation of final themes and participants were able to support final themes as a representation of their true meanings constructed during the interview.
(Dillard, 2016). Lastly, I included extra room in the interview protocol guide for me to do my memo-writing during interviews.

**Ethical Considerations**

It was crucial to maintain ethical practices throughout this study. I ensured that this study was ethically sound by maintaining honesty, by seeking IRB approval, and by adhering to the ethical guidelines of the IRB, especially by not harming any participant. In the data collection and analysis processes, participants were identified by pseudonyms to safeguard their anonymity. Oral consent was sought from participants before the in-person and Zoom interview, the purpose of the study was explained to them, and they were informed that with their permission, they would be contacted for member checking. Furthermore, academic integrity and honesty were applied in all stages of the study, and participants were made aware that their participation was voluntary, they could leave the interview any time, and their real identities were concealed. Data from the audio transcripts of their interviews were stored away in a secure encrypted manner. Member checking was used to seek participant feedback on findings. Furthermore, participants were reminded several times during data collection that their participation was voluntary. For example, participants were generally emotional talking about their diagnosis and experience of living with uterine fibroids. One participant said it was like reliving the experience and we had to pause a few times during the interview. The researcher reminded the participant that she could stop the interview or skip the question if it was uncomfortable or difficult to talk about her experience with fibroids, but the participant chose to continue with the interview.
Chapter IV
Results

Through the lens of the culture-centered approach (CCA) and the patient-centered communication model, this study aimed to gain an in-depth understanding of the lived experiences of Black women with uterine fibroids in the United States.

The results speak to the study’s three main research questions:

RQ1 How do Black females with uterine fibroids navigate diagnosis and management of their condition?

RQ2 How has culture played a role in the way Black females with uterine fibroids manage their condition? (e.g., seeking information about treatment options).

RQ3 How do Black females with uterine fibroids characterize communication with their health care providers?

Themes

Guided by the research questions, findings have been organized around the ten key themes identified in the analysis: using birth control and surgical techniques; managing symptoms of excessive bleeding, pain (physical and emotional) and fatigue; incorporating fibroid management into prenatal care; adopting a healthier lifestyle; searching for accurate medical information; conservative cultural values regarding reproductive health; spirituality in seeking treatment; adopting high pain tolerance and delaying seeking treatment; doctors dismissing symptoms/not listening to patients and their needs, and racial bias during patient-provider consultations.
Participant Descriptions

To provide context for each participant’s unique backgrounds, participant’s basic demographic information has been provided in this section, see Table 4.1 for participant demographics. Additionally, Table 4.2 summarizes the research questions, themes, and provides exemplar quotes. A total of 11 female participants who self-identified as Black or African American and had received a fibroid diagnosis were interviewed for this research. Ten were included in the summary of findings. The first interviewee was a close acquaintance who met the participant inclusion criterion; however, her interview was conducted as a pilot to test, modify, and strengthen the interview protocol. She provided feedback regarding the clarity of the research questions. For example, she advised that I define cultural identity for participants by stating what I mean by cultural identity when asking respondents how they would describe their cultural identity.

Each participant voiced a unique experience of living with uterine fibroids. Of the ten participants, three self-identified as Black African American females. The remaining seven identified as Black females. Each interview lasted 30-60 minutes. Each participant is referred to by a pseudonym; some participants chose a pseudonym for themselves; for others, the researcher provided a pseudonym.

French. French is 42 years old and self-identifies as a Black female. She is originally from Botswana but became a U.S. citizen through marriage. She disclosed that she has no children and will never be able to have any because after she received her fibroid diagnosis in 2010, and she opted to have a hysterectomy in 2019 to permanently treat her fibroids. French tried using birth control to regulate her painful periods and
heavy menstrual bleeding before her hysterectomy. French lives outside the Midwest but did not disclose the state she lives in.

**QR.** QR is 38 years old and self-identifies as a Black female. She has roots originating from Namibia but relocated to the U.S. 19 years ago. QR is married and has four children, including a set of twins. QR has not had any surgical procedures to treat her fibroid. She has only considered adopting a healthier lifestyle to try and shrink her 5-cm fibroid and prevent it from growing. QR disclosed that she discovered she had a 5-cm fibroid growing in her womb while she was pregnant with her second child in 2016. At the time of her interview, QR was living in California.

**Penny.** Penny is 34 years old and self-identifies as a Black female. Her parents originated from Malawi, but she was raised in the U.S. since 2005. She received her fibroid diagnosis in 2021. Penny has no children but disclosed that she desires to have children someday. Therefore, she opted for a robotic myomectomy to remove her fibroids and preserve her uterus and fertility. At the time of the interview, Penny was living in Omaha, Nebraska.

**Tia.** Tia is 39 years old and self-identifies as a Black female. She was born in Jamaica but relocated to the U.S. many years ago. She did not specify what year she relocated to the U.S. Tia received her fibroid diagnosis in 2018. She is not married and has no children. She refused to undergo a hysterectomy for her large fibroids. She has tried natural remedies such as herbal teas to manage her condition. She disclosed that she is a graduate student. At the time of her interview, Tia was living in South Carolina.

**Alice.** Alice is 37 years old and self-identifies as a Black African American female. Alice did not mention that she has any roots in Africa. She was born and raised in
the United States as an African American. She said she received her fibroid diagnosis sometime around 2020. Alice used birth-control, which negatively affected her menstrual cycle causing heavy menstrual bleeding. She believes the use of hormonal birth-control contributed to her development of uterine fibroids. She has not undergone any surgical treatment for her condition. She has opted to adopt a healthier lifestyle and exercise to manage her condition. At the time of her interview, Alice was living in Georgia.

**Lisa.** Lisa is 34 years old and self-identifies as a Black female. Lisa is originally from Zimbabwe but relocated to the U.S. just over two years ago. After her fibroid diagnosis around May 2023, Lisa has not opted for any treatment for her fibroids. She has adopted a healthier lifestyle and incorporated exercise to manage her condition. She relies on iron supplements to replenish her iron deficiency caused by heavy menstrual bleeding due to her fibroids. Lisa disclosed that she is a graduate student, is not married and has not yet had children. At the time of her interview, Lisa was living in Atlanta.

**Liz.** Liz is 46 years old and self-identifies as a Black female. She was born and raised in Tanzania but relocated to the U.S. in 1996. She was diagnosed with fibroids in 2006. She is married and has two children. Liz disclosed that she had four miscarriages due to fibroid-related complications during her pregnancies. Liz has undergone several iron infusions to help her manage her severe anemia caused by fibroids. She underwent a myomectomy to remove her fibroids which have regrown. At the time of her interview, Liz was living in Denver, Colorado.

**Tashyeni.** Tashyeni is 60 years old and self-identifies as a Black African American female. Tashyeni was born and raised in the U.S. by African American parents. She mentioned she has children but did not specify how many. She has not had any
surgical or non-surgical treatments for her fibroids because they were not symptomatic. She disclosed that she was diagnosed with fibroids ten years ago but only recently started experiencing heavy menstrual bleeding and was considering going for a “Dilatation and Curettage, D&C,” a procedure to manage her heavy bleeding. At the time of her interview, Tashyeni was living in Omaha, Nebraska.

**Prisca.** Prisca is 42 years old and self-identifies as a Black female. She was raised by Zambian parents but lives in the U.S. She was diagnosed with fibroids a few years ago but did not specify the exact year. She disclosed that she is married to a white American man which makes it easier for her to communicate with health care providers of any race. She has two children. Prisca disclosed that it was difficult to fall pregnant due to fibroids and that she underwent a myomectomy to manage her fibroids. At the time of her interview, Prisca was living in Atlanta, Georgia.

**Kelly.** Kelly is 34 years old and self-identifies as a Black African American. She said her cultural roots are in Nigeria and the United States. She was diagnosed with fibroids in 2015. Kelly is not married and has not yet had children but desires to have children in the future. She disclosed that she is considering freezing her eggs while she manages her fibroid condition. Kelly has had several blood transfusions due to severe low iron in her body, which is caused by heavy bleeding from fibroids. She believes in self-advocacy during hospital visits to seek quality treatment for her condition. At the time of the interview, Kelly was living in Houston, Texas.
Table 4.1

Participants Demographics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Race/Ethnicity</th>
<th>Year of Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>French</td>
<td>42</td>
<td>Black</td>
<td>2010</td>
</tr>
<tr>
<td>QR</td>
<td>38</td>
<td>Black</td>
<td>2016</td>
</tr>
<tr>
<td>Penny</td>
<td>34</td>
<td>Black</td>
<td>2021</td>
</tr>
<tr>
<td>Tia</td>
<td>39</td>
<td>Black</td>
<td>2018</td>
</tr>
<tr>
<td>Alice</td>
<td>37</td>
<td>Black/African American</td>
<td>2020</td>
</tr>
<tr>
<td>Lisa</td>
<td>34</td>
<td>Black</td>
<td>2023</td>
</tr>
<tr>
<td>Liz</td>
<td>46</td>
<td>Black</td>
<td>2006</td>
</tr>
<tr>
<td>Tashyeni</td>
<td>60</td>
<td>Black/African American</td>
<td>2013</td>
</tr>
<tr>
<td>Prisca</td>
<td>42</td>
<td>Black</td>
<td>Unspecified</td>
</tr>
<tr>
<td>Kelly</td>
<td>34</td>
<td>Black</td>
<td>2015</td>
</tr>
</tbody>
</table>

Note. Prisca did not specify the year of her diagnosis. Eight out of ten participants self-identified as Black/African, while two out of ten participants self-identified as Black/African American.
### Table 4.2

**Research Questions, Themes, and Exemplars**

**RQ1: How do Black females with Uterine fibroids navigate diagnosis and management of their condition?**

<table>
<thead>
<tr>
<th>Using birth control and surgical techniques</th>
<th>“I don't care what anybody says, they [doctors] know what causes uterine fibroids to grow. They know it is somehow linked to hormones. But they are pushing birth control on the youth.” Alice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing symptoms of excessive bleeding, pain (physical and emotional) and fatigue</td>
<td>Some participants reported that they had tried to maintain a facade socially, despite their pain. One said, “It means my health [is] taken from me by these little monsters that are just sucking away my blood and I just want them out of my body. Uterine fibroids are ‘monster’ sucking benign tumors that obstruct your life and create a life of distress. I just think they are little monster sucking demons.” Tia</td>
</tr>
<tr>
<td>Incorporating fibroid management into prenatal care</td>
<td>The fibroids had grown and were taking up space in her womb. QR said: “The fibroids were encroaching on the space for the babies to grow and the doctors are always very hesitant to do any surgery to remove them unless they really pose some life-threatening danger.”</td>
</tr>
<tr>
<td>Adopting a healthier lifestyle</td>
<td>“At this point I'm seeking ways to deal with the fibroids naturally using a non-invasive method. I am doing research on how to shrink my fibroids naturally, whether it's through changing my diet or changing certain habits.” Lisa</td>
</tr>
<tr>
<td>Searching for accurate medical information</td>
<td>“I used to go to Google and Web Med and diagnose myself. But then you find something’s completely different. So, I don't believe that people should Google, and misdiagnose themselves.” Liz</td>
</tr>
</tbody>
</table>
RQ2: How has culture played a role in the way Black females with uterine fibroids manage their condition?

Conservative cultural values regarding reproductive health

[Culturally] discussions about menstruation and reproductive issues were not encouraged. She said: “We didn't talk about things like that and maybe that's why I didn't know so much about the existence of fibroids. It's just not stuff that we talked about that much.” French

Spirituality in seeking treatment

“There’s so much information that I wanted, and I love my God. Trying to explore that option [hysterectomy] is like going against God and your values. We never got enough information about fibroids or periods because people were not speaking [about them].” Liz

Adopting high pain tolerance and delaying seeking treatment

“My mother always believed that we [must] go through [pain]. So, we go through it and deal with it. That's how I was raised. So, my pain tolerance is very high, because I'm sure it's because of my mother, because of the way she just kind of programmed us. There are things in life you [must] deal with, as a female deal with it.” Tashyeni

RQ3: How do Black females with uterine fibroids characterize communication with their health care providers?

Doctors dismissing symptoms/not listening to patients and their needs

“[I] was going to a doctor with hopes that they would assist in diagnosing and finding out what was going on, but they sort of dismissed some of the symptoms I had.” Lisa

Racial bias during patient-provider consultations

“America has made me become more conscious about race. I don't understand why I [must] care about it. I keep asking this question, what does the color of my skin, or [my] culture have to do with how [doctors] [medically] treat me.” Tia
RQ1: How do Black females with uterine fibroids navigate diagnosis and management of their condition?

Although participants’ experiences varied from the onset of symptoms to the diagnosis of uterine fibroids and the pathway to manage their condition, all their lived experiences were centered around five emergent themes: searching for accurate medical information; using birth control and surgical techniques; managing symptoms of excessive bleeding and pain (physical and emotional); incorporating fibroid management into prenatal care; and adopting a healthier lifestyle.

Using Birth Control and Surgical Techniques

Four out of ten participants disclosed that they had used birth control to regulate their hormones and heavy menstrual bleeding caused by fibroids. Participants who had used birth control mentioned that their doctor had recommended birth control for managing heavy bleeding and pain, but it did not help them.

Generally, participants were against the use of birth control to regulate heavy bleeding and felt their situation was not improving. One participant, Alice, reported that she had a negative experience with an intrauterine device (IUD) birth control, which she believes is linked to her fibroid growth. She noticed that her periods got heavier while on the IUD birth control and decided to remove it. Alice said: “I don't care what anybody says, [the doctors] know what causes uterine fibroids to grow. They know it is somehow linked to hormones. But they are pushing birth control on the youth.”

Another participant, Kelly, shared that she was offered birth control as a solution for heavy bleeding but did not want to take it because she did not want extra hormones in her body. After taking birth control, she experienced abdominal pain, and the birth control
was ineffective. Another participant, Liz, mentioned that she stopped using birth control because she was gaining weight. On the contrary, other participants never accepted their doctor’s recommendation to use birth control. For example, Tia explained that she refused to use birth control pills because she does not believe in pills that address only the symptoms of the issue and not the root cause. Penny and Tashyeni shared similar sentiments and made it very clear that they were against the use of birth control to regulate heavy menstrual bleeding.

Regarding surgical management of fibroids, some participants reported that they faced their diagnosis and management of uterine fibroids by going for surgery. One participant, Kelly, reported that after a series of tests, her doctor discovered she had endometriosis with her fibroids. She recounted her fibroid surgery, describing that from her three projected fibroids, about 11 or 12 fibroids were removed, ranging in multiple sizes, with the largest size being 10-cm, which is the average size of a grapefruit. The second fibroid was the size of a plum causing her uterus to be inverted. She further shared that after her surgery to remove her fibroids, she has had to regularly monitor her fibroid growth and has experienced re-occurring fibroids. Kelly likened the re-occurring nature of fibroids after surgery, to the growth of a tree. She said, “[Fibroids are] like a tree, you're cutting the branches, [but] branches can grow back. [The root cause is not being addressed].”

Another participant, Penny, managed her fibroids by going for robotic surgery, explaining that when she went for a check-up a year after diagnosis, her fibroid had grown and was almost the size of her uterus. She ended up having a robotic myomectomy
to remove the fibroid because nothing was helping her condition despite everything she had tried.

**Managing symptoms of excessive bleeding, pain (physical and emotional) and fatigue**

For other participants, their diagnosis experience included doubling up on menstrual products. Two participants mentioned that they had to use up more pads than usual due to heavy menstrual bleeding. Alice mentioned how she doubled up pads while Kelly mentioned that almost every hour in a day, she changed very large pads designed for heavy menstrual flow and extra night protection, because of her heavy menstrual bleeding with blood clots larger than a quarter. Another participant, Penny, shared the excessive need to change pads. She explained that she went through 36 pads in one week because of heavy menstrual bleeding, and this excessive need to change pads posed a financial burden. Another participant, Liz, expressed fear of messing up her bedding while bleeding heavily. She said, “You feel like you sleep like a high school kid because you're scared to make a mess on your bed because you're bleeding a lot.” Liz further described the severe symptoms she experienced due to fibroids. She said: “I would throw up and since I was young, it’s just something that has happened and I thought, it's something normal. But right now, knowing what I know, I feel like, it's just a little monster.”

Regarding pain management and then fatigue, most participants mentioned that they had experienced physical pain associated with uterine fibroids and described their diagnosis experience as adaptation to pain. Some participants reported that they had tried to maintain a facade socially, despite their pain. For example, Kelly said: “I have to just push through and take as much medication as I can when cramping, so that I can just stay
at work.” She further described her overall diagnosis experience prior to having a myomectomy surgery to remove fibroids as extreme cramping from month to month.

Another participant, Alice, described her process of living with uterine fibroids as a painful one and had to manage it by taking pain medication. She said: “I had pain during my ovulation time period, like I would have really bad pains in my leg, almost to the point where I can't walk, and it would last for 24 hours.” Referring to both pain and fear, Alice described how her fibroid diagnosis affected her mental health and intimate relationship with her partner. She said: “Having sexual intercourse can be painful, especially if the person is larger. It can cause extreme pain. The most pain I've experienced is sexual intercourse, and that caused a lot of stress for me because it was scary.” Similarly, Prisca also mentioned that she experienced painful sexual intercourse caused by having fibroids.

French said she had lived with uterine fibroids for at least nine years and described the pain as debilitating. She stated that she had lived with fibroid symptoms well before her diagnosis in 2010 until 2019 when she had a hysterectomy. Still in line with managing symptoms of excessive bleeding, pain and fatigue, Tia described her diagnosis experience and interpretation of fibroids as burdensome. She said:

It means my health [is] taken from me by these little monsters that are just sucking away my blood and I just want them out of my body. Uterine fibroids are ‘monster’ sucking benign tumors that obstruct your life and create a life of this stress. I just think they are little monster-sucking demons.

Additionally, Tia mentioned making regular visits to the clinic due to fibroid pain and heavy bleeding. She said: “They know me at the clinic. I live there, I just don't sleep
there. When you go to the clinic and they know your name, you have been there too much.” Participants generally expressed that their fibroid diagnosis experience included multiple hospital visits to seek treatment for uterine fibroids and reported that they were discovered during medical checkups. Most participants highlighted that ultrasounds which are usually recommended by doctors, were not 100% accurate.

Other participants described experiencing emotional pain from living with uterine fibroids and its implications for bearing children. Liz said her doctor had told her to remove her fibroids and her life would return to normal. Liz explained that she relaxed and thought everything was fine after her myomectomy until reality sank in. She said: “I got a wake-up call after I lost four pregnancies, it was a very painful process.”

Additionally, four participants expressed some sort of uncertainty about the future because of the unpredictable effects of living with uterine fibroids after diagnosis. Three other participants expressed that they developed a negative self-perception reporting being self-conscious and having low self-esteem. On the contrary, two participants mentioned that they had not experienced any pain associated with living with uterine fibroids. QR reported that she has lived with uterine fibroids for seven years now. Unlike most participants who reported negative experiences of living with uterine fibroids, QR says apart from the fibroids being a potential threat to her pregnancy, she did not experience negative effects of fibroids in her daily life.

**Incorporating fibroid management into prenatal care**

For some participants, fibroid diagnosis, care, and management accompanied prenatal care. Two participants mentioned that their doctors closely monitored their fibroid growth while they were pregnant, as they were considered a high-risk pregnancy
and because they were over the age of 35. One participant, QR, described that she carried her pregnancy with twins to full term despite having a 5-cm fibroid growing in her uterus while pregnant. She had received her fibroid diagnosis about seven years ago when she was pregnant. However, with her twin pregnancy, the fibroids had grown and were taking up space in her womb. QR said: “The fibroids were encroaching on the space for the babies to grow and the doctors are always very hesitant to do any surgery to remove them unless they really pose some life-threatening danger.”

Another participant, Liz, reported the mental trauma that she experienced because of four miscarriages, despite her fibroids being closely monitored by her doctor during her pregnancies. She also mentioned that she successfully carried two pregnancies to term after her four miscarriages but still carries the emotional pain from her miscarriages, which were traumatizing. Liz further expressed concerns about the possibility of reoccurring fibroids during her next pregnancy after the surgical removal of her fibroids. She mentioned that her doctors had not anticipated or disclosed to her the possibility of a miscarriage due to fibroids.

**Adopting a healthier lifestyle**

A third way participants managed their fibroid diagnosis and managed their condition, was by adopting a healthier lifestyle to try and lose weight with the hope of shrinking or eliminating their fibroids. Some of these methods included turning to homeopathy, taking natural remedies such as traditional herbal teas, changing their diets to plant-based diets, juicing vegetables and fruits, exercising, and cutting out junk food and take-away food. One participant mentioned avoiding foods with soy.
One participant, Tia, described that she turned to traditional medicine and herbal remedies when a doctor gave her the option of going for surgery to remove her fibroids because they were growing, but she was reluctant to do the surgery because of the cost, which she could not afford as a graduate student, and also because she was informed of the possibility of bleeding out on the table during surgery. Tia said in her culture, instead of rushing to seek medical attention, people tend to seek treatment for their condition using traditional herbs. She said: “When it comes to treating a sickness, we will turn to bush [herbs]. Bush is a herb of medicine. So, the first option is not to seek pills.” Other participants also said that they had turned to traditional herbal tea to treat their fibroids instead of seeking medical treatment.

Tia added: “I found this thing on Facebook that is called Asian healing tea. I think it’s good to shrink your fibroids because I've tried it.” She further reported that her belly reduced in size after using the ancient healing tea although it is expensive. Tia further revealed that the pain she had experienced during her period had reduced after changing her diet to a plant-based diet. She also reported that she had heard of many ways of dealing with fibroids but was not sure of the side effects, so she turned to Facebook communities to see what people were doing to treat their fibroids. Tia said: “A lot of people are trying natural remedies which doctors don't sanction, so that's how I go about seeking treatment, and I try the natural ones because I feel more comfortable.”

Alice mentioned that after her diagnosis, she has managed her condition by turning to homeopathy as her doctor had not given her any options. She added that working with a homeopath helped her identify the root cause of her fibroids and find ways to prevent further growth. Six weeks after undergoing surgery, Penny described her
fibroid healing process as a lifestyle-changing event. She adopted a healthier diet in effort to prevent her fibroids from regrowing. Another participant, Kelly, followed a holistic approach of consistently taking supplements and reported she had improved post-surgery because her pain had significantly reduced. As part of fibroid management after diagnosis, the participant mentioned that she and her friends sought to shrink her fibroids using a natural noninvasive method.

Other participants also reported seeking information on non-surgical methods to shrink fibroids. One participant, Lisa, said: “At this point I'm seeking ways to deal with the fibroids naturally using a non-invasive method. I am doing research on how to shrink my fibroids naturally, whether it's through changing my diet or changing certain habits.”

One participant, Tashyeni, had initially said to herself: “I'm not really going to invade my body, I'll just let it do what it does. My gynecologist said, if it's not bothering you then it's okay. Tashyeni explained that she did give attention to her condition when she went through menopause until recently when she started bleeding heavily.

**Searching for accurate medical information**

Although some participants expressed that they had adequate access to fibroid information, most generally described their accessibility to information about uterine fibroids as lacking and/or limited. For example, Penny said: “I feel like people still don't know what a uterine fibroid is. I feel like it should be something common that we all should be aware of but we're not.”

A common initial barrier to information access was accurate diagnosis of their condition. For example, French said: “I only ever came across this information because I was dealing with this problem. If I hadn't gotten that diagnosis, I don't know if I would
have easily found that information, or even known where to find it.” Also, doctor’s offices were not a useful source of information. For example, Tia said: “When I speak to my gynecologist or doctor, they offer surgery. There aren't any quick flyers or handouts they can give you and say try to eat more foods like this for your fibroids.”

Participants like French, who had access to the internet, turned to the internet for information because she found “abundant” information there. However, “some of it [is] more credible than others.” She said: “I typically look for anything that's on a hospital site, or clinical notes that my doctor provided.” However, another participant, Lisa, cautioned against searching the internet for information because it could lead to misdiagnosis. She said: “There isn't much information around uterine fibroids. The first time that I heard of uterine fibroids was from my profession as a medical technologist, I conducted tests to determine if patients’ fibroids were non-cancerous.” Echoing Lisa’s point, Liz said: “I used to go to Google and Web Med and diagnose myself. But then you find something's completely different. So, I don't believe that people should Google, and misdiagnose themselves.”

Some participants, however, turned to online communities for support. Participants mentioned that after receiving their fibroid diagnosis, they sought support and information from communities of other women living with fibroids through social media. While describing their experiences about searching for information from the internet, other participants raised the issue of social media influencers being their support system and sources of information. Kelly said: “There’s different organizations and influencers that support fibroid information. There's an African American organization called We Can Wear White, and a social media influencer called Fibroid Queen. I
socialized on social media, especially in July during fibroid awareness month, to know what fibroids are.” She further revealed that Fibroid Queen has a program or boot camp where she teaches and educates people about fibroids using a holistic approach to shrink fibroids.

Generally, participants sought information about fibroids through online search engines, hospital notice boards, social media, friends, doctors, social media influencers, and fibroid advocates. All participants mentioned they had searched for information in one of these ways. Participants generally felt information is available but must be intentionally sought.

By educating themselves about fibroids, participants expressed the ability to ask their gynecologists the right questions about their condition. For example, Kelly said: “Even though they've grown back. I've taken the chance to educate myself and made it a point to educate other women, because I've learned that a lot of women suffer in silence, especially African American women.” Two other participants, Tashyeni and Prisca, mentioned that they had sought guidance from their gynecologist on how to manage their fibroids and make a treatment choice. Prisca said that her gynecologist guided her in the steps to take and provided options to choose from on how to treat the fibroids. Although participants sought various avenues for knowledge about fibroids, most participants presumed that their knowledge about fibroids was limited.

In summary, many participants expressed negative feelings about limited access to accurate medical verified information about uterine fibroids. Most participants mentioned that they only came to know what uterine fibroids were after their diagnosis. Participants said that they had hoped their health care providers would give them
sufficient information on what next to do after receiving fibroid diagnosis. Most participants were concerned that they had not been given information on how to prevent further fibroid growth and reoccurring fibroids as well as information on diet and lifestyle changes, they needed to make to shrink their fibroids. Instead, participants said that they had to make individual efforts by seeking fibroid information for themselves.

All participants generally described uterine fibroids as non-cancerous growths, masses, or tumors. One of the participants described uterine fibroids as monsters. Most participants expressed their unique perspective on what uterine fibroids mean to them based on their experiences of living with them. Participants generally referred to fibroids as tumors without a known root cause, a nuisance they wish they never had, a disease which needs awareness, a source of financial burden and social distress and little monsters. Participants described how they navigated fibroid care and management and were generally concerned about the impact of severe fibroid symptoms and their reproductive health. Of the ten participants in the study, most participants disclosed that they had experienced heavy bleeding and menstrual pain in their journey with uterine fibroids. Each participant shared different ways they tried to manage their uterine fibroids. Two participants emphasized the importance of advocating for themselves after their fibroid diagnosis.

Participants described experiencing insomnia, extreme fatigue, challenges with clothing choice, uncertainty about the future and low self-esteem, which negatively impacted how they socialized with other people.

**RQ2 How has culture played a role in the way Black females with uterine fibroids manage their condition?**
Participants were asked to describe their cultural identity and then asked if they thought their culture identity had influenced how they cope with uterine fibroids.

**Conservative cultural values regarding reproductive health**

Most participants said that discussions about periods and reproductive challenges were prohibited in their cultures. Reflecting on her hysterectomy to permanently remove her fibroids due to heavy menstrual bleeding, one participant, French, said that culturally, when she was growing up, discussions about menstruation and reproductive issues were not encouraged. She said: “We didn't talk about things like that, and maybe that's why I didn't know so much about the existence of fibroids. It's just not stuff that we talked about that much.”

A common initial barrier to talking about reproductive health was the cultural value of the uterus, which is a huge part of a woman’s identity in most participants’ cultures. French said that deciding about a hysterectomy is difficult among people in her Botswana culture because that is not something most people would be very comfortable with from a cultural standpoint. For example, French said: “Your uterus and other reproductive organs are a huge part of what makes you a woman. To have that not function the way that it's supposed to can make you feel less of a woman.”

Echoing French’s point, Liz said that discussions about menstrual periods were discouraged in her culture. Highlighting that she grew up in Tanzania but relocated to the U.S. many years ago, Liz explained that although she grew up in a modern city, “talking about our period or missed period, how you feel, was something that I don't think was talked about. You couldn’t ask a grown-up [about periods] but could ask within your circle of friends.”
Culture also influenced participants’ preference in choosing the gender of the doctor. One participant was more open to speaking about her body with female doctors. For example, Prisca said:

Being open with a doctor of the same sex plays a big part [role], because my culture has shaped me in a way that I share what's happening with my body with the physician, and that’s the way culture has helped us be open to somebody of the same sex on what's going on with you. So usually, I tend to choose a physician that's of the same sex as me, [since I am] a woman, I want to see a [female doctor]. But I don't mind seeing a gynecologist that’s a man.

Although French said that she had engaged with gynecologists who were both male and female, her first choice would be to choose a female gynecologist. She said: “I would always first and foremost, choose a woman, someone that I feel may have experienced something that I was experiencing myself or someone who can see patients as more than just patients but as people with real experiences.” Other participants also said that they were more comfortable discussing their conditions with health care providers they could relate with based on similarities in gender and ethnicity. For example, Tashyeni echoed French’s point about preferring a female doctor, which made them more comfortable to be open about their condition.

Another participant, Penny, said when deciding which gynecologist to see, she often picked Black doctors, especially foreign Black doctors in the U.S. Similarly to Penny, Tashyeni reported that she had honest discussions about her uterine fibroids with a Black doctor. She said:
Because my doctor is Black, we can have an honest discussion, not to say that a white doctor couldn't have an honest discussion, but I just feel my doctor understands more, and she has a little bit more insight about fibroids.

Most participants mentioned that culturally acceptable practices influenced their interactions with their doctor. However, a few participants reported that they had to go against acceptable cultural practices to interact with their doctors in the best interests of their health. For example, French said:

Well, I'm not very sure, but like I said, I feel like I had to set aside quite a bit of what I saw as culture, and just focus on making decisions that were best for me under my doctor's guidance. So, yeah, … in my interactions with my doctor, I didn't consider so much of what would be culturally acceptable within my own community. But I just got to a point where I had to deal with the problem that I had, and I just wanted it to go away and that was what kind of drove my interactions with my doctor, and I will say that it was easier for me. I've had gynecologists that were both male and female.

On the contrary, one participant, Prisca, described how her culture and upbringing influenced her view about her body. Unlike other participants whose cultures are conservative, there is some openness in Prisca’s culture in discussing issues pertaining to women’s bodies and the changes they go through. She said that she was raised by Zambian parents and grew up in the U.S. She disclosed that her cultural identity was very strong. She said:

I was raised in a very traditional home with strong values, and morals and my mother told me about being a woman at an early age. When I was very young, she
started telling me about my body and what to expect when you're growing up and again in my culture, we're very traditional, especially when we become mature. We have a ceremony that we get accustomed to and follow, and that is very important which I love, because my culture tends to have these other women that come and teach us about our body and what to expect, and what we are going to see and what we're going to feel and our emotions, all those things.

Prisca also appreciated her cultural traditions and month-long ceremonies which involved elderly women mentoring young ladies as a rite of passage into womanhood. Additionally, she mentioned that this is a practice that she would like to continue and pass onto the next generation. Despite the mentorship Prisca went through, her culture did not educate her about fibroids. She attributed her education about fibroids to her mother’s experience of living with fibroids.

Participants raised multilevel barriers that affected how they sought treatment for fibroids. One participant, QR raised the cultural influence of the power of authoritative figures, stating that doctors and health care providers are authoritative figures in her culture because of their perceived educational knowledge. As a result, it was not customary practice for people in her culture to seek more than one medical opinion about their condition. For example, QR exercised caution in speaking about her condition or seeking other healthcare opinions by adhering to an acceptable cultural practice of respecting those in authority. She perceived her doctor as a person in authority, by saying in her Namibian culture, which is rooted in an African upbringing, people follow whatever the doctor says. She said “On rare occasions have I sought a second or third or fourth opinion on a diagnosis from a doctor. I would say, you will take the initial
diagnosis, and whatever they recommend.” Another barrier to seeking timely treatment for uterine fibroids was the issue of living in denial. Kelly said that within her culture the initial fibroid diagnosis is often accompanied by denial until the condition requires urgent medical attention and treatment is no longer an option but a necessity. As a result, she now treats anything in her body that requires medical attention as an urgent matter. She said: “Since [my] diagnosis, anything that's medical, I typically run to a doctor, I want to seek help when I can.” It was common for participants to delay seeking treatment for fibroids. For example, Lisa said her cultural identity influenced how she copes with uterine fibroids. She said:

As Africans, I think we don't always seek medical attention. To some extent, we find ways to deal or live with uterine fibroids, and the reason why I say this is because I noticed that the people, I interacted with who had fibroids went for such a long time, for years without seeking medical attention when it came to uterine fibroids, and it could go back to the fact that maybe the information wasn't there. It wasn't something that they thought of looking for. But I think that culture influences how we cope with or [manage] uterine fibroids.

**Spirituality in seeking treatment**

The findings also presented other cultural aspects that restricted participants from talking about what they were experiencing in their bodies from a young age. For example, one participant, Liz, raised the aspect of religion being a barrier to learning about reproductive health within her culture. She reported that when she was in high school, she did not have much access to information because she went to a strict Catholic boarding school where she could not express herself about many sensitive issues about
her body; she said that considering a hysterectomy made her feel like she was rebelling against her culture. Liz later discovered that most of the Black girls she grew up with had fibroids. She said:

There's so much information that I wanted, and I love my God. Trying to explore that option [hysterectomy] is like going against God and your values. We never got enough information about fibroids or periods because people were not speaking [about them].

Also, a cultural aspect of turning to spiritual or religious prayer instead of physical treatment for fibroids after a fibroid diagnosis, posed as a barrier to speaking about fibroids and a delay to seeking treatment for the condition. For example, Penny said:

I'm a woman of faith; I'm saved. I've given my life to Christ. So, one of the first things that I did when I found out [I had fibroids] was, I went to prayer. I spent time in prayer and speaking to the Lord.

Penny said because she had not yet had children, her doctor encouraged her to take her time to decide on whether to opt for surgery or not. She explained that after spending time in prayer, she explored natural remedies to treat her fibroids before she opted for surgery, because she was very fearful of being cut open. When deciding what treatment option to take for her fibroids, Penny’s spiritual aspect of her cultural identity also led her to seek counsel from her spiritual mentor and her family. Penny said: “I spent some time in prayer and fasting. I consulted my spiritual father who was my pastor at that time, and then I consulted my family to see what we could do.”
Another participant, Tia, said she opted to explore natural remedies instead of surgical treatment for her fibroids because she believed “the Lord placed herbs on the earth to heal our bodies and food is medicine.” Additionally, Lisa said her cultural identity played a role in coping with uterine fibroids. She admitted that her culture influenced how she coped with her condition. She said:

It [culture] influences how I cope with my situation and being a person of faith. I believe in God, and I'm believing that when I ask God to help me—either give me the strength or take away the fibroids—I believe that God is going to do it. So, my faith influences the way that I handle the situation. I know that this isn't permanent. It's a temporary situation, and I believe that God will eventually take that [pain] away from me or remove the uterine fibroids.

Apart from spirituality, participants said that through their cultural upbringing, they had developed the ability to endure their pain and hide it from other people, which often resulted in them delaying seeking medical attention to address the symptoms of their condition they were experiencing.

*Adopting high pain tolerance and delaying seeking treatment*

A common cultural belief that participants raised was the need for Black women to appear strong despite the pain they experienced from their condition. Participants often indirectly referred to the concept of the “Strong Black Womanhood (SBW) Schema” which is a result of Black historical oppression, and a “multidimensional construct often internalized by African American women to overcome oppression such as racism and sexism” (Watson-Singleton, 2017, p. 779).
Most participants reported that they had a high pain tolerance because of the cultures they were raised in where women must appear strong even though they are experiencing pain in their bodies. For example, Tashyeni said based on her religious upbringing in a Christian home, she has held on to a lot of cultural and religious values from her upbringing and said that her mother taught her that there are certain things females must endure, including pain. She said:

My mother always believed that we [must] go through [pain]. So, we go through it and deal with it. That's how I was raised. So, my pain tolerance is very high, because I'm sure it's because of my mother, because of the way she just kind of programmed us. There are things in life you [must] deal with, as a female deal with it.

Referring to painful periods, another participant QR said that in her culture of African origin, people do not complain unless their condition is serious. Typically, people will wait for the condition to become extremely intolerable before they can complain about it.

Similarly to Penny and Tashyeni, Tia reported that she defines her cultural identity in the Jamaican heritage which has its roots in Africa. She said: “In Jamaica it's a cultural thing to be strong, to look and to be strong. So, your ability to cope with pain is higher. You have a greater tolerance for pain.”

Additionally, Tia reported the need to mask her pain at her place of work. Repeating that her pain tolerance is very high, she admitted to masking her pain, stating:
When I'm in pain I'm still going to go to work. I'll pretend like, nothing is wrong. I downplay the symptoms that I have, because at work you must put your best foot forward and pretend like you're not ill and get the job done.

Similarly other participants shared about tolerating fibroid pain and the need to hide their pain to avoid looking incompetent at their jobs or in school. In summary, participants’ conservative cultural values shaped how they interacted with their health care providers, which resulted in them being cautious and moderate in how they disclosed their reproductive health concerns. Some participants’ religious beliefs informed their perception of seeking treatment for their condition. Participants generally adopted high pain tolerance while others turned to prayer and spiritual guidance which consequently led to a delay in seeking treatment for uterine fibroids.

RQ3 How do Black females with uterine fibroids characterize communication with their health care providers?

Findings revealed themes about doctors dismissing symptoms/ not listening to patients and their needs; racial bias during patient-provider consultations; and multilevel barriers to receiving timely, quality treatment for uterine fibroids.

**Doctors dismissing symptoms/not listening to patients and their needs**

Participants said in their cultures it is important to identify the root cause of their condition rather than focusing on treating symptoms. One participant, Tia, raised an issue about differences in treatment opinion between the patient and the doctor. She believed that relocating to the U.S. and not eating the traditional food she grew up eating has contributed to her getting fibroids. Tia was of the view that her doctors did not have
adequate knowledge about fibroids and their causes. She also said her doctor had dismissed the effectiveness of traditional herbs as a treatment for fibroids. She said:

My way of thinking is different from my doctors, and that has caused a difference in opinion in what they think will work, and what I think will work because I think they want to either remove the fibroids using surgery, or they want to give me pills to manage my symptoms.

Another participant, Alice, perceived that the doctors downplayed the seriousness of fibroids to normalize them, stating that even if there were health concerns around the size of her uterine fibroids, she was not sure if she would be taken seriously. She recounted past experiences where she was told “What you're feeling is normal” adding “I've heard this before, so it almost makes you feel like, it's not specific to you, you feel helpless like there's no actual solution.” Participants interpreted the lack of seriousness about the severity of their condition as the dismissal of their symptoms by health care providers. Alice further lamented that she was of the view doctors made her think she was just a victim of fibroids, arguing that:

Instead, [doctors]should help you figure [a treatment plan after a fibroid diagnosis]. These are things you should or shouldn’t do to help avoid the fibroids from growing, but my doctor did the complete opposite. She tried to put me back on birth control while we [knew] there was some type of link [between fibroid growth and hormonal birth control]. I just don't think you're given other options besides a pill or surgery or just to live with it.

Participants expected their doctors to have knowledge and experience on how to treat their fibroids and identify the root cause. For example, Lisa said, “I’m not sure if the
physicians that I go to completely understand what it is like to live with fibroids or how to deal with patients who have fibroids apart from physicians suggesting the most extreme measures to take.” When asked to elaborate on the extreme measures her doctors suggested to address her fibroids, she said she was referring to suggestions such as rushing to have kids, which was not culturally acceptable to her, lamenting that “there has to be a root cause, and I would rather have someone address the root cause rather than for me to sort of sweep that under the carpet.”

Additionally, Lisa said before she discovered she had fibroids, her doctor had initially suggested that the symptoms she was experiencing were related to her mental health. She said that “[the doctor] would suggest solutions that had to do with how I took care of myself [mentally] physically, whereas the real issue was more on the inside, and not so much about my surroundings or my mental health.” Like other participants, Lisa also mentioned times when the doctor dismissed her symptoms instead of identifying the root cause of her condition. Expressing her frustration, she said, “[I] [was] going to a doctor with hopes that they would assist in diagnosing and finding out what was going on, but they sort of dismissed some of the symptoms I had.” Lisa also said that the suggestions her doctor made about her symptoms had nothing to do with addressing the underlying fibroid condition she had.

Participants raised the importance of trust in patient-provider relationships and information sharing. Trust played a crucial role in the amount of information participants disclosed to their health care providers about their condition. Trust also determined participants’ comfort in asking questions during doctor’s visits. Participants responses established that trust was important in patient-provider relationships to help them be open
about their condition while seeking treatment. Participants said if there is trust between a patient and their health care providers, it is easier for the patient to be honest about their symptoms. Therefore, trust served as a pathway for honesty and transparency about fibroid symptoms during doctor’s visits. For example, Penny said:

I’ve always been honest with my doctor. If you're not going to be honest with your doctor, they might find out anyhow, so you might as well. I always apply the honesty approach, but I was blessed enough to have a doctor that I could communicate with, and that did listen to what I was saying about my symptoms.

Although two participants, Tashyeni and QR, reported that they had built trust with their health care providers, other participants had not established trust with their health care providers. Furthermore, participants were of the view that their doctors did not have their best interests when pushing for surgery or pills to treat their fibroid symptoms. Participants believed that their doctors prescribed expensive treatments for their financial gain. For example, Tia said: “The reality is that they [doctors] have to make money, so they have to keep you coming back to the clinic to manage the symptoms. But it's not about curing your fibroids.” Similarly, Tashyeni felt that doctors in general do not listen to patients and instead push their financial agenda. She said:

I think in medicine, money drives everything. I don't even think it's a race thing. I think it's a money thing because I feel like medical providers [prey] on clueless females who don't matter. It is about money; especially if you have insurance. I don't think it is a color issue. I don't think it's a race thing. I think it's a money thing.
On the contrary, other participants believed that racial bias played a key role in the way health care providers responded to Black women with uterine fibroids. The next section delves into the negative perceptions participants had about the link between race and the experiences they had while communicating with health care providers.

**Racial bias during patient-provider consultations**

Participants perceived that their race and accents played a role in the negative treatment they experienced from their health care providers during hospital consultations for their fibroids. Negative treatment participants experienced included their dismissed pain, not having a say in their treatment options, being rushed during healthcare visits, and participants’ perception that information about uterine fibroids treatment was withheld from them by their doctors. For example, Alice perceived that her doctors were not making an effort to figure out fibroid cause and prevention and to help patients navigate their diagnosis. She reported that her doctor believed only Black people get uterine fibroids and it is normal. Alice reflected aloud: “This is normal, this is just part of the Black experience, right? And I am sure your mom has it [fibroids], and I'm sure your sister has it [fibroids]. But it's like normalizing it but it’s not normal.” Participants felt that health care providers of their race would understand their condition better. Although most participants reported that they had experienced negative treatment from their doctors, Participants like QR, Tashyeni, and Prisca experienced positive communication with their doctors. Surprisingly, when participants were asked to share whether race played a role in the way they communicated about their condition, in general, four out of ten participants agreed that race played a role, while five out of ten participants didn’t
think race played a role in how they communicated about their uterine fibroids. One participant was undecided.

In addition to their dismissed symptoms and the root cause of their condition being unidentified, participants felt that they lacked the freedom to make their own treatment choices for their condition. Participants expressed the desire to be heard by their doctors during patient-provider consultations. Participants felt rushed during hospital visits and that their doctors did not disclose enough information about uterine fibroids. For example, Kelly argued that often African American women are not listened to. Referring to doctors, she said: “They think our pain level is not as severe or they feel as if maybe we might be faking it.” She further said that society has proven that health care providers’ opinions of Black women play a role in how Black female patients are treated by health care providers, and how Black female patients communicate to their health care providers about their pain.

To summarize, participants felt dismissed by their health care providers. As a result, participants generalized the concept of dismissal of patients by health care providers. The findings uncovered a clash between the Voice of Lifeworld versus the Voice of Medicine from the participants’ responses of their experiences with their health care providers. Participants. Racial bias posed as a barrier to patient-provider communication during hospital consultations. The results agreed with literature that effective communication between patients and health care providers is vital but often limited.

Chapter IV Conclusion
This chapter discussed the findings of this study. The chapter began by introducing the emergent themes guided by the research questions. The next section of the chapter provided a brief description of each participant interviewed for this research. The proceeding section examined emergent themes about each research question. Lastly, a brief recap of key findings was highlighted. The next chapter zooms into the meanings of the findings and links them to current literature and the study’s research questions, before concluding.
Chapter V
Discussion

This chapter briefly summarizes the study’s findings; situates the findings within the literature review that informed this study; and discusses study implications and limitations.

The purpose of this qualitative study was to gain an in-depth understanding of the lived experiences of Black women with uterine fibroids in the U.S., including the cultural implications of seeking treatment for fibroids. To examine this phenomenon, three research questions were posed:

**RQ1:** How do Black females with uterine fibroids navigate diagnosis and management of their condition?

**RQ2:** How has culture played a role in the way Black females with uterine fibroids manage their condition?

**RQ3:** How do Black females with uterine fibroids characterize communication with their health care providers?

Regarding RQ1, Black women with uterine fibroids navigated their diagnosis and management of their condition by using birth control and surgical treatments such as myomectomy and hysterectomy. Participants who navigated their diagnosis and management of their condition by using birth control to regulate their hormones and heavy bleeding were against the use of birth control and reported that the birth control intervention did not work. Apart from French who had a hysterectomy, participants who had used other surgical techniques to manage their condition were fearful that their fibroids would return. For example, Liz who had a myomectomy reported that her fibroids had returned. The results in this study were consistent with extant research that
has found the high risk of reoccurring fibroids after surgery (Eltoukhi et al., 2014). The study’s results agreed with previous research that birth control and surgical interventions are commonly prescribed as treatment for patients with severe fibroid symptoms. Except for a hysterectomy, birth control and surgical treatments do not prevent fibroids from regrowing (Dillard, 2016; Eltoukhi et al., 2014; Mutai et al., 2015).

Participants desired information about more treatment options and how to prevent further fibroid growth, specifically non-surgical treatments to alleviate heavy bleeding and menstrual pain. Participants were clearly not interested in taking birth control or surgical treatments for their fibroids. For example, Tia chose not to have a hysterectomy despite her doctor’s recommendation.

Participants managed symptoms of excessive bleeding, pain, and fatigue by relying on excessive number of menstrual products, painkillers, iron infusions, and blood transfusions. Additionally, they reported regular hospital visits, which all caused a financial burden. This correlates with previous studies which indicated that Black women experience debilitating fibroid symptoms compared to women of other ethnicities (Berman et al., 2022; Dillard, 2016; Henshaw et al., 2022).

Black women resorted to hiding their pain at work, in school, and in public settings. Based on cultural beliefs, it was common for participants to appear strong despite the pain they experienced from their fibroid condition. This speaks to existing literature on the need for women to hide their diseases to avoid public stigma (Igboeli et al., 2019). These findings are also consistent with previous research that Black women are prone to experience severe fibroid symptoms and have a high pain tolerance (Watson-Singleton, 2017). Fibroid diagnosis influenced women's mental health and caused mental
trauma. They reported experiencing emotional pain, negative self-perception, and low self-esteem. Congruent with previous research, uterine fibroids and the associated symptoms affected women’s quality of life (Fuldeore & Soliman, 2017).

Participants also incorporated fibroid management into their prenatal care with fears of miscarriages and life-threatening dangers. Participants who had not yet had children expressed concern about their fertility and the high-risk pregnancy associated with fibroids. Furthermore, participants adopted a healthier lifestyle, which consisted of diet change, exercise, homeopathy, traditional herbal teas, herbal remedies, and weight loss. Participants had anticipated shrinking their fibroids by adopting a healthier lifestyle and wanted to adopt traditional remedies because of cultural beliefs that “food is medicine,” as found in previous research that discusses how food is used as an intervention to treat illness and diseases (Yao et al., 2023). Additionally previous studies explored the link between fibroid growth and vitamin D deficiency (Igboeli et al., 2019; Yu et al., 2018). Therefore, the possibility of fibroids shrinking by diet, weight loss, and exercising can be further studied to gain more insight.

One of the ways participants managed their fibroid condition was by searching for accurate medical information. Participants turned to the Internet, (Facebook, Instagram, Google, and WebMD) and social media influencers, but feared misdiagnosis of their symptoms. Although information on the internet is not always reliable, the internet was a source of awareness about fibroids after participants had received their diagnosis and started searching for fibroid information. Participants had also turned to online communities for support. This is in line with literature that states that patients turn to the internet due to the lack of information about uterine fibroids. In previous research,
Participants’ internet usage and education had a positive correlation with fibroid awareness (Ekpo et al., 2014). Literature suggested that the lack of information about fibroids is often overlooked and neglected by some healthcare organizations, especially when setting up an agenda for interventions for women's reproductive health research (Dillard, 2016).

Participants expected accurate medical information from their health care providers and felt that their health care providers withheld information from them. This resulted in a lack of trust between the patients and their health care providers as participants believed that health care providers were looking out for their own financial gain and not their overall well-being. This made it difficult for participants to open up about their condition with their providers. The study’s findings underscores the importance of patient-centered communication and a culture-centered approach to healthcare (Dillard, 2016; Dutta, 2007; Koenig, 2014; Stubbe, 2020).

In response to RQ2, regarding the role of culture in the way Black women with uterine fibroids manage their condition, this study found that participants held conservative cultural values regarding reproductive health. This agrees with research that has found that speaking about disease and menstruation or undergoing certain medical procedures is a taboo in Sub-Saharan African cultures and some African American cultures (Igboeli et al., 2019; Orellana et al., 2021; Winfield, 2022). The cultural value of the uterus was directly linked to the value of womanhood. This finding aligned with previous studies that highlighted the cultural value of the uterus as a significant symbol of womanhood (Igboeli et al., 2019). For example, when a hysterectomy was prescribed or suggested by the doctors, participants reported that they were likely to decline that
treatment and ask for information about other treatment options so that they could choose the treatment that was best for them. Furthermore, participants sometimes rejected medical intervention due to cultural beliefs.

Additionally, some participants (e.g., QR) did not seek a second or third opinion from other doctors regarding her condition, owing to their cultural beliefs to take the word of an authoritative figure as final. The results in this study found that participants were often comfortable with a doctor of the same race and gender as themselves. This is because they felt a doctor with similarities to them understood their experience better.

Cultural factors like living in denial, turning to spirituality, and adopting high pain tolerance delayed participants from seeking treatment for their condition. This was in line with their cultural expectations. Although cultural values influence participants’ interaction with health care providers, some participants reported that they went against their cultural values. For example, French openly talked about a hysterectomy with her doctor and agreed to have the procedure, even though doing so went against her cultural beliefs and practices.

For RQ3, regarding their interaction with healthcare providers, Black women characterized communication with their health care providers as dismissive. Participants were often told that it's common or it's normal for Black women to have fibroids. One participant, Lisa, said her doctor had initially attributed her symptoms to physical and mental health issues instead of fibroids. Owing to negative experiences of interactions between patients and physicians, participants desired to be heard and understood. The study’s results suggested that doctors had internal biases, sometimes lacked connection with their patients, and in some cases, failed to apply empathy. This is consistent with
previous research, which has found that racial biases play a key role in the way health care providers and patients perceive expectations and management of pain and disease across different ethnic groups, leading to delayed treatment of uterine fibroid disease (Al-Hendy et al., 2017; Aninye & Laitner, 2021; Thorpe et al., 2022).

Participants reported racial bias during consultations with their healthcare provider. Participants perceived that health care providers did not listen to them, dismissed their symptoms based on their race and accents, and that their experiences of living with uterine fibroids were not understood by their doctors, leading to a lack of patient satisfaction with hospital visits. This study’s results aligns with previous literature that found that lack of patient satisfaction was due to health care providers not providing clarity on available information about the management and advanced treatment options for fibroids (Igboeli et al., 2019). The lack of patient satisfaction was further attributed to a lack of management and treatment plan to prevent further fibroid growth. Additionally, these results agree with existing literature, which state that successful patient-centered communication involves health care providers engaging with patients in a nonjudgmental and non-stigmatizing way. For example, French said that after failing to get treatment, she gave up and decided to have a hysterectomy even though she didn’t yet have children because of the lack of fibroid treatment options which could have preserved her womb.

Perceptions patients had towards the health care providers may have been informed by cultural values, beliefs, and history of racial discrimination in healthcare systems, leading to medical mistrust. This finding aligns with those of previous studies that has found that Black women and women in general tend to experience delays in timely diagnosis or treatment for various reasons such as historical medical mistrust,
medical errors, culture, gender, and racial issues (Al-Hendy et al., 2017; Charifson et al., 2022; Eltoukhi et al., 2014; Orellana et al., 2022). Furthermore, participants developed a high pain tolerance which often delayed them from seeking medical treatment for their fibroids. The results are consistent with literature about the concept of the “Strong Black Womanhood (SBW) Schema,” a “multidimensional construct often internalized by African American women to overcome oppression such as racism and sexism”; these racial disparities have a negative impact on patient-provider interactions and treatment interventions (Watson-Singleton, 2017, p.779).

Participants expected health care providers to inform them about the root cause of uterine fibroids and not simply treat their symptoms. This speaks to the concepts of the voice of lifeworld versus the voice of medicine (Mishler, 1997). Patients tend to emphasize the voice of the lifeworld, focusing on health and illnesses within the context of everyday lived experiences (Mishler, 1997). Patients who use the voice of the lifeworld are concerned about their feelings and the way they experience these feelings in their daily lives and various events (du Pre & Overton, 2021). In case of fibroid patients, for example, pain in the lower abdomen affects their ability to work efficiently and socialize in their everyday life. Living in pain also comes with financial implications. On the other hand, healthcare providers tend to emphasize the voice of medicine, which focuses primarily on evidence, measurement, and precision. Health professionals trust evidence, for example, they may use phrases such as “fibroids are genetic,” “fibroids are normal,” “fibroids are non-cancerous,” and “the exact causes of fibroids are not known.” According to du Pre and Overton (2021), this disconnect can result in patients feeling dismissed or unheard by their physicians who do not show empathy towards their
patients. Health care providers avoid the perspective of the lifeworld issues and quickly revert to the voice of medicine because of their view that some patients’ lived experiences are irrelevant to the patient's medical condition. Another reason for dismissing or interrupting patients during consultations, based on the findings of this study and literature consulted for this study, is that providers may be uncomfortable speaking about uterine fibroids due to the lack of their experience with the condition. For example, Tia said she felt dismissed by her doctor when she suggested the use of herbs to shrink her fibroids.

**Theoretical and Practical Implications**

This study contributes to the literature on how patient-centered care can be fostered through broadening cultural understanding of health (Dutta, 2007; Koenig, 2014; Stubbe, 2020). This research highlights the importance of studying the lived experiences of Black women with uterine fibroids, their cultural perspectives, and patient-provider interactions as they navigate and manage their condition. This is especially important because Black women with uterine fibroids are understudied.

It is important for health care providers to practice supportive listening and clear communication and cultivate trustworthy relationships with their patients, which is critical for fibroid diagnosis and treatment. Positive interactions between patients and providers yield greater patient satisfaction. It is important for health care providers to practice supportive listening, which in turn encourages self-disclosure among patients, leading them to be open and forthcoming about their pain experiences (Basnyat et al., 2022). This implies that when patients are dismissed or not heard, it makes it difficult for them to be open with their health care providers. Participants desired easily accessible,
accurate medical information about uterine fibroids and often felt dismissed and unheard by their physicians. This study recommends that health care providers specifically, OBGYN’s and gynecologists, receive training in culture-centered care regarding fibroid treatment to address any racial biases that they may have and to allow them to center the voices of Black women with fibroids by acknowledging their unique perspective of their condition. Health care providers can also make use of health messaging on social media platforms, hospital notice boards, posters, and pamphlets to improve health communication about uterine fibroids. In addition, institutions such as Churches and universities can incorporate awareness about uterine fibroids through departments such as Black Studies, Women and Gender Studies, Multi-cultural Affairs Office, and research conferences to educate females about abnormal menstrual bleeding and uterine fibroids.

This study also recommends that health care providers avoid generalizing patients’ experiences. Every patient must be taken seriously regardless of race, ethnicity, or culture. Health care providers need to practice active listening by allowing each patient the opportunity to speak about their feelings and their condition and to ask and answer questions in a relaxed manner, especially because some participants felt like they were just a statistic and were rushed during consultations. These findings underline the CCA theory, which does not generalize cultural beliefs and practices but seeks to capture emerging cultural messages and everyday meanings from participants, through the co-construction of data by the research team and community members (Dutta, 2018). Furthermore, individual health narratives are fundamental to understanding and improving patient-provider communication within a diverse cultural context (Ross & Castle Bell, 2017). It is important to include Black women in the decision-making
process of fibroid treatment management, legislation, and policies about fibroids and reproductive health.

This study also recommends that healthcare providers raise awareness on the differences between the concept of the voice of lifeworld versus the voice of medicine, bridging the gap between these two voices to avoid misunderstandings when patients seek fibroid treatment (Mishler, 1997).

**Limitations and Future Research**

Firstly, due to the sample size of ten participants, the findings of this study are limited and cannot be generalized to larger populations in the U.S. Therefore, future research can consider including a larger sample size. Further, data in this study was collected over a period of one month due to the time frame to complete the master’s program. Future studies can consider a longitudinal study design to gain an in-depth insight about the lived experiences of Black women with uterine fibroids and potentially generalize those findings to larger populations.

Future studies can aim to understand participants’ access to and interpretation of accurate medical information about fibroids. For example, it might be worth investigating how health care providers and institutions can partner with social media influencers and online fibroid communities to provide more easily accessible and accurate medical information about uterine fibroids. Future research can encourage more health organizations to prioritize uterine fibroids when setting the agenda, legislation, and policies regarding women's reproductive health around uterine fibroids (Dillard, 2016). Also, since most participants in this study were not aware that their fibroids could contain cancerous tumors like uterine sarcoma, future research can consider including a dialogue
with healthcare professionals and patients to raise awareness about the possibility of the presence of cancer amongst uterine fibroids and what patients can do to minimize potential risks by making diet and lifestyle changes. Lastly, to amplify the voices of Black women with uterine fibroids, future studies might consider an autoethnographic approach to investigating this topic.
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Appendix A

Sample Interview Questions

1. **Diagnosis and management of uterine fibroids**
   A. Have you been diagnosed with uterine fibroids?
   B. In your own words what are uterine fibroids?
   C. Could you share with me about the experience of living with uterine fibroids?
   D. What do uterine fibroids mean to Black women?
   E. How do Black women seek treatment for uterine fibroids?
   F. Why do Black women think they are mostly affected by uterine fibroids?
   G. Why are Black women more vulnerable to Uterine fibroids and why does it go undiagnosed or treated for prolonged periods of time?
   H. In your view how would you describe the accessibility of information about uterine fibroids?

2. **The role of culture**
   A. How do Black women define culture?
   B. What does culture mean to Black women?
   C. Does culture impact Black woman’s’ decisions to seek treatment for fibroids?
   D. How does culture affect fibroids patients’ communication about their health?

3. **Communication with healthcare providers**
   A. How does culture affect participant communication with healthcare providers?
   B. Does race play a role in the way Black women communicate about uterine fibroids?
   C. How do Black women feel about patient-provider communication regarding uterine fibroids?
   D. More questions will emerge from interviews with participants and will be included in the interview guide.
Appendix B

IRB Protocol & Consent Form

IRB PROTOCOL # 0471-23-EX

Interview # _______ Date _____________ Time _____________ Participant code ________

Screening Questions

Interview Protocol Elements (Examples of possible questions)

Survey questions inclusive of demographic and screening questions:

Three participant inclusion criteria: gender, age, and geographic location.

- Screening Questions for Recruitment to the study via Facebook and Instagram flyer
  
  - Do you identify as an African American female?
  
  - Are you 19 years or older?
  
  - Do you live in the Midwest, United States?
  
  - Have you received uterine fibroid diagnosis from a medical professional? Please do not respond to screening questions here, email me privately at dmwikisa@unomaha.edu if you fit the recruiting criteria and are interested in participation in this study).
IRB PROTOCOL # 0471-23-EX 

Interview # Date Time Participant code

Planned Interview Protocol – Subjects will be asked where they want to be interviewed.

Central Question: How do self-identified Black females (aged 19-60) across America experience the process of living with uterine fibroids and seeking treatment?

Introductory Statement: Hi, my name is Diana Mwikisa, and I am a graduate student at the University of Nebraska at Omaha. Thank you once again for taking time to talk with me today. As I mentioned earlier, I am conducting a qualitative study about Black women’s journey with uterine fibroids. The purpose of the study is to understand the lived experiences of Black women with uterine fibroids. I estimate this interview to last 30 minutes to 1 hour. If at any time you would like to stop for a break, please let me know. As discussed before, would it be alright if I audio record this interview? I would like to record the interview to make sure I make a note of all your comments. Please be reminded that audio recordings and any interview notes I take will be kept confidentially. During the study, only I will have access to these materials. The results of the study may be published in a professional journal or presented at professional academic meetings. Data from the study will contribute to limited research about Black women with uterine fibroids and aims to provide insight into the needs of Black women with uterine fibroids. Your identity will be hidden for this study and information shared will not be linked to you without your permission, in any published reporting. You can choose a fake name not linked to your identity, or I can provide a name for you. Feel free to drop out of this interview at any time because your participation is voluntary. I would be happy to share a summary of my findings with you at the end of the study. With your permission, I would like to ask you a few questions about your experiences of living with uterine fibroids. Do you have any questions? Shall we proceed?

*(Before recording the Zoom interview, remind subjects to turn off their camera and use their pseudonym instead of their name. Remember to start recording on Zoom once participant gives consent to participate in the interview and is aware it will be recorded) *Make sure to check settings that recording is going onto the cloud and check that audio transcript is on). *Assign a pseudonym for participant.

<table>
<thead>
<tr>
<th>Research Question &amp; Est. Time Allotment (30-60 minutes)</th>
<th>Main Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>To establish a clear question the participant can answer in detail as they choose.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Estimated Time: 10 minutes.</th>
<th>A. Have you been diagnosed with uterine fibroids?</th>
</tr>
</thead>
<tbody>
<tr>
<td>RQ#1 How do Black females with uterine fibroids face the diagnosis and management of their condition?</td>
<td>B. In your own words what are uterine fibroids?</td>
</tr>
<tr>
<td></td>
<td>C. Could you share with me the experience of living with uterine fibroids?</td>
</tr>
<tr>
<td></td>
<td>D. What do uterine fibroids mean to you?</td>
</tr>
<tr>
<td></td>
<td>E. How do you seek treatment for uterine fibroids?</td>
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<tr>
<td></td>
<td>F. In your opinion, who do you think is most affected by uterine fibroids?</td>
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<tr>
<td></td>
<td>G. Do you know anyone (friends) with uterine fibroids? How do they seek treatment for their fibroids? What do they do?</td>
</tr>
<tr>
<td></td>
<td>H. In your view how would you describe your accessibility to information about uterine fibroids?</td>
</tr>
</tbody>
</table>
IRB PROTOCOL # 0471-23-EX

Estimated Time: 10 minutes.

RQ#2
How has culture played a role in the way Black females with uterine fibroids manage their condition? (e.g., seek information about and treatment options).

A. How would you describe your cultural identity?
B. Do you think your cultural identity has influenced how you cope with your disease? If yes, how?
C. What role do you think your cultural identity plays in how you interact with your doctor?
D. Do you think that you are well educated about uterine fibroids?
E. In your opinion, what treatment options exist for fibroids?

Estimated Time: 10 minutes.

RQ#3
How do Black females with uterine fibroids characterize communication with their healthcare providers?

A. In your view, how would you describe your communication with healthcare providers during hospital visits?
B. How does your cultural identity influence your communication with healthcare providers?
C. Does race play a role in the way you communicate about uterine fibroids?
D. How do you feel about patient-provider communication regarding uterine fibroids?
E. More questions will emerge from interviews with participants and will be included in the interview guide.

Concluding Statement: Thank you for your participation by responding to the interview questions for this study. If at any point during my data collection and analysis I may need to ask follow-up questions, would you be open to answering further questions? Once I am done with my paper, I will be happy to share my results with you. Remember the purpose of this study is to learn and understand how Black women experience living with uterine fibroids. This study is for academic research purposes, and data will be stored away in a password-secured manner to maintain confidentiality. Your real name or any name linked to you will remain concealed throughout the study and after the study. Thank you!

Personal Reminders *(Remember to end the Zoom recording and save the recording in a password-secured locked folder with the audio transcriptions). * Note that the direction of the interview can change depending on the responses. *Make sure to write memos during and after the interview about anything that was noteworthy during the interview. *Remember to reflect and do researcher repositioning before and after the interview. Extra personal notes (for memoing) Note to self * Use space below for personal memo notes.
IRB PROTOCOL # 0471-23-EX

Recruitment email

Subject: Interview Recruitment Request

Dear _ (Name of Fibroid Foundation Recruitment Personnel):

I am Diana Mwikisa, and I am a graduate student at the University of Nebraska at Omaha.

I’m interested in Black women’s journey with uterine fibroids. I would like to understand the lived experiences of Black women with uterine fibroids. I understand that you recruit research participants for studies about uterine fibroids and encourage women to share their stories about living uterine fibroids. I was wondering if I could post a digital flyer on your Facebook and Instagram platforms, inviting respondents to participate in my study through interviews?

Each interview is expected to last about 30 minutes to an hour. It will cover topics such as experiences of diagnosis and management of uterine fibroids, the role of cultural identity when seeking information about uterine fibroids and treatment options, and patient-provider communication about uterine fibroids.

I’d like to conduct the interview in person and via Facebook for those who are far to reach. The interview will be audio recorded via Zoom for transcription purposes. However, to ensure confidentiality, interview notes and audio recordings will be stored in a password-secured place during the study. Also, no identifiers linking any respondent to this study will be included without their permission in any sort of report that might be published.

Further, a respondent may decline to answer any question they do not wish to answer and decide to withdraw from the study at any time. Finally, if desired, I would be glad to share with you a
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summary of my findings at the end of the study. I hope you will be able to assist me with recruiting respondents to participate in this study. If so, I would appreciate your feedback within a week when my digital flyer can be uploaded on your Facebook and Instagram posts. If you have any questions about the study or about my background, please call me at 402-968-8830 or email me at dmwikisa@unomaha.edu (or diana.mwikisa@gmail.com).

I look forward to hearing from you!

Kind Regards,
Diana Mwikisa
Graduate Student
School of Communication
University of Nebraska Omaha
ASH 107X
dmwikisa@unomaha.edu
402-968-8830 (cell phone)
IRB PROTOCOL # 0471-23-EX

Recruitment Facebook/Instagram Script
Hi, my name is Diana Mwikisa, and I’m a graduate student at the University of Nebraska at Omaha. I am working on a study that aims to understand the lived experiences of Black women with uterine fibroids. If you fit the recruitment criteria on the flyer posted below, I would like to talk to you about your experiences with uterine fibroids. I would like to send you an e-mail with more information about how the study will be conducted to help you decide if you’d like to participate in the study, and I was wondering if you could e-mail me privately if you are interested in participating and sharing your story to raise awareness about the needs of Black women with uterine fibroids. Please do not respond to the questions on the flyer here, e-mail me at dmwikisa@unomaha.edu to ensure your confidentiality. If you have any additional questions, you can email me or you can contact the Institutional Review Board (IRB) at sirb@unmc.edu or 402-559-6463. Thank you!
Recruitment Phone Script

Hello. May I speak to [name of subject]? [If the subject is not available, then attempt to contact the subject later using the phone number provided. If the subject’s phone goes to voicemail on the phone number provided, provide your name, phone number, e-mail address, and a brief description of the study to the individual on the line and request that the subject contacts you. If necessary, provide this information in a voice mail.] [If the subject is available, follow the script below.] My name is Diana Mwikisa, and I’m a graduate student at the University of Nebraska at Omaha. I am working on a study that aims to understand the lived experiences of Black women with uterine fibroids. I understand that you emailed me to phone you, and I would like to talk to you about my study on uterine fibroids. I’d like to provide you with more information about how the study will be conducted to help you decide if you’d like to participate in the study, is this a good time to talk? If not, what would be the best time to contact you? Should you wish to participate in the study we will schedule a Zoom or in-person interview at a convenient date, time, and site of your choice. Thank you!
Appendix C

Digital Recruitment Flyer

Black Women's Journey with Uterine Fibroids

A Call for Research Participants
Share your story to raise awareness

Do you identify as a Black or African American female living in the United States?

Are you 19 years or older?

Have you received uterine fibroid diagnosis from a medical professional?

If your answer is yes to all these questions and you wish to participate in my study, email me!

• PLEASE DO NOT RESPOND TO THE QUESTIONS ABOVE HERE!

PLEASE EMAIL ME PRIVATELY!!!
dmwikisa@unomaha.edu
Appendix D

IRB Approval Letter

July 17, 2023

Diana Mwikisa, BA
School of Communication
UNO - VIA COURIER

IRB # 0471-23-EX

TITLE OF PROPOSAL: Black Women’s Journey with Uterine Fibroids

The Office of Regulatory Affairs (ORA) has reviewed your application for Exempt Educational, Behavioral, and Social Science Research on the above-titled research project. According to the information provided, this project is exempt under 45 CFR 46.104(d), category 2. You are therefore authorized to begin the research.

It is understood this project will be conducted in full accordance with all applicable HRPP Policies. It is also understood that the ORA will be immediately notified of any proposed changes for your research project that
A. affect the risk-benefit relationship of the research
B. pose new risks which are greater than minimal
C. constitute a new risk to privacy or confidentiality
D. involve sensitive topics (including but not limited to personal aspects of the subject’s behavior, life experiences or attitudes)
E. involve deception
F. target a vulnerable population
G. include prisoners or children
H. otherwise suggest loss of the exempt status of the research.

You are encouraged to contact the ORA to discuss whether changes to exempt research requires review by ORA.

Please be advised you will be asked to update the status of your research yearly by responding to an email from the Office of Regulatory Affairs. If you do not respond, your project will be considered completed.

Sincerely,

Signed on: 2023-07-17 11:58:48.396

Gail Kotulak, BS, CIP
IRB Analyst III
Office of Regulatory Affairs